HIV Testing and Counselling for Children

A Training Course for Counsellors

Participant’s Workbook
Foreword

HIV is having a devastating impact on Zimbabwe’s children. Of the 1.3 million people currently living with HIV in Zimbabwe, it is estimated that 132,938 are children (MoHCW, 2007). The national Prevention of Mother to Child Transmission (PMTCT) programme is playing a critical role in the national effort to reduce the incidence of HIV in children. However children continue to be infected with HIV, either at birth or later in childhood. During 2007 it was estimated that 17,370 children below the age of 15 years were newly infected with HIV (MoHCW, 2007).

The national scale up of Paediatric HIV and AIDS Care and Treatment is having a dramatic impact on the prognosis for children infected with HIV in Zimbabwe. It is estimated that approximately 40% of children in need of ART were accessing treatment in 2007.

HIV Testing and Counselling (HTC) is a critical entry point to prevention, treatment, care and support services. Access to HTC services for children promotes early identification of HIV infection in infants and children. They may then be referred for treatment, care and support. HIV-exposed infants who are uninfected may benefit from intensified follow-up, care and prevention measures that will help to ensure they remain uninfected. Children requiring Post Exposure Prophylaxis can also be identified.

As part of its commitment to ensuring universal access to prevention, treatment, care and support for children, the MOHCW has set out clear guidelines to ensure that children have access to quality HTC, follow up care and support services. Such services depend on the availability of quality counselling services. The Government’s Ministry of Health and Child Welfare has developed this course to ensure that counsellors are trained to effectively fulfil this role. It is aimed that this standardised national training will ensure access to high quality counselling services for children and their families across Zimbabwe.

Dr O Mugurungi

Chief Coordinator

AIDS & TB Programme
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Acknowledgements

This training manual has been developed to guide the implementation of the Ministry of Health and Child Welfare’s National Guidelines for HIV Testing and Counselling for Children. It is the result of a collaborative effort between different people and organisations.

The Ministry of Health and Child Welfare would like to sincerely thank all individuals and representatives of various organisations who made invaluable contributions in the development of this HIV Testing and Counselling for Children Training Manual.

Special acknowledgement and appreciation goes to the technical review team for their dedication and commitment in assisting in the development of this manual (See Annex 1).

The Ministry of Health and Child Welfare sincerely thanks the Clinton Foundation HIV/AIDS Initiative whose financial support made the development of this training manual possible.
Acronyms

ART Antiretroviral Therapy
ARVs Antiretroviral drugs
CRC Convention on the Rights of the Child
ELISA Enzyme-linked immunosorbent assay
HIV Human Immunodeficiency Virus
HTC HIV Testing and Counselling
IEC Information, Education and Communication
MoHCW Ministry of Health and Child Welfare
MTCT Mother To Child Transmission
PITC Provider Initiated Testing and Counselling
PMTCT Prevention of Mother to Child Transmission
UN United Nations
VCT Voluntary Counselling and Testing

Definition of a “Child”

A “child” is any individual under the age of 18 years (UN Convention on the Rights of the Child, 1990).

For the purposes of this training manual, a “child” refers to all individuals from 0 to 18 years.

Definition of an “Emancipated Minor”

An “emancipated minor” is a child below 16 years of age who is married, pregnant or a parent (MoHCW, 2007a)
Introduction for the Participant

HIV Testing and Counselling (HTC) is a critical entry point to prevention, treatment, care and support services. Access to HTC services for children promotes early identification of HIV infection in infants and children. They may then be referred for treatment, care and support. HIV-exposed infants who are uninfected may benefit from intensified follow-up, care and prevention measures that will help to ensure they remain uninfected. Children requiring Post Exposure Prophylaxis can also be identified.

However access for children to HTC and follow up counselling services has been limited. The unique needs of children and the legal and ethical issues surrounding HTC for children present a challenge for policy makers and service providers. Yet as part of its commitment to ensuring universal access to prevention, treatment, care and support for children, the MOHCW has set out clear guidelines to ensure that children have access to quality HTC, follow up care and support services.

Such services depend on the availability of quality counselling services. Counsellors providing HTC and follow up support services for children encounter children at varying developmental stages, with different life circumstances, experiences and vastly different needs. Quality counselling for children meets these different needs and has the potential to make a significant difference in the lives of children and families.

Counsellors have a central role to play in the delivery of quality HTC and follow up care and support services for children and their families. The MOHCW has developed this course to ensure that counsellors are trained to effectively fulfil this role.

Purpose of this Workbook

This workbook is to be used by participants attending the HIV Testing and Counselling for Children training course, both in the initial 5 day training course but also as a self assessment, reference and supervision tool once back in the workplace. It contains course content material, worksheets and assessment forms. This workbook should be used in conjunction with other training manuals e.g. Basic Counselling, PMTCT, OI/ART.

Goal of the Training Course

The overall goal of this training course is to train counsellors to provide appropriate, effective HIV counselling for children accessing HIV testing and follow up care and support services.
Objectives of the Training Course

On completion of this training course, participants should be able to:

- Demonstrate an understanding of the different needs of children
- Demonstrate an understanding of the impact of HIV on children
- Describe the core principles of counselling children
- Recognise and acknowledge the impact of self awareness, attitudes and beliefs in the provision of HIV counselling for children
- Describe the role of HIV counselling for children and the responsibilities of the child counsellor
- Provide pre and post HIV test counselling for children, demonstrating competence in:
  - Assessment of the counselling needs of individual children and their families
  - Use of appropriate, child friendly counselling skills and techniques which effectively meet the needs of individual children and their families
  - Sharing of appropriate information in an appropriate manner for individual children
  - Dealing with difficult issues (e.g. sharing of sensitive information, appropriate management of legal and ethical dilemmas)
- Provide appropriate follow up HIV counselling as required, including disclosure and ARV related counselling
- Implement self care strategies for counsellors
- Action plan for the delivery of child friendly HIV Counselling services within their workplace
- Implement quality assurance strategies within their workplace

Structure of the Training

The HIV Testing and Counselling for Children training curriculum is divided into two stages:

**Stage One: 5 day Training Course:** Knowledge and Skills Building (Modules 1 – 7)

**Stage Two: Practical:** On completion of the 5 day course, counsellors will return to their workplace where they are required to complete seven self reflection assessments within three months of completing the 5 Day Training. They will be assessed and supported within the field by their trained supervisor.
## Course Timetable

<table>
<thead>
<tr>
<th>Time</th>
<th>DAY ONE</th>
<th>DAY TWO</th>
<th>DAY THREE</th>
<th>DAY FOUR</th>
<th>DAY FIVE</th>
</tr>
</thead>
<tbody>
<tr>
<td>08:00</td>
<td>Registration</td>
<td>Re-cap Day 1 Principles of Counselling Children</td>
<td>Re-cap Day 2 Pre Test Counselling</td>
<td>Re-cap Day 3 Counselling for Blood Tests</td>
<td>Re-cap Day 4 HTC for Children - Case Studies and Role Play</td>
</tr>
<tr>
<td>09:00</td>
<td>Registration</td>
<td>Re-cap Day 1 Principles of Counselling Children</td>
<td>Pre Test Counselling</td>
<td>Follow Up Counselling</td>
<td>HTC for Children - Case Studies and Role Play</td>
</tr>
<tr>
<td>10:00</td>
<td>Pre Course Assessment</td>
<td>Pre Test Counselling</td>
<td>Pre Test Counselling</td>
<td>Follow Up Counselling</td>
<td>HTC for Children - Case Studies and Role Play</td>
</tr>
<tr>
<td>09:00</td>
<td>Pre Course Assessment</td>
<td>Skills and Techniques for Counselling Children</td>
<td>Pre Test Counselling</td>
<td>Follow Up Counselling</td>
<td>HTC for Children - Case Studies and Role Play</td>
</tr>
<tr>
<td>10:00</td>
<td>Pre Course Assessment</td>
<td>Pre Test Counselling</td>
<td>Pre Test Counselling</td>
<td>Follow Up Counselling</td>
<td>HTC for Children - Case Studies and Role Play</td>
</tr>
<tr>
<td>10:30</td>
<td>TEA</td>
<td>TEA</td>
<td>TEA</td>
<td>TEA</td>
<td>TEA</td>
</tr>
<tr>
<td>10:30</td>
<td>TEA</td>
<td>TEA</td>
<td>TEA</td>
<td>TEA</td>
<td>TEA</td>
</tr>
<tr>
<td>11:30</td>
<td>TEA</td>
<td>TEA</td>
<td>TEA</td>
<td>TEA</td>
<td>TEA</td>
</tr>
<tr>
<td>13:00</td>
<td>TEA</td>
<td>TEA</td>
<td>TEA</td>
<td>TEA</td>
<td>TEA</td>
</tr>
<tr>
<td>14:00</td>
<td>TEA</td>
<td>TEA</td>
<td>TEA</td>
<td>TEA</td>
<td>TEA</td>
</tr>
<tr>
<td>15:15</td>
<td>TEA</td>
<td>TEA</td>
<td>TEA</td>
<td>TEA</td>
<td>TEA</td>
</tr>
<tr>
<td>15:30</td>
<td>TEA</td>
<td>TEA</td>
<td>TEA</td>
<td>TEA</td>
<td>TEA</td>
</tr>
</tbody>
</table>
## Course Timetable for those attending without basic counselling training

<table>
<thead>
<tr>
<th>DAY ONE</th>
<th>DAY TWO</th>
<th>DAY THREE</th>
<th>DAY FOUR</th>
<th>DAY FIVE</th>
<th>DAY SIX</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>08:00 – 09:00</strong></td>
<td>Registration</td>
<td>Counselling Communication Skills</td>
<td>Re-cap Day 1 Principles of Counselling Children</td>
<td>Re-cap Day 2 Pre Test Counselling</td>
<td>Re-cap Day 3 Counselling for Blood Tests</td>
</tr>
<tr>
<td><strong>09:00 – 10:00</strong></td>
<td>Pre Course Assessment</td>
<td>Skills and Techniques for Counselling Children</td>
<td>Pre Test Counselling Skills</td>
<td>Follow Up Counselling, Care and Support</td>
<td>HTC for Children - Case Studies and Role Play</td>
</tr>
<tr>
<td><strong>10:00</strong></td>
<td>TEA</td>
<td>TEA</td>
<td>TEA</td>
<td>TEA</td>
<td>TEA</td>
</tr>
<tr>
<td><strong>10:30 – 11:30</strong></td>
<td>Concepts of Counselling</td>
<td>Self Awareness, Attitudes and Beliefs</td>
<td>Skills Building for Counselling Children</td>
<td>Pre Test Counselling Case Studies and Role Play</td>
<td>Disclosure</td>
</tr>
<tr>
<td><strong>11:30 – 13:00</strong></td>
<td>Types of Counselling</td>
<td>Legal and Ethical Issues</td>
<td>Disclosure</td>
<td>Models of HTC service delivery for children</td>
<td></td>
</tr>
<tr>
<td><strong>13:00</strong></td>
<td>LUNCH</td>
<td>LUNCH</td>
<td>LUNCH</td>
<td>LUNCH</td>
<td>LUNCH</td>
</tr>
<tr>
<td><strong>14:00 – 15:15</strong></td>
<td>Ethics in Counselling</td>
<td>Understanding Children</td>
<td>Legal and Ethical Issues - Case Scenarios and Role Play</td>
<td>ARVs and Adherence</td>
<td>Action Planning for Child Friendly services</td>
</tr>
<tr>
<td><strong>15:15</strong></td>
<td>TEA</td>
<td>TEA</td>
<td>TEA</td>
<td>TEA</td>
<td>TEA</td>
</tr>
<tr>
<td><strong>15:30 – 16:30</strong></td>
<td>Counselling Process</td>
<td>Understanding the impact of HIV on Children</td>
<td>HIV Testing for Children</td>
<td>ARVs and Adherence - Case Studies and Role Play</td>
<td>Preparations for Practicum</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Post Course Assessment</td>
<td>Evaluation</td>
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</table>
Module One: Introduction and Course Overview

Introduction to Module

This module introduces the participants to the course in HIV Testing and Counselling for Children. It provides them with a background to the course, its goals, objectives and structure. It creates an opportunity for participants to get to know one another and aims to establish an interactive and participatory learning environment for the training course.

Module Objectives

The main objectives of this module are to:

- Welcome all participants and facilitators
- Introduce one another
- Introduce participants to the goals and structure of the course
- Identify personal and group expectations
- Establish ground rules
- Administer the pre-course assessment

Overview of Sessions

Session 1: Introduction and Course Overview

Session 2: Pre-Course Assessment
Session 1: Introduction and Course Overview

Objectives

The main objectives of this session are to:

- Welcome all participants and facilitators
- Introduce one another
- Introduce participants to the goals and structure of the course
- Identify personal and group expectations
- Establish ground rules
- Administer the pre-course assessment

Activities

- Activity 1: Discussion - Getting to Know One Another
- Activity 2: Discussion - Expectations for the Course
- Activity 3: Discussion - Establishing Ground Rules
- Activity 4: Presentation – Introduction and Course Overview
Introduction and Course Overview

HIV in Children, Global Summary at end 2007 (UNAIDS, 2007)

<table>
<thead>
<tr>
<th>People living with HIV/AIDS in 2007</th>
<th>33.2 million</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children living with HIV/AIDS in 2007</td>
<td>2.5 million</td>
</tr>
<tr>
<td>Children newly infected with HIV in 2007</td>
<td>0.42 million</td>
</tr>
<tr>
<td>Child AIDS deaths 2007</td>
<td>0.33 million</td>
</tr>
</tbody>
</table>

HIV in Children in Zimbabwe

While Zimbabwe has reported a decline in HIV prevalence, it remains one of the countries most affected by HIV in the world with 15.6% of adults aged 15-49 years living with HIV (MoHCW, 2007). This is having a devastating impact on the nation’s children. Of the 1.3 million people living with HIV, approximately 10% (132,938) are children.

Estimated Number of people living with HIV and AIDS in Zimbabwe, end of 2007 (MoHCW, 2007)

<table>
<thead>
<tr>
<th>Estimated Number</th>
<th>Upper and Lower Bounds</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total (adults and children)</td>
<td>1,320,739</td>
</tr>
<tr>
<td>Adults</td>
<td>1,085,671</td>
</tr>
<tr>
<td>Women (15-49)</td>
<td>651,402</td>
</tr>
<tr>
<td>Children (0-14)</td>
<td>132,938</td>
</tr>
<tr>
<td>Adult Prevalence</td>
<td>15.6%</td>
</tr>
</tbody>
</table>
HIV Infection in Children

The high rate of HIV infection in children is the result of the following:

1. **Burden of HIV infection in women** - 21% of women of reproductive age are HIV positive

2. **Rate of Mother to Child Transmission of HIV** - In 2004 it was estimated that a total of 40,000 new HIV infections occurred among children below the age of 15 years, with MTCT accounting for up to 90% of these childhood infections

3. **Older children infected through horizontal transmission** - Although national prevention strategies are being implemented, older children continue to be infected through horizontal transmission such as child sexual abuse and early sexual debut.

**Prognosis for Children with HIV**

In the absence of appropriate care, support and treatment, between 50% and 80% of HIV infected children who are infected at birth die before their second and fifth birthdays respectively (MoHCW, 2007). Yet there is clear evidence that use of ART in children results in child survival rates of up to 85% after 24 months of treatment and that Cotrimoxazole prophylaxis reduces morbidity and mortality by up to 50% (MoHCW, 2007).

In 2007, it was estimated that 260,000 people were in urgent need of antiretroviral therapy in Zimbabwe and 72,000 (20%) were children aged below 15 years of age.

**Benefits of HIV Testing for Children**

HIV testing and counselling is a critical entry point to prevention, treatment, care and support services. It is imperative that children have access to appropriate diagnostic and counselling services to ensure early identification of infants and children who are HIV-infected. They may then be referred for treatment and care. HIV exposed infants and children who are uninfected may benefit from intensified follow-up, care and prevention measures that will help to ensure they remain uninfected. Children requiring Post Exposure Prophylaxis may also be identified.

**Benefits for the Child**

Every child has an inherent right to life, to information about themselves and to appropriate health care and support (Legal Obligation according to the UN Convention on the rights of the Child)

To facilitate early knowledge of HIV status

To improve access to HIV prevention, treatment, care and support services
**Barriers to HTC for Children**

In spite of the clear advantages of early diagnosis of HIV in infants and children, there have been significant barriers in the past to the provision of quality HTC services for children and their families. These include:

- Lack of clear guidelines and policies on HIV testing and counselling for children, including legal and ethical issues surrounding age of consent
- Inadequate HTC services for children, including cadres trained in child counselling
- Inadequate laboratory infrastructure for early infant diagnosis of HIV
- Inadequate child friendly organisational structures and procedures
- Lack of perceived benefits of testing children by society, communities and families, leading to:
  - Negative attitudes towards testing children
  - Reluctance of families to have their children tested

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**Benefits for the Parent/Guardian**

To assist parents to take care of their child through accessing HIV prevention, treatment, care and support

Knowledge of their child’s HIV status and subsequent access to appropriate care can reduce stress

Supportive counselling can help them to develop coping mechanisms.

Encourage parents to know their status

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**Benefits for the Community**

To encourage communities to acknowledge that HIV in children is a reality

To advocate for better support to HIV infected children and families

To assist in the reduction of stigma and discrimination
HTC for Adults v. Children in Health Institutions in Zimbabwe

Addressing the Need for HTC for Children

Various strategic documents have been developed on the acceleration of HIV services in order to meet the national targets towards attaining universal access to prevention, treatment and care services by 2010. In line with its commitment to the Convention on the Rights of the Child (CRC), the Government of Zimbabwe has committed itself to undertaking all appropriate legislative, administrative and other measures to ensure that children have access to HIV testing and counselling services.

The MoHCW’s Strategic Plan for Paediatric HIV Prevention, Treatment, Care and Support calls for the expansion of testing and counselling services for children. This has been followed by National Guidelines for HTC for children in 2007. The purpose of these guidelines is to provide national standards that must be adhered to by all institutions, organizations and individuals for the provision of high quality HIV testing and counselling services for children in Zimbabwe. The guidelines provide a guide on how to expand and increase access of HTC services for children whilst at the same time maintaining quality.

Requirements for HTC for Children

The provision of optimal testing and counselling services for children requires that:

- Relevant policies and procedures are in place
- Services be child friendly
- Services have an uninterrupted supply of HIV test kits
- Trained diagnostic personnel are available
- Appropriate referral systems for follow up care, support and treatment are established
Quality HTC for Children Depends on Quality Counsellors

Central to the delivery of appropriate, effective services for children accessing HIV testing is the need for well trained, committed child counsellors.

What is a Child?

A child is defined as “any individual below the age of 18 years” (UN Convention on the Rights of the Child, 1990).

Children and HTC

The child counsellor encounters children across a broad age range, at varying developmental stages, with different life circumstances, experiences and with vastly different needs. Many are particularly vulnerable with demanding counselling needs.

For example, one child presenting for HIV testing may be an HIV-exposed infant while another may be a sexually active adolescent. Children presenting may be sick and symptomatic for HIV. Others may be well. They may be orphaned, living with extended family members and grieving multiple losses and trauma in their live. Others may have little or no support network, such as children living on the street or children living in child headed households. Children may be physically well but may have been sexually abused. An increasingly difficult issue is that of minors attending for HTC without a guardian.

Challenges in HTC for Children

HTC for children is immensely rewarding yet provides many challenges for even the most experienced counsellor. The diversity of this group results in considerable differences in the counselling needs of individual children and their families presenting for HIV testing and counselling.

Child Counsellors for HTC

Quality counselling addresses the needs of individual children. Child counsellors therefore require:

- Knowledge and understanding of children
- Skills in assessment of the needs of individual children
- Skills in communicating effectively with children
• Skills and techniques for sharing appropriate information in a way which children can understand

• Skills in assisting children to cope with difficult situations

• Skills in working with families

• The right attitude and beliefs

Whilst some children may not know the details of the HIV test and its implications, other children may be able to be fully involved in the HTC process. Yet all the children have extensive counselling needs and these must be met appropriately.

**Follow Up Counselling, Care and Support for Children with HIV**

HIV testing and counselling is only the beginning for children testing HIV positive. The child and the family then have a critical need for sustained, skilled counselling and support as the child progresses through childhood into adulthood.

**Counselling can make a difference for children and families**

Quality counselling has the potential to make a significant difference in the lives of children and their families infected and affected by HIV. Children testing HIV positive can be helped to understand and cope with events in their lives and, when they are ready, to understand the implications of their result, to look forward to a meaningful life ahead and be helped to feel accepted, valued and loved. Families can be helped to come to terms with the implications of their child’s status and to access appropriate support services post test. Children who test negative can be assisted to implement prevention strategies.

**You have a vital role to play**

Quality counselling for Zimbabwe’s children depends on you! If children and their families are to have access to HTC services and follow up support which appropriately meets their needs, counsellors need a standardised, high quality training. The Ministry of Health and Child Welfare has developed this course to meet this need.

**Goal of the Training Course**

The overall goal of this training course is to train counsellors to provide appropriate, effective HIV counselling for children accessing HIV testing and follow up care and support.
Objectives of the Training Course

On completion of this training course, participants should be able to:

- Demonstrate an understanding of the different needs of children
- Demonstrate an understanding of the impact of HIV on children
- Describe the core principles of counselling children
- Recognise and acknowledge the impact of self awareness, attitudes and beliefs in the provision of HIV counselling for children
- Describe the role of HIV counselling for children and the responsibilities of the child counsellor
- Provide pre and post HIV test counselling for children, demonstrating competence in:
  - Assessment of the counselling needs of individual children and their families
  - Use of appropriate, child friendly counselling skills and techniques which effectively meet the needs of individual children and their families
  - Sharing of appropriate information in an appropriate manner for individual children
  - Dealing with difficult issues (e.g. sharing of sensitive information, appropriate management of legal and ethical dilemmas)
- Provide appropriate follow up HIV counselling as required, including disclosure and ARV related counselling
- Implement self care strategies for counsellors
- Action plan for the delivery of child friendly HIV Counselling services within their workplace
- Implement quality assurance strategies within their workplace
Module 2: Working with Children in the context of HIV

Introduction to Module

Working with children requires a deep understanding of them in order to meet their needs. This module introduces participants to the impact that their own personal attitudes, values and beliefs can have on their role in working with children. It then aims to equip participants with knowledge and understanding of the way children think, feel and respond to different events in their lives and the factors which influence this. Finally it explores the impact of HIV on children.

Module Objectives

At the end of this module participants should be able to:

- Demonstrate an understanding of self awareness and its role in the provision of quality HIV counselling for children and their families
- Ensure that issues which conflict with their own personal values and beliefs do not influence their role in counselling children appropriately
- Describe the different needs of children
- Demonstrate an understanding of the different factors that influence the way children think, feel and behave
- Demonstrate an understanding of the range of physical, psychological and social stressors on children with HIV
- Be cognisant of the range of emotions that children with HIV may experience
- Adopt an individualised approach to assessing and understanding each child as part of the process of meeting their needs appropriately and effectively

Overview of Sessions

Session 1: Self Awareness, Attitudes, Values and Beliefs

Session 2: Understanding Children

Session 3: Understanding the Impact of HIV infection on Children
Session 1: Self Awareness, Attitudes, Values and Beliefs

Objectives
At the end of the session participants should be able to:

- Define “Self Awareness”
- Identify their own personal attitudes, values and beliefs around working with children and providing HIV counselling for children and their families
- Describe the impact that their attitudes, values and beliefs can have on their role in providing quality HIV counselling for children and their families
- Ensure that issues which conflict with their own personal values and beliefs do not influence their role in counselling children appropriately

Activities

- Activity 1: Discussion – Exploring Self Awareness, Attitude, Values and Beliefs
- Activity 2: Presentation – Self Awareness, Attitudes, Values and Beliefs
- Activity 3: Group Work – Dealing with Difficult Issues in HIV Counselling for Children
# Worksheet 1

Exploring Self Awareness, Attitudes, Values and Beliefs

<table>
<thead>
<tr>
<th>Value / Belief Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children should always be quiet</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Children make lots of noise which slows me down when I am trying to work</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Children will give up hope if they are told they are HIV positive</td>
<td></td>
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<td></td>
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<tr>
<td>Children should work hard, not play all the time</td>
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<tr>
<td>Children cannot understand complicated things like HIV</td>
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<tr>
<td>Adults find it difficult to show love to children</td>
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<tr>
<td>Children should not ask questions</td>
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<tr>
<td>It is not that important to counsel children</td>
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<tr>
<td>Children born with HIV will die at a very young age</td>
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<td>There is no advantage to knowing a child’s HIV status</td>
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<tr>
<td>It is easier to work with adults rather than children</td>
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<tr>
<td>It is difficult to communicate with children</td>
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<tr>
<td>HIV counselling for children will make my days even busier and harder</td>
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<tr>
<td>Toys, games and paintings in the waiting room are a waste of limited resources</td>
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Self Awareness, Attitudes, Values and Beliefs

Values, Attitudes and Beliefs

We are all different. Every individual has different sets of values, attitudes and beliefs. What do we feel is important? What is right? What is wrong? How should one behave?

These are influenced by a variety of factors, as shown in the diagram.

Self Awareness

All counsellors need to be aware that their values, attitudes and beliefs can influence the way they approach a child and family’s situation, the way they react to their needs and the approach they take in counselling the child and family.

Quality counselling therefore requires counsellors to be self aware. This is defined as an awareness of their own personal values, beliefs and attitudes. As in the diagram above, these are all influenced by a variety of factors and every individual is different.

Self Awareness and the Responsibilities of the Counsellor

Every individual is entitled to their own personal values, beliefs and opinions. However, the role of the counsellor is a privileged one. Children and families attending for HTC, follow up care and support are extremely vulnerable. They have placed themselves in your care to receive accurate information, to seek support and to help them find ways of dealing with their experiences. Quality counselling meets the needs of the child and family, taking into account their own situation and experiences.

Counsellors need to understand and acknowledge the potential impact that their personal values, attitudes and beliefs can have on their role. Counsellors will then be equipped to recognise when the child’s and/or family’s issues conflict with their own values and beliefs and to then ensure that this does not affect their role in providing quality HIV counselling for children.

Scenarios Causing Possible Conflict

HIV counselling for children is associated with numerous potentially sensitive issues and difficult scenarios. There are therefore a variety of situations which may cause potential conflict for the counsellor and challenge their values, attitudes and beliefs. Examples include:
• Belief that children are too young to hear about sensitive issues (e.g. death, HIV, sex)
• Fear of talking about difficult issues with children and of their responses
• Over-identification with the child and family’s situation (e.g. the counsellor would not want his/her own child to be exposed to such information; the counsellor’s child may be HIV positive)
• Strong disagreement with the family’s approach to the situation
• Fears for own health and exposure to HIV infection
• Inadequate skills in controlled emotional involvement, coping with stressful situations and handling conflict
• Exposure of the child and family to the counsellor’s religious beliefs

**Strategies for Dealing with Conflict**

Strategies to assist counsellors to deal with situations which conflict with their own values, attitudes and beliefs include:

• Identification of his/her own values, attitudes and beliefs towards working with children and HIV counselling for children
• Acknowledging the influence of their personal values, beliefs and attitudes on their role
• Adherence to an impartial, non judgmental approach
• Referring the child and family to another counsellor in the event that the counsellor is unable to fulfil his/her role
• Accessing support and counselling from colleagues and supervisors
• Ensuring that the best interests of the child are the primary consideration at all times

**Summary**

• Every individual has their own personal values, attitudes and beliefs
• Self awareness is an understanding of one’s own values, attitudes and beliefs
• Counsellors’ own values, attitudes and beliefs can influence the way they approach a child and family’s situation, the way they react to their needs and the approach they take in counselling the child and family
• Counselling for children in the context of HIV commonly presents situations which may cause conflict for the counsellor

• Counsellors need to understand and acknowledge the potential impact that their personal values, attitudes and beliefs can have on their role

• Counsellors need to implement strategies to ensure that conflict situations do not affect their role in providing quality HIV counselling for children
### Worksheet 2

**Case Scenarios / Role Play**

*Dealing with Difficult Issues in HIV Counselling for Children*

<table>
<thead>
<tr>
<th>Case Scenario 1</th>
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</thead>
<tbody>
<tr>
<td>Rachel is 5 years old. She has been unwell for the past year with recurrent ear infections, diarrhoea and herpes zoster. Her mother was advised by her local clinic that she should bring Rachel to you for HIV testing. During the pre test counselling session, Rachel’s mother informs you she has changed her mind and does not want Rachel to be tested.</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Case Scenario 2</th>
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<tbody>
<tr>
<td>Thabani is 10 years old. He has been sick on and off for the past 4 years with septic sores, chronic cough and two admissions to hospital with pneumonia. He is also short for his age. Thabani’s uncle has brought him for HIV testing. When you call them in to your counselling room, the uncle tells Thabani to stay behind in the waiting room. The uncle explains that he would like Thabani to be tested for HIV but does not want Thabani to be told the reason for the blood test today as he will not be able to cope with the results if they are positive.</td>
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<table>
<thead>
<tr>
<th>Case Scenario 3</th>
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<tbody>
<tr>
<td>An HIV positive mother has brought her 19 month old daughter Eunice to you for HIV testing. During pre test counselling, Eunice’s mother informs you that a friend told her that it is possible to cure a baby with HIV with faith healing. She asks you if this is correct.</td>
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<tr>
<th>Case Scenario 4</th>
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<tbody>
<tr>
<td>Tadiwa is 9 years old. His mother died 2 years ago and he now lives with his father and step mother. He has been brought to you for HIV testing by the step mother. During pre test counselling, you identify that the step mother has plans for Tadiwa to go to stay in the rural areas with other relatives if he tested HIV positive. If he tests HIV negative, he will remain with the father and stepmother.</td>
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<table>
<thead>
<tr>
<th>Case Scenario 5</th>
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<tbody>
<tr>
<td>Thembani is 15 years old. She has a 19 year old boyfriend and she discloses to you that they are having a sexual relationship. She feels that it is important that she has a HIV test but does not want her mother to know about her boyfriend or that she is having the test.</td>
</tr>
</tbody>
</table>
Session 2: Understanding Children

Objectives

At the end of this session participants should be able to:

- Explain why it is important for counsellors to understand the way children think, feel and behave
- Outline the different needs of children
- Describe the different factors which influence the way children think, feel and respond to events in their lives
- Appreciate the need for an individualised approach to assessing and understanding children as part of the process of meeting their needs appropriately and effectively

Activities

Activity 1: Presentation – Understanding Children
Understanding Children

Children are not little adults. Adults are independent beings who are in a position to make independent decisions and choices about issues affecting them. They are able to articulate what they think and how they feel. They have had opportunities to develop coping mechanisms and to establish support systems to help them through difficult experiences.

In contrast, children are vulnerable. They are dependent on adults to assist them in meeting their needs. If these needs are not met, their healthy development and survival is threatened. They may not be able to articulate what they think and how they feel and they may be unable to cope with the different experiences they are faced with. As such, children infected and affected by HIV are particularly vulnerable. Their experiences are commonly overwhelming. Counselling can assist children with these challenges but it requires that the counsellor understands the needs of children; the way children think, feel and behave; the way they communicate their needs; and the way they cope with difficult situations.

Understanding children helps us to:

- Understand their needs
- Understand the way children think and feel about events in their lives
- Understand the way they communicate their needs
- Understand the impact that events may have on them
- Recognise and anticipate potentially traumatic events in their lives
- Recognise the impact of our own actions on children
- Develop appropriate responses which effectively meet their needs
- Assist them to cope with difficulties in their lives
- Reduce the negative impact of events in their lives, thus improving their quality of life

Definition of a Child

A child is any individual below the age of 18 years (UN Convention on the Rights of the Child, 1990)

However, all children are different. For example, the way a 2 year old thinks, feels, behaves and responds to events is considerably different to that of a 16 year old. Yet they are both children. Furthermore, one 10 year old child may think, feel and behave very differently from another 10 year old.
In order for children to develop healthily, they have a variety of different needs which must be met. These will now be discussed.

**The Needs of Children**

The needs of children can be considered in 4 dimensions: **physical**, **psychological**, **social** and **spiritual** needs.

**Physical Needs**: to have shelter, food, physical care, clean water, clothing

**Psychological**: to feel loved, valued and cared for; to feel accepted and respected; to be supported and understood; to be given choice; to have hopes and goals; to be able to trust; to have honest communication

**Social Needs**: to have a supportive home environment; socialisation with peers; access to education

**Spiritual Needs**: to have peace of mind; sense of belonging; sense of purpose

If these needs are not met then the healthy development and survival of the child is at risk.

**Challenges in Meeting these Needs**

For millions of children around the world, realisation of these needs is threatened by considerable challenges. Examples of these include:

- Poor health and disease
- Inadequate access to appropriate health care
- Death of family members
- Poverty
- Cultural and societal attitudes towards children, including gender issues
- Conflict of any form within and outside the home
Obligation to Meet the Needs of Children

Adults have a moral and social obligation to meeting the needs of children. But they also have a legal obligation to do so. In 1990 the UN Convention on the Rights of the Child set out clear policy on the rights of the child in which it recognises the various needs of children. These rights include:

- Every child has the inherent right to life.
- A child who is capable of forming his or her views has the right to express those views freely in all matters affecting him or her.
- Every child has the right to freedom of expression, including the freedom to seek, receive and impart information and ideas of all kinds, through media of the child’s choice.
- No child shall be subjected to arbitrary or unlawful interference with his or her privacy.
- Parents or legal guardians have the primary responsibility for the upbringing and development of the child and the best interests of the child will be their basic concern.
- It is every child’s right to enjoy the highest attainable standard of health and facilities for the treatment of illnesses and rehabilitation of health. No child will be deprived of his or her right of access to such health care services.
- Every child has a right to a standard of living adequate for the child’s physical, mental, spiritual, moral and social development.

Why children are different

All children are different. The needs of children, the way they think, feel and behave, the way they communicate their needs and the way they respond to difficulties in their lives is influenced by various factors, including:

1. Age and Developmental Stage
2. Understanding of Events
3. Past Experiences
4. Sense of control
5. Resilience
6. Support Systems

These different factors will now be discussed in detail.
1. **Age and Developmental Stage** (ECI, 2004).

All children are on a journey of great change, from the day they are born right through to adulthood. Importantly, on this journey, it is not only the child’s physical abilities that develop but the way they think, understand and behave.

At different points in this journey, a child will:

- Think differently about the world around him/her
- Have different understanding about events affecting him/her
- Respond differently to events affecting him/her
- Communicate his/her needs differently

The following section has been taken from the International HIV/AIDS Alliance’s Publication *Building Blocks: Africa wide briefing notes, 2006*

**0 to 1 year: Consistency and Continuity**

At this stage, children learn about the world through their senses. They respond to faces, voices and bright colours, discover their hands and feet, smile, start to understand and say a few words, sit up, crawl, stand and start to explore and to play with objects.

They need:

- Consistent caregivers who respond to them
- Physical affection, including being held close and cuddled to help them feel secure
- Talk, stories, things to look at, touch, hear and play with
- Physical protection and a safe environment to explore

**1 to 3 years: Encouragement, Enthusiasm and Independence**

At this stage, children learn to walk and run, understand and speak words, communicate ideas and feed themselves. They become more independent and develop friendships but prefer familiar people.

They like to help, can solve simple problems, enjoy learning new skills and show pride in accomplishments, but get frustrated if they cannot do things.
They need:

Opportunities to play with other children and develop independence
Encouragement and praise
Someone who listens to and talks to them

3 to 5 years: Initiative and Inspiration

At this stage, children talk a lot, ask questions, like to play with friends, learn to share, feel angry or guilty if they think they have failed; and become competitive, especially with their siblings and playmates. They also become more adventurous and start to imitate adults.

They need:

Opportunities to participate in activities, explore and make choices
Help to learn to use language well through reading, talking and singing
Praise when they try new things and do things well.

6 to 8 years: Curiosity and learning

At this stage, children show increased interest in the world, people, letters and numbers. They become more physically confident, start to take responsibility, play cooperatively and build trust with friends, and use words to express feelings.

They need:

Support to develop additional language, physical and thinking skills
Encouragement with school work
Opportunities to learn cooperation and self-control, to take responsibility and complete tasks

8 to 10 Years: Exploration and Understanding (ECI, 2004)

At this stage, children have increased ability to understand things clearly, and need to put meaning to the events affecting them. They want to learn more about why things are as they are.
They Need:

- Explanations about why things are the way they are
- Encouragement to learn new things
- Opportunities to boost their self-esteem and confidence
- Lots of acknowledgement, constructive criticism and praise

### 10 to 18 years

Teenagers are complex. They are still defined as ‘children’ yet their needs are rapidly evolving as they progress towards adulthood. They are in a transition period in which their personality is developing and they begin to learn the skills to cope with adulthood. The need to conform with peers is often a strong desire during this stage. It is a period of possible conflict as they learn to prepare themselves and make decisions about their lives ahead.

Those who feel confident and able to trust others with their feelings may discuss them openly whilst others may feel that no one will understand them and attempt to deal with these emotions alone. Adolescents need considerable support.

They Need:

- Opportunities to develop personality and sense of purpose in life
- To feel a sense of belonging and acceptance by peers
- Open, honest communication with those they can trust
- Strong support networks

### Summary of Age and Child Development

In summary, the way children grow and develop through these different stages of childhood is fundamental to understanding the different needs of children, the way they think, feel and behave.

### 2. Understanding of Events

Adults generally cope better with difficult events in their lives if they understand more about them. Similarly, children need to be helped to understand the world around them. However this need is commonly overlooked due to the common belief that children are too young to understand certain information.
Whilst this may be true in many circumstances, there is ALWAYS something that can be said to children to help them understand more, whatever their age or developmental stage. For example, a 5 year old child may not yet be ready to be told that they have HIV. However the child may be helped to understand more about his/her situation with an explanation like the example below.

Understanding children’s need for developmentally appropriate information and their need to be involved in issues affecting them is an important part of understanding children and meeting their needs.

3. Past Experiences

It has been shown that even very young children remember traumatic events. Children’s past experiences have a direct impact on the way they feel about current and future experiences and the way they cope and respond to them. Distressing, traumatic experiences in the past may lead to difficulties coping with similar events in the future.

For example, a child who has been traumatised whilst having blood taken in the past is very likely to be anxious and afraid of having blood taken in the future. Similarly, a child who has been treated in an unfriendly, aggressive manner by counsellors in the past may be fearful of counsellors in the future. Conversely, a child who was approached in a welcoming, friendly manner and was encouraged to share how they were feeling is more likely to feel that counsellors are there to listen to their problems and to help them.

Understanding children involves identifying children’s negative and positive experiences and recognising the impact they may have had on children.

4. Sense of Control

Another factor which influences the way children think, feel and respond to the world around them is their sense of control. If children feel they do not have control over something affecting them, this may lead to feelings of helplessness, fear and anxiety. Every effort must be made to involve children, to listen to their views, to give them choices and to make them feel important. This can help children to cope better. Creative strategies are required to help increase children’s sense of control. Such
strategies may appear to be simple to us but can have significant impact on children when all decisions are usually made for them.

5. Resilience

*Resilience* is the term used to describe the child’s ability to ‘bounce back’ (Mallman, 2002). In the same way that all children are different, some children are more resilient than others. Resilient children are better equipped to cope with stressful events. All children have the potential to be resilient but it must be developed. Therefore resilience must be encouraged in all children to help them cope with the stressful events in their lives.

**Developing Resilience**

Resilience can be encouraged and developed using different strategies.

a) *Assist the child to feel loved, secure and cared for*

Many of the emotions which children experience when faced with difficult situations can be alleviated if the child knows they are loved and cared for.

b) *Spend time with the child*

Adults need to invest time and energy in to understanding the child and making him/her feel important. If a trusting, open relationship can be established, the child is more likely to feel he can ask the questions on his/her mind. These questions must be answered honestly. In this way the child will be helped to cope better due to a better understanding and sense of self worth.

c) *Create opportunities for Children to Express themselves*

Adults tend to express themselves through direct talk with others. However, children require other means of expressing themselves. Creative activities often enable children to express themselves in greater depth than through speech and are powerful tools to help children express themselves. They can be adapted for each individual child and their individual needs. Examples will be discussed later in Module 3.

6. Support Systems

The support systems available to a child have a significant impact on the way he/she will respond to events in his/her life. If the child lives within a strong, loving, supportive environment in which he feels secure, he/she will be better equipped to deal with difficult events. However, if the environment is not supportive, the child will be less able to cope with these difficulties. Support
systems may take many different forms and include parents, caregivers, other relatives, clinic staff, peers, church members, teachers, social welfare officers and community members.

The Need for an Individualised Approach

All children are different in the way that they think, feel and behave, the way they communicate their needs and the way they respond to difficulties in their lives. An individualised approach to assessing and understanding each child is therefore essential. This requires commitment and skill but ensures that appropriate measures can then be implemented to effectively meet the needs of each individual child.

Summary

- A child is any individual under the age of 18 years
- Children have a variety of needs which must be met for their healthy development and these are considered in 4 dimensions: physical, psychological, social and spiritual
- All children are potentially vulnerable as they are dependent on others for realisation of these needs
- Understanding children helps us to understand the needs of children and the way they think, feel and respond to events in their lives
- All children are different - there a variety of factors which influence the way different children think, feel, behave and respond to difficult situations in their lives
- Understanding children assists us to develop appropriate responses to effectively meet the needs of individual children
Session 3: Understanding the Impact of HIV infection on Children

Objectives

At the end of the session participants should be able to:

- Demonstrate an understanding of the physical, emotional and social impact of HIV on children
- Explain and appreciate the wide range of emotions which children with HIV may experience

Activities

Activity 1: Discussion – Understanding the Impact of HIV infection on Children

Activity 2: Presentation – Understanding the Impact of HIV infection on Children
Understanding the Impact of HIV infection on Children

**Acknowledgment:** The following presentation has been adapted from “Paediatric HIV Home Based Palliative Care Manual: Enhancing Care Initiative” (ECI, 2004)

**Children, HIV and Vulnerability**

Any child is vulnerable as they have not yet acquired the physical, emotional and social abilities required to adjust and cope independently with life. Children with HIV are even more vulnerable due to the wide range of stressors impacting on them. These can dramatically affect the children’s quality of life.

In order to effectively meet the needs of the children they encounter, counsellors need to have an understanding of the range of physical, emotional and social stressors which make children with HIV vulnerable. If counsellors are able to recognise and understand these, they may then help to alleviate their impact, thus improving the quality of life of those children.

**Physical Stressors**

A child with HIV is faced with overwhelming physical stressors. Although the prognosis for children with HIV has dramatically improved, HIV remains a chronic, lifelong condition for which there is currently no cure. In the absence of treatment with ART, the child becomes progressively weaker as the immune system and other parts of the body are damaged. The child is more susceptible to opportunistic infections. The symptoms of these infections and conditions are commonly painful and debilitating and dramatically affect the child’s quality of life. Children are entirely dependent on their parents or caregivers and need immense love and support to help them cope with the physical impact of HIV.

In the event that children are treated with ART, they may still become sick, continue to need medication, medical investigations and treatment.

**Emotional Stressors**

Children with HIV have significant emotional needs. Whilst these may be more difficult to identify than the more obvious physical needs, they are just as significant. Children with HIV face tremendous emotional challenges as a result of their own diagnosis but also commonly that of their loved ones. When a child should be playing and enjoying childhood, he/she faces recurrent illnesses, the need to care for sick relatives, grief for the loss of relatives, fear of the future and stigma and discrimination. These emotional needs will be discussed further in later modules.
Social Stressors

Children with HIV commonly face extreme social stressors and these in turn influence their physical and emotional needs. For example:

- May not be cared for properly as parent is sick
- May be cared for by elderly relatives, siblings or people who do not want to be caring for them
- Living in poverty
- Inadequate nutrition
- Poor access to health services
- Unable to attend school
- Frequent change in residence
- Unable to interact and socialise with peers

Possible emotional reactions

Like adults, HIV has an enormous impact on children. However the physical, emotional and social stress on children is considerable. A child is commonly unable to make sense of the many traumatic events happening around them. A child is dependent on others for love, care and support.

The impact of HIV may result in a variety of emotions in children which will now be discussed. These emotions significantly impact on their quality of life and include:

<table>
<thead>
<tr>
<th>Loss of Control / Helplessness</th>
<th>Confusion</th>
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<tbody>
<tr>
<td>Fear and Anxiety</td>
<td>Anger</td>
</tr>
<tr>
<td>Loneliness</td>
<td>Abandonment</td>
</tr>
<tr>
<td>Sadness</td>
<td>Mistrust</td>
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</tbody>
</table>

Each emotion will now be discussed in turn, addressing the potential causes and effects of each. Inform participants that you will be asking them to draw on their own experiences of different emotions to assist them to recognise the way children may be feeling.
**Loss of Control / Helplessness**

Children with HIV may frequently experience feelings of helplessness due to the range of events which occur beyond their control. Examples include:

- Loss of parents / siblings
- Frequent change of residence
- Recurrent illness and frequent medical investigations
- Drop out from school
- Child abuse

**Fear and Anxiety**

Numerous events occur in the lives of children with HIV which may make them feel afraid or anxious. These usually result from not understanding what is happening to them. Common fears are:

- Will my mother/father die?
- Who will look after me then?
- What is happening to me?
- Will I keep having painful tests?
- Will I die too?
- What happens when I die?
- Will people find out that I am positive?
- What happens if my ARVs stop working?
- Will I be able to get married and have children?

**Loneliness**

All children need to feel safe and loved by others but those with HIV commonly face circumstances which lead them to feel lonely. These include:

- One or both parents may be dead
- Other family or friends may not be in a position to provide the love the child needs
- Stigmatised and discriminated against by friends, family, communities
**Sadness**

Children with HIV may be grieving the loss of parents, siblings, other relatives and friends. They may also be feeling intense sadness about their own health and social circumstances. They may realise that they too, like their relatives who were also sick, may die.

**Confusion**

Confusion often arises from an inability to make sense of things. Children with HIV commonly face a variety of situations which they are unable to make sense of. This is then exacerbated when adults do not explain events appropriately as a result of being unsure of what to say to them.

Adults often think children do not need to know what is happening in their lives. But children DO need to be helped with the many questions they may have. For example:

- Why did my mother/father die?
- Why do they ask me to leave the room while they talk about me?
- Why do I keep getting sick, even though I take the antibiotics?
- Why does everyone I love get sick?
- Why do I have to carry on taking this medicine if I am feeling better?
- But I have never had sex, so why am I positive?
- Why am I sick more often than my friends?
- Why do I have to take lots of medicines/blood tests?
- Why do I have to miss so much school?
- What have I done wrong?
- Why do people talk about me / tease me?

**Anger**

One stage of the grief process is anger. Like adults, children may experience this anger, particularly as they may not have been given any explanations for the death of their loved one(s). They may feel that someone is to blame for the death of their parent(s) or sibling(s). A child may not know how to express this anger. They may also feel anger surrounding their own HIV status.
**Abandonment**

All children need a great deal of love and a sense of security, yet children who have lost parents or loved ones may feel a sense of abandonment as a result of questions including:

- Where is our mother/father? Why does he/she not want to take care of us anymore?
- Why have we been sent to live here? They don’t want us
- Who will look after us now?

**Mistrust**

Understandably, adults have a strong desire to protect children which leads them to sometimes withhold information that may hurt the child. However children can be extremely perceptive and quickly sense when they are not being told something. Children need to be able to trust adults in their lives. Mistrust can be very damaging - if children are not told the truth, they may imagine or fantasise something that is far worse.

**Changes in Behaviour**

All these different emotions may be expressed in different ways, which may be misunderstood. When caring for children with HIV, we need to be aware of the way some of these may be expressed. Then we can try to understand why a child may be behaving as he is, how he may be feeling and how we may help him. For example, an aggressive child may be extremely afraid and that maybe his/her way of expressing this fear.

Sadness, anxiety and fear are often expressed in behaviour changes, which may include:

- Withdrawal
- Bed wetting
- Aggression
- Self-harm
- Clinging
- Regression
Summary

Children living with HIV infection are exposed to numerous physical, emotional and social stressors. Understanding these and the emotions they may generate is fundamental to understanding the children counsellors are working with. The key to truly understanding children is to listen and learn from the children themselves. The following testimonies of children living with HIV demonstrate this clearly.

Acknowledgement: These extracts are taken from “Our Story” by Africaid, 2006

“I completed TB treatment and it was confirmed that I no longer had TB. But I kept on feeling sick which made me confused, wondering what the real problem was in my life and with my health.”

“In the beginning, I wasn’t happy because no one was telling me what was happening, why I was sick. I couldn’t play with my friends.”

“Before I was told that I had HIV, I felt sick and helpless but I did not know what it was. I had big tonsils and I felt lonely when people laughed at me.”

“I used to always get sick. I would go to the clinic for medicine which made me better for a while but not for long. I soon got sick again. People used to tell me my blood was weak. No one would play with me because I was always sick.”

“Before I was told that I was HIV positive, I felt very sick. I had lots of skin problems and I was feeling very embarrassed.”
Module 3: Counselling Children

Introduction

Counselling children shares many of the underlying principles and approaches used in counselling adults. However, there are also some fundamental differences - specific approaches, skills and techniques are required in order to counsel children effectively and appropriately. This module reviews the principles of counselling as applied to children and then describes these skills and techniques.

Module Objectives

At the end of this module participants should be able to:

- Define counselling
- Demonstrate an understanding of potential challenges in the provision of effective counselling for children
- Describe the core principles of counselling for children
- Implement strategies to overcome challenges in counselling children
- Utilise essential skills and techniques required for effective counselling for children

Overview of Sessions:

- Session 1: Principles of Counselling for Children
- Session 2: Skills and Techniques for Counselling Children
Session 1: Principles of Counselling for Children

Objectives

At the end of this session participants should be able to:

- Demonstrate an understanding of potential barriers to effective counselling for children
- Outline the core principles of counselling for children
- Describe the qualities of a good child counsellor

Activities

Activity 1: Discussion – Principles of Counselling for Children

Activity 2: Presentation – Principles of Counselling for Children
**Principles of Counselling for Children**

**What is Counselling?**

- A process or a therapeutic relationship between counsellor and client(s)
- Helps a client to adjust and cope better with situations they face and the emotions they experience
- Gives the client correct information to make informed decisions

However, quality counselling requires individual skills and the right environment (MoHCW, 2007b)

**The Aim of Counselling for Children**

*What is the purpose of counselling for children? What are we aiming for?*

Counselling is important for children in a variety of different situations. It is intended to:

- Help them to cope with the situations they face, challenges they experience and their emotions
- Help them to develop coping strategies to minimise the negative impact of the situations they face
- Help them to make choices and decisions that will improve their quality of life
- Equip them with accurate and appropriate information in a way that they can understand
- Empower them by involving them in their care
- Assist them to develop goals and to recognise and build on their own strengths
- Promote their sense of self control, self esteem and reduce anxiety

**Counselling Process**

The Counselling Process describes the different stages of counselling. It is a useful tool for counsellors as it helps to guide them through the different stages of counselling. However, it should not be applied too rigidly - a flexible, individualised approach is required for every child and family.
The different stages of the Counselling Process for children and their families are: (MoHCW, 2006)

- Preparing
- Welcoming and building relationships
- Gathering and providing information
- Problem solving, decision making and planning

Potential Barriers to Quality Counselling for Children

There are various barriers to the delivery of quality counselling for children. These include:

- Misunderstanding of children’s needs.
- Belief that children are too young to be involved in discussions about issues affecting them
- Belief that children will not understand
- Difficulties communicating with children
- Desire to protect children from certain information
- Families not wishing to involve children
- Inadequate number of counsellors with skills in counselling children

Impact of not counselling children

By not counselling children in difficult circumstances, we make them even more vulnerable:

- They are unable to understand events in their lives
- They may experience a range of emotions which may negatively impact on their quality of life
- They cannot be assisted to develop coping strategies to reduce the impact of events in their lives
- They may not be equipped with correct information regarding their situation
HIV Counselling for Children

Counselling is particularly important for children who are infected and affected with HIV. There are particular times when HIV counselling is required for children and their families, which include:

- Pre and post HIV testing
- Disclosure of HIV status
- Loss of family members and/or friends
- Child’s own illness
- ART counselling
- Difficult situations such as stigmatisation, change in social circumstances and specific concerns of the child

The purpose of this training is to focus on the counselling involved when providing HIV testing and follow up care and support for children. This will be discussed in detail in Modules 3, 4 and 5.

Counselling for Children is Child Focused

Counselling for children recognises the child as the most important concern. It aims to protect the best interests of the child at all times. It acknowledges and respects the child’s thoughts, opinions and beliefs as the child is the authority on what he/she is experiencing and feeling. Counselling involves the child and adopts child friendly techniques for communicating with the child, providing them with opportunities to tell their own story and assisting them to cope with situations they face.

Counselling for Children is Family Centred

Counselling for children recognises the child as one part of a family unit. The child’s needs and experiences are intertwined with and directly related to the family unit within which he/she is living. The structure of the family unit may differ from one child to the next but each child is viewed within the context of that family unit. Counselling children acknowledges the role of the family in the child’s life and respects their opinions, concerns and wishes. It also acknowledges that family members may well have significant counselling needs themselves.

However, it is also important to note that whilst the role of the family is recognised and respected, there may be times when there is conflict between the needs and rights of the child and the wishes of the family. This will be discussed further in Module 5.

Counselling for children promotes counselling them together with the family, in the same room, as a means of encouraging a common understanding and a supportive child-caregiver relationship.
However, it also respects the needs of some children to be counselled without the family present and this opportunity for children is ensured where appropriate.

Core Principles of Counselling Children

The aims of counselling children are achieved by adhering to a variety of core principles. Many of these principles also apply when counselling adults. These will now be discussed in detail.

Confidentiality

Counselling for children is confidential. According to their level of understanding, children are informed that the information they choose to share with the counsellor is private and will not be shared with others. However there may be specific circumstances when the information may be shared if it is in the best interest of the child. The child will be informed whenever such circumstances arise.

Acceptance

Counselling for children involves an attitude of positive regard, unconditional warmth and understanding towards the child and his/her family’s circumstances. When the child and/or family feel accepted they are able to be more open about themselves and their situation.

Individualism

Counselling for children acknowledges each child as a unique individual, with their own experiences and concerns. It involves careful, skilled assessment of the needs of each individual child and their family and a flexible approach to counselling in order to meet those needs and concerns.

The requirement for such individualised care and support is one of the most challenging yet most vital part of counselling for children.

Non-judgmental

Counselling for children is non-judgmental. It respects the individual opinions, thoughts and behaviour of children and their families, even when these conflict with the views of the counsellor. The counsellor is genuinely interested in the child and family without prejudice. It also avoids negative “labeling” of the child.
Self Determination

Counselling for children acknowledges that children have the right and need to be involved in their own care and decisions which affect them. According to the age and development of individual children, the counsellor uses different skills and techniques to involve the child in decision making where possible.

Controlled Emotional Involvement

Counselling for children involves a genuine care and emotional concern for the child and family. The counsellor empathises with the child and family in a controlled and objective way.

Purposeful Expression of Feelings

Counselling for children ensures that the child and / or family are given opportunities to express their emotions. It utilises child-friendly techniques and ensures that the child and family have space and time to verbalise or demonstrate how they feel about events in their lives.

Open and honest

Counselling for children is open and honest. It never involves lies or deceiving the child. It respects the needs and rights of children for accurate, honest information. Where it is considered inappropriate to share all information with the child until a later date (e.g. disclosure of HIV status) then the counsellor is committed to sharing appropriate information in a way that the child can understand and cope with (e.g. “Unfortunately your body is not as strong as it should be which is why you are getting sick. But we have medicines which will help to make your body stronger again so that you do not become so sick”). The nature and content of this information is discussed and agreed beforehand with the family.

Consistent

Counselling for children is consistent. It does not involve providing the child with different information and confusing messages. It acknowledges that information shared in the wrong way, at the wrong time by people not trained to do it could be harmful to the child and family. Where possible, children are counselled by the same counsellor – this encourages the development of trusting, open relationships in which the child feels able to share information and avoids the need for the child to continually repeat his/her experiences and concerns to different people.
Voluntary

Counselling for children is voluntary. Depending on the age and development of the child, it is usually sought by a family member or caregiver but neither child nor family is coerced into counselling.

Conducive Environment

Counselling for children aims to help children feel safe and secure. A child friendly environment is essential and assists children to feel comfortable and relaxed in a non-threatening environment.

*NB Adherence to the core principles of counselling for children promotes the delivery of effective and appropriate counselling for children and their families. However, this relies upon the availability of appropriately trained, skilled counsellors.*

Qualities of a good Child Counsellor

Quality counselling for children relies on good counsellors. But what does this mean? There are various characteristics of a ‘good counsellor’ and these relate to personal attributes, knowledge, skills and attitudes.

<table>
<thead>
<tr>
<th>Personal Attributes</th>
<th>Knowledge</th>
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</thead>
<tbody>
<tr>
<td>Flexibility and creativity</td>
<td>Understanding of the needs of children</td>
</tr>
<tr>
<td>Empathy</td>
<td>Knowledge of when and where to refer children</td>
</tr>
<tr>
<td>Respect for the viewpoints and needs of children</td>
<td>and their families</td>
</tr>
<tr>
<td>Integrity</td>
<td>Up to date knowledge of HIV in children</td>
</tr>
<tr>
<td>Compassion and sensitivity</td>
<td>Knowledge about services available for those</td>
</tr>
<tr>
<td>Warmth, acceptance, genuineness</td>
<td>testing positive</td>
</tr>
<tr>
<td>Impartiality and objectivity</td>
<td>Understanding of the impact of HIV on children</td>
</tr>
<tr>
<td>Optimism and confidence</td>
<td></td>
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<tr>
<td>Open mindedness</td>
<td></td>
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<tr>
<td>Drive and persistence</td>
<td></td>
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<tr>
<td>Trustworthiness</td>
<td></td>
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<tr>
<td>Patience, tolerance</td>
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Summary

Counselling for children is intended to:

- Help them to cope with the situations they face, challenges they experience and their emotions
- Help them to develop coping strategies to minimise the negative impact of the situations they face
- Help them to make choices and decisions that will improve their quality of life

<table>
<thead>
<tr>
<th>Attitude</th>
<th>Skills</th>
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<tbody>
<tr>
<td>Positivity</td>
<td>Effective communication with children</td>
</tr>
<tr>
<td>Willingness to learn from the children themselves</td>
<td>Ability to articulate thoughts and ideas</td>
</tr>
<tr>
<td>Concern for children</td>
<td>Ability to establish trust and rapport with children</td>
</tr>
<tr>
<td>Commitment to protecting the best interests of the child at all times</td>
<td>Ability to recognise difficult situations beyond abilities and refer accordingly</td>
</tr>
<tr>
<td>Commitment to taking the time and effort to understand the needs of individual children</td>
<td>Ability to assess individual needs of different children and adapt counselling accordingly</td>
</tr>
<tr>
<td>Commitment to taking the time and effort to meet the needs of individual children</td>
<td>Ability to work with strong emotions</td>
</tr>
<tr>
<td>Commitment to taking the time and effort to understand the needs of individual children</td>
<td>Ability to utilise child friendly techniques</td>
</tr>
<tr>
<td>Commitment to taking the time and effort to meet the needs of individual children</td>
<td>Ability to discuss sensitive issues in an appropriate way with children of varying developmental stages and level of communication</td>
</tr>
<tr>
<td>Commitment to taking the time and effort to understand the needs of individual children</td>
<td>Ability to recognise and manage the different emotions which children may experience</td>
</tr>
<tr>
<td>Commitment to taking the time and effort to meet the needs of individual children</td>
<td>Ability to work with families</td>
</tr>
</tbody>
</table>
• Equip them with accurate and appropriate information in a way that they can understand
• Empower them by involving them in their care
• Assist them to develop goals and to recognise and build on their own strengths
• Promote their sense of self control, self esteem and reduce anxiety

Counselling is particularly important for children infected and affected by HIV

Counselling for children is child-focused, family centred and adheres to a variety of core principles

Quality counselling for children relies on good counsellors with appropriate personal attributes, knowledge, skills and attitudes
Session 2: Skills and Techniques for Counselling Children

Objectives

At the end of this session, participants should be able to:

- Describe potential challenges in the provision of effective counselling of children
- Demonstrate an understanding of the importance of specialised skills and techniques for counselling children
- Utilise child friendly skills and techniques to promote quality counselling for children

Activities

Activity 1: Presentation – Skills and Techniques for Counselling Children

Activity 2: Individual Exercise – Creative Expression
Skills and Techniques for Counselling Children

Counselling Children

Effective counselling requires assessment and understanding of the way an individual is thinking, feeling and coping with events in their life. When counselling children, there are various factors which make this process difficult and thus act as challenges in effective counselling. These include:

- The age and developmental stage of the child may make it difficult for children to articulate their thoughts and feelings
- Children may find it difficult talking with strangers
- Children may find it difficult to trust adults or strangers
- Children are commonly not given the opportunity to talk or be listened to
- Counsellors may have inadequate training or experience in counselling children
- Counselling children may require more frequent/regular sessions than counsellors may be able to commit to
- Attitudes and beliefs of counsellors may affect their willingness or commitment to engage children in counselling

Overcoming Communication Challenges

One of the most important skills required of child counsellors is the ability to overcome challenges in communicating with children. The aim is to assist children to communicate openly and honestly. In turn, the counsellor is able to accurately assess and understand what the child is thinking and feeling and identify how best to meet their needs. This is achieved with the use of child friendly counseling skills and techniques which are adapted according to the age, development and individual needs of each child.

Skills and Techniques for Counselling Children

Counselling requires a variety of skills and techniques for both adults and children. However when counselling a child, the process is enhanced when we use certain skills that take into account the child’s developmental stage, current needs and context. Some of these skills and techniques include:

1. Establishing a relationship

Establishing a relationship with the child at the beginning of the counselling session is essential. Children need to feel safe, secure and confident that they can trust the counsellor in order for them
Joining is also an important part of counselling for adults but joining with children involves a variety of different techniques, including:

- Welcoming the child and caregiver in a warm friendly manner
- Stand up to greet the child and the caregiver. Get down to the child’s level to greet him/her where necessary
- Offer the child the seat nearest you, indicating you are interested in him/her
- Acknowledge the child, showing them clearly that you are interested and happy to see him/her, not just the caregiver
- Introduce yourself so that the child and caregiver can get to know you
- For children who can talk, take time to ask the child to introduce him/herself. Show the child you want to know from him/her, not just the caregiver. This is important even for very young children
- Talk with the child about something they are interested in, that they like to do, that they have done that day or play a game with them
- Use positive body language at all times, such as leaning towards them, looking directly at the child, use of friendly facial expressions
- Explain to the child that your role is to talk with children to find out what problems they are having so that you can try to help with those problems.

2. Open Ended Questions

Children are often ignored – rather than talking with children, adults tend to talk about them. They are commonly left to sit quietly and are not engaged in conversations.

Counselling for children requires that children are asked questions, providing them with an opportunity to tell their own story and to describe how they are feeling. This may well be the first time in their life when they have been given such an opportunity and is an extremely important part of understanding and assessing the child’s needs.

Asking children questions involves:

- Asking open ended questions, such as “Can you tell me about….?”
- Asking simple, straightforward questions
Using words that they will understand

A non-threatening, sensitive and caring approach

Looking at things from the child’s point of view

Patience. Do not rush the child – he/she may need time to gain the confidence or words to reply to your question

3. Listening

In the same way that children are often not asked questions, they are often not listened to. Effective counselling requires that children are not only asked questions but that they are listened to. This may be an unusual experience for the child and the role of the counsellor is to show the child that you really want to hear what they have to say:

- Use positive body language to show the child you are really listening and that you are interested (e.g. maintain eye contact, lean forward, positive facial expressions)
- Make the child feel that she/he is the most important person to you at that time
- Encourage the child that you are listening by responding with Yes, OK etc
- Do not interrupt - wait for the child to finish talking
- Do not judge what the child is saying or show shock, anger or other negative emotions
- Observe the child’s verbal and non verbal behaviour

4. Clarify and Summarise

Children may find it difficult to articulate clearly what they are thinking and feeling. Counsellors therefore need to regularly clarify and summarise what the child has been saying in order to ensure that they have gained an accurate understanding of what the child is saying.

- Occasionally summarise what the child has been saying
- Ask the child to confirm that this is what he/she meant?
- If it is not clear what the child is saying, encourage the child in an open, friendly manner to explain further what he/she meant so that you really understand. Avoid discouraging them from talking further.
5. Empathy

Use of empathy in counselling children is an important technique for showing the child that he/she has your support. It helps to give them strength.

- Show the child that you understand what they have been / are going through
- Do not pity or sympathise with the child as this can make the child feel more helpless
- Help the child to realise their strengths

6. Providing Opportunities for Children to Express Themselves

As stated earlier, children may find it very difficult to articulate or share how they are thinking and feeling. Creative, visual strategies are powerful tools for providing children with an opportunity to express themselves. In turn, these assist the counsellor to understand more about the child.

These techniques require time, commitment and the right attitude but if children are provided with these opportunities, the results are very rewarding.

Examples include Drawing, Story Telling, Drama and Play

Acknowledgement: The following section is from “Guidelines for Counselling Children who are infected with HIV or Affected by HIV”, SAT, 2003.

Drawing

Drawing can be a powerful activity for opening ‘hidden cupboards’ in a child’s life. It enables children to communicate their emotional state without having to put it into words. Most children enjoy drawing and it is a useful practical tool for counselling

When using drawing as a counselling tool, it is helpful to:

- Give the child different materials to use (e.g. pencils, pens, paints, crayons )
- Ask the child to draw something related to what you would like them to explore (e.g. ask them to “Draw a picture of your family having fun” or “Draw a picture of something that makes you angry”)

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• Gently follow up by asking the children to describe what is happening in their drawing

• Use ‘open’ questions to encourage them to talk more about what they have drawn and why (e.g. How do the people in the drawing feel about what is happening?)

**Story Telling**

Children tend not to like lots of direct questions or long lectures. When they are finding it difficult to talk about painful issues, listening to a story about someone in a similar position can be very comforting. It can give the children the sense of being understood, and it can help them to recognise that they are not alone. A story can also serve as a useful tool for problem solving around their own situation.

When using story telling as a counselling tool, it is helpful to:

• Use a familiar story, fable or folktale to convey a message to the child, perhaps using animals to represent humans

• Avoid using real names or events

• At the end of the story, encourage the child to talk about what happened e.g. ask about the message of the story to confirm that the child has understood its relevance

• If helpful, ask the child to make up a story, based on a topic that you give them e.g. *Tell me a story about a little girl who was very sad*

**Drama**

Drama or role play is an excellent way for children – and friends, siblings and other family members – to raise issues they want to communicate with others, but find difficult to discuss directly.

When using drama as a counselling tool, it is helpful to:

• Give the children a topic to perform – such as “*A Day in my Life*” – that is related to issues you want to explore with them

• After the performance, encourage each child to discuss what happened in the drama and what issues came up

• Ask questions to explore specific areas such as “*What was the happiest / saddest part of the day?*”
Play

Adults often think play serves no serious purpose. Yet play is an important way that children explore their feelings about events and make sense of their world. When children play, much of their activity involves imitation or acting out, which helps us to begin to understand what type of emotions they are experiencing.

When using play as a counselling tool, it is helpful to:

- Give the child a variety of play materials including simple everyday objects and toys
- Ask the child to show you parts of their life using the play materials e.g. “Show me what you like to do with your family”. While the child is using the objects to show you, you can ask him or her also to tell you what is happening
- Follow and observe what the child is doing and do not take over the play. If you want to check that you have understood what the child is communicating, make comments e.g. “I see the mummy doll is so sick she cannot get out of bed” and see if the child agrees
- If the child gets stuck and cannot proceed further ask him or her questions such as “What is going to happen next?” or “Tell me about this person”. Such questions can help them to continue.

Summary

Effective counselling requires assessment and understanding of the way an individual is thinking, feeling and coping with events in their life. When counselling children, there are various factors which make this process difficult and thus act as challenges in effective counselling.

One of the most important skills required of child counsellors is the ability to overcome challenges in communicating with children. This then enables the counsellor to accurately assess and understand what the child is thinking and feeling and identify how best to meet their needs.

This is achieved with the use of child friendly counseling skills and techniques which are adapted according to the age, development and individual needs of each child.
Worksheet 3

Creative Expression

1. Draw a picture showing what makes you happy

2. Draw a picture showing what makes you sad

3. Write a short story describing a time in your life when you felt Happy, Angry, Confused, Lonely or Sad

4. Prepare a short role play of a time in your life when you felt Happy, Angry, Confused, Lonely or Sad

5. Prepare a child-friendly explanation of HIV (What is it?, How does it affect the body?)
Module 4: HIV Testing and Counselling for Children

Introduction

In this module the counsellor applies the knowledge and understanding, skills and self knowledge gained in the previous modules to the process of HIV Testing and Counselling for children. It addresses the underlying principles of HTC for children, legal and ethical issues and the counselling process. Above all, it aims to equip counsellors with the practical skills and techniques required when counselling children for HIV testing.

Module Objectives

At the end of this module participants should be able to:

- Demonstrate an understanding of legal and ethical issues encountered in HTC for children
- Ensure that HTC for children is delivered in accordance with the Zimbabwean law and ethical code of conduct
- Describe the various methods of HIV testing for children and their rationale
- Demonstrate competence in pre and post test counselling for children and their families, using appropriate skills and techniques
- Counsel children effectively for blood tests, thus reducing any negative impact that these may have on the child and family
Session 1: Legal and Ethical Issues related to HTC for Children

Objectives

At the end of the session participants should be able to:

- Demonstrate an understanding of common legal and ethical issues encountered in HTC for children
- Describe the legal and ethical principles guiding HTC for children
- Define the age of consent as applied to children and HTC
- Define informed consent as applied to children and HTC
- Ensure that consent for HTC for children is applied in adherence with national policy and guidelines
- Manage difficult legal and ethical issues appropriately

Activities

Activity 1: Presentation – Legal and Ethical Issues related to HTC for Children

Activity 2: Case Scenarios / Role Play – Managing Legal and Ethical Issues
Legal and Ethical Issues Related to HTC for Children

Legal and Ethical Principles to HTC for Children

Counsellors providing HTC for children are commonly presented with various ethical and legal dilemmas. The Government of Zimbabwe has established clear policies and guidelines to ensure that children have access to HTC services which adhere to both national and international legal and ethical standards. Counsellors have a responsibility to ensure that they have accurate knowledge and understanding of these principles in order to protect the best interests of children at all times.

Five main legal and ethical principles guiding HTC for children will be discussed. These are: Rights of the Child, Best Interests of the Child, Age of Consent, Informed Consent and Confidentiality.


Zimbabwe is a signatory to the UN Convention on the Rights of the Child and is therefore committed to upholding the rights of the child. Child rights are ethical principles that bind all service providers to do all that is necessary and available to provide the best possible care for children.

- Every child has the inherent right to life.
- A child who is capable of forming his or her views has the right to express those views freely in all matters affecting him or her.
- Every child has the right to freedom of expression, including the freedom to seek, receive and impart information and ideas of all kinds, through media of the child’s choice.
- No child shall be subjected to arbitrary or unlawful interference with his or her privacy.
- Parents or guardians have the primary responsibility for the upbringing and development of the child and the best interests of the child will be their basic concern.
- It is every child’s right to enjoy the highest attainable standard of health and facilities for the treatment of illnesses and rehabilitation of health. No child will be deprived of his or her right of access to such health care services.
- Every child has a right to a standard of living adequate for the child’s physical, mental, spiritual, moral and social development.

The Government has declared that it is every Zimbabwean’s right to know his or her HIV status regardless of the individual’s age. Therefore HTC should be made available to children when indicated, ensuring that their rights are not violated and post-test treatment, care and support services are available. Furthermore, HTC services must be provided in an environment where child rights are respected.
2. The Best Interests of the Child

The second guiding principle is that:

“the best interests of the child shall be a primary consideration”

When counsellors face legal and ethical dilemmas, this principle guides the counsellor in how to manage the situation. If the counsellor acts in the best interests of the child at all times, the child will be protected and legal and ethical principles upheld.

3. Age of Consent

Age of Consent presents many challenges to policy makers and service providers due to the varying needs and circumstances of children between the ages of 0 and 18 years of age. In particular, age of consent and access to HTC for adolescents without parental consent has raised considerable debate. With the age of majority at 18 years and the age of sexual consent at 16 years, should adolescents or “minors” be able to seek HTC without the consent of a caregiver?

The Ministry of Health and Child Welfare’s National Guidelines for HTC for Children clearly define age of consent for children accessing HTC:

16 Years or Above:

In Zimbabwe, the law states that any child who is aged 16 years or above and is requesting HIV testing should be considered able to give full informed consent.

Below 16 years of age:

The consent of a parent/guardian is required before performing an HIV test on a child who is below 16 years of age.

Age of consent for children below the age of 16 years must be handled with extreme care in order to ensure that the rights of the child and the family are upheld. By law, the counsellor cannot engage a child below the age of 16 years without the consent of their parent/guardian.

Whilst this policy has been set out to protect the best interests of the child, there are particular scenarios in which this presents difficulties for the counsellor.

a) What happens to a child with no guardian?

b) What happens to a child below the age of 16 years who is requesting an HIV test in the absence of their guardian?

c) What happens to a child who has been sexually abused or assaulted?
Counsellors must be equipped with accurate knowledge and skills to deal with these scenarios.

**a) Children with no guardian**

In the event that a child has no guardian, it is the responsibility of service providers to refer the case to a Probation Officer such as a Social Welfare Officer or Police Officer prior to proceeding with HTC. This Officer can act as guardian for the child and appropriate care and support services can be established.

**b) Children presenting on their own**

An HIV test cannot be carried out on children below 16 years of age without the consent of their guardian. Whilst the law is clear, this scenario presents a difficult ethical dilemma for service providers as they may not wish to turn away a child who is actively seeking knowledge of their HIV status.

The exception to this rule is children below 16 years of age who are married, pregnant or are parents. These should be considered “mature or emancipated minors” and should not be denied access to HIV testing and counselling services. A mature minor presenting on his/her own is therefore able to consent for testing.

**c) Rape and Sexual Abuse**

Statutory rape is a criminal offence where a man above 16 years of age has sexual intercourse with a girl below the age of 16 years, despite the consent of that girl.

A woman who has sexual intercourse with a boy below 14 years of age can be prosecuted for sexual assault. Where it is a man who performs some sexual act with such a child or has anal intercourse with the child it amounts to criminal offence of indecent assault or sodomy.

It should be borne in mind that a counsellor can only deal with such children below 16 years of age with the consent of the guardian. Therefore where the guardian has brought the child then the counsellor has to inform him or her of the sexual abuse. Where there is no guardian, the counsellor - while bound by the right to privacy relating to the child’s HIV status - can exercise the “best interests of the child” principle and report the criminal conduct against the child in accordance with laid down procedures.

**4. Informed Consent**

The fourth key legal and ethical principle guiding HTC for children is that of “Informed consent.”

Informed Consent refers to a child or parent/guardian being given an opportunity to consider:
• the benefits and potential difficulties associated with having access to information regarding the child’s HIV status

• an understanding of the testing procedure

• taking a decision for the child to be tested (or not to be tested) for HIV. The child or parent/guardian should be able to consider the implications of a positive HIV test result on the child’s life and the life of his or her family.

The welfare of the child must be the primary concern when considering testing a child for HIV. When a child is brought to a facility providing HTC, the counsellor should meet with the parent/guardian to determine the reason for testing. If the counsellor feels that testing is not in the best interest of the child, then the counsellor may use his or her discretion to postpone testing.

However, counselling should be provided to both the child and the parent or guardian even if the counsellor does not carry out testing of the child. The counsellor or other service provider should also use this opportunity to discuss and encourage HIV testing for the parent/guardian so that they can also benefit from knowing their HIV status.

HIV testing must be voluntary, with the child or parent/guardian making an informed decision about taking an HIV test. The counsellor should explain the procedure and make sure that the child or parent/guardian is requesting HIV testing without coercion. While approaches to obtaining informed consent can be flexible, the fundamental value to be applied is respecting the choice of the child or parent or guardian in instances where the child cannot give consent.

Elements of Obtaining Informed Consent (MoHCW, 2007a)

The three crucial elements in obtaining truly informed consent in HIV testing are:

• providing pre-test information on the purpose of testing

• the treatment, care and support available once the test result is known

• ensuring understanding by the child (if of an appropriate age) and parent/guardian, while respecting their autonomy

It is only when these elements are in place that a child and/or parent/guardian can make a fully informed decision on whether or not the child should be tested for HIV.

Written or Verbal Consent

There is no distinction at law between written or verbal consent as both can be binding. Therefore it is acceptable for counsellors to have verbal consent only, before providing HTC services.
Informed Consent for Children Presenting with a Parent or Guardian

The application of the term “informed consent” varies according to the child’s age as detailed below. In all cases, the overriding consideration should be the best interests of the child. However, it is critical that an assessment of the child’s development and understanding is carried out.

Below is a general guide for different age groups and their capacity to give consent.

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Capacity to Give Consent</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 to 6 years</td>
<td>The child at this stage is totally dependent on the parent or legal guardian and therefore incapable of giving consent. The decision for the child to be tested is solely the parent’s or guardian’s responsibility.</td>
</tr>
<tr>
<td>7 to 15 years</td>
<td>At this stage the child may have the capacity to understand the implications of the test and hence be able to agree (assent) or disagree to the test. However, the law still requires that consent for HIV testing be obtained from the parent or guardian, unless the child is an emancipated minor.</td>
</tr>
<tr>
<td>16-18 Years</td>
<td>The child can give his or her own consent for HIV testing</td>
</tr>
</tbody>
</table>

Informed Consent for Children presenting on their own

Again, children presenting on their own for HTC services present the counsellor with an ethical dilemma. However, Zimbabwean law is clear - HIV testing services cannot be provided to any child who is below 16 years of age and is not accompanied by a parent/guardian. The exception to this rule is when the child is considered an emancipated minor.

HIV testing services CAN be provided to a child who is above 16 years of age without the parent’s or guardian’s consent. The counsellor should ensure that the child has an adequate support system and has access to treatment and care services as necessary.
Informed Consent for Children in Special Circumstances

There are children in special circumstances where Informed Consent presents particular challenges, including Sick Children, Orphans and Vulnerable Children and Sexually Abused Children.

1. Sick children

In Zimbabwe HIV testing for sick children is part of the standard of care for optimum management of the child’s condition, in cases where HIV testing will result in better care for the child. Both the child and the parent or legal guardian must receive appropriate counselling on the importance of knowledge of the child’s HIV status for better management and care of the child.

2. Orphans and vulnerable children

Children who do not have a caregiver pose a challenge to providers of HTC services as they do not have a support system in place. Counsellors should refer these children to a Probation Officer such as a Social Welfare Officer, magistrate, Police Officer or Medical Superintendent. HIV testing services cannot be provided before ensuring that consent has been obtained from a guardian and that the child has adequate support systems in place.

3. Sexually abused children

Since knowledge of the child’s HIV status will assist in the management of the child, an HIV test should be carried out as part of the standard of care for sexually abused children. Management of the HIV positive child should be in accordance with the MOHCW’s ART guidelines.

All children who have been sexually abused must have access to HIV testing and PEP as soon as possible after the incident, but within 72 hours.

5. Confidentiality

Confidentiality is an agreement between a service provider and child or parent/legal guardian that information revealed by the child or parent/legal guardian in a relation of trust will not be disclosed to others without the permission of the child or parent/legal guardian.

Confidentiality is one of the guiding principles for the provision of HTC services and must be protected at all times. The child’s privacy should be respected. It is important to remember that a child’s positive HIV status at any age may be assumed to mirror that of the parents and can result in the family being stigmatized.
**Shared Confidentiality** is when a child or parent/legal guardian attending an HTC facility involves significant others in the HTC process, including receiving the HIV test result. These others may include family members, friends, relevant health workers involved in the medical care in clinical settings, or court officials. Shared confidentiality has been shown to help people living with HIV and those affected by HIV to reduce stigma and denial. It also helps them to be accepted and supported by the community.

**Confidential Record Keeping**

All records of the HTC service provision for the child must be managed in accordance with appropriate standards of confidentiality, as prescribed by the MOHCW. Only persons with a direct role in the management of the child should have access to these records.

**Summary**

- HTC for children commonly presents ethical and legal dilemmas.
- HTC for children is guided by five main legal and ethical principles - *Rights of the Child, Best Interests of the Child, Age of Consent, Informed Consent* and *Confidentiality*.
- Every Zimbabwean has the right to know his/her HIV status regardless of age.
- The best interests of the child shall be a primary consideration.
- In Zimbabwe, the law states that any child who is aged 16 years or above and is requesting HIV testing should be considered able to give full informed consent. The consent of a parent/guardian is required before performing an HIV test on a child who is below 16 years of age.
- Mature or “emancipated minors” should not be denied access to HIV testing and counselling services. A mature minor presenting on his/her own is therefore able to consent for testing.
- The application of “informed consent” varies according to the child’s age and development.
### Worksheet 4

**Case Scenarios / Role Play – Managing Legal and Ethical Dilemmas**

<table>
<thead>
<tr>
<th>Case Scenario 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sibongile is 15 years old. She has attended your facility alone, requesting an HIV test. During pre-test counselling, she shares with you that she has a 17 year old boyfriend but reports that they are not having a sexual relationship.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Case Scenario 2</th>
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</thead>
<tbody>
<tr>
<td>Beatrice is 9 years old. Both her parents are late and she is living with her maternal aunt. Beatrice is well with no significant health problems reported but her aunt would like her to be tested for HIV as that was the cause of her parents’ death. During your conversation with the aunt, Beatrice continually re-enters the consulting room asking what you are talking about.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Case Scenario 3</th>
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</thead>
<tbody>
<tr>
<td>Henry is 11 years old. He lives on the streets and has been brought to you by two members of a local church who have come to know him through their feeding programme for street children. They are concerned about his health as they have observed he suffers with recurrent skin infections, continues to lose weight and now has herpes zoster. Whilst Henry waits in the waiting room, they ask you if he could be tested for HIV.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Case Scenario 4</th>
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</thead>
<tbody>
<tr>
<td>Thando is 16 years old. She has come to your facility with her father. Her mother died 3 years ago with TB. Thando’s father explains that she completed TB treatment 4 months ago and was recently treated at the local clinic for Herpes Zoster. He informs you that they were referred to you for HIV testing. Following your suggestion, Thando’s father agrees to leave the room while you talk with Thando alone. She then becomes very distressed, informing you that she does not want an HIV test. She tells you her father treats her very badly.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Case Scenario 5</th>
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</thead>
<tbody>
<tr>
<td>Rudo is 12 years old. She is brought to see you by one of the carers at the local Children’s Home. The carer informs you that Rudo is an orphan and has been staying with them for the past three months. In that time, she has had recurrent episodes of diarrhoea and is rapidly losing weight. Whilst her previous medical history is unknown, Rudo informs you that she has been sick on and off for many years. The carer tells you that the Children’s Home had phoned your health facility to organise for Rudo to come for a blood test. Rudo appears to be shocked by this news and asks you what the blood test is for.</td>
</tr>
</tbody>
</table>
Session 2: HIV Testing

Objectives

At the end of the session participants should be able to:

- Describe the different methods of testing for HIV in children
- Describe the challenges associated with testing infants for HIV
- Explain the rationale behind the use of different tests in infants and older children
- Demonstrate an awareness of the importance of laboratory standards and quality assurance in HTC for children

Activities

Activity 1: Presentation - *HIV Testing in Children*
HIV Testing in Children

HIV Testing

There are currently two main types of HIV tests available and approved in Zimbabwe:

- HIV antibody test – e.g. rapid test
- Antigen test e.g. PCR test

The choice of test used is determined by a number of different factors, including:

- Age of the individual being tested
- Availability of the tests
- Affordability of the tests
- Suitable laboratory infrastructure available

The HIV tests will now be reviewed and applied to their use in HIV testing for children.

HIV Antibody test

The HIV antibody test, or ELISA test, is the standard method of testing for HIV. This test looks for antibodies to HIV in the blood.

- When an individual is infected with HIV, the body makes antibodies to the virus
- This is the body’s immune response to the infection
- These antibodies are usually detectable in the blood within 6 – 12 weeks of becoming infected with HIV
- The time between infection and the development of antibodies to HIV is known as the window period
- The HIV antibody test requires a small sample of the individual’s blood which is then tested.
- If the test is ‘reactive’ or ‘positive’, this means that antibodies to HIV are present in the blood
What does this mean?

Generally, a ‘reactive’ or ‘positive’ test confirms that the individual has been infected with HIV.

It must always be remembered however that if the individual is still in the window period then the test result may be negative. The individual needs to have a repeat HIV antibody test within three months.

The Exception to the rule!

There is one notable exception to a positive test confirming HIV infection - children under the age of 18 months.

- Antibodies to HIV can be passed from mothers to their babies through the placenta
- These antibodies may be present in the baby’s blood for up to 18 months after birth
- Antibodies to HIV may also be passed through breastfeeding

This therefore means that the HIV antibody test is unreliable for:

1. **Children less than 18 months of age, born to an HIV positive mother**

   A positive result using the HIV antibody test confirms the presence of antibodies to HIV but it is not possible to identify whether these are antibodies from the HIV positive mother or the child. NB This scenario does confirm the mother’s HIV status

   A negative result would confirm that there are currently no antibodies to HIV in the infant’s blood and that the infant is either uninfected or within the window period

2. **Children who are currently being breastfed by an HIV positive mother OR who have been breastfed by an HIV positive mother within the previous 3 months**

   Children currently being breast fed or recently breastfed by an HIV positive mother have been ‘HIV exposed’. They are at risk of being infected with HIV. It is unclear whether a positive HIV antibody test has detected antibodies from the mother or the infant.
Testing Children for HIV with the HIV Antibody Test

Testing Children less than 18 months of age
Children less than 18 months therefore require a different method of testing in order to confirm HIV infection. These will be discussed later in the presentation.

Testing of children above 18 months of age
By the age of 18 months, maternal antibodies in the baby's blood have decreased sufficiently so that they no longer interfere with the HIV antibody test. Therefore children above 18 months of age can be tested using the HIV antibody test in accordance with national HIV testing algorithms approved by MOHCW.

Testing children <18 months

The unreliability of the HIV antibody test in children less than 18 months has been a considerable barrier for testing children. In many parts of the world, it has been impossible to confirm HIV infection in this age group. Instead, a presumptive diagnosis of HIV infection has had to be made on the basis of clinical signs and symptoms.

However, there are currently other possibilities for testing for HIV infection in children less than 18 months. To date, accessibility remains a challenge due to their cost and the laboratory infrastructure required to offer these tests. Fortunately however, as the international world recognizes the critical need for access to HIV testing services for children less than 18 months, these tests are now becoming more accessible. These tests include:

Antigenic tests:
- Deoxyribonucleic acid (DNA) or ribonucleic acid (RNA) polymerase chain reaction (PCR) tests
- P24 antigen test

Viral culture

These tests are not widely available in Zimbabwe although MOHCW is piloting the use of DNA PCR for diagnosis of HIV infection in infants.
MoHCW Recommendations for testing children

In light of the above, the Ministry of Health and Child Welfare has set out clear policies and guidelines for the testing of HIV in children, as follows:

**Testing of children above 18 months of age**

By the age of 18 months, maternal antibodies in the baby’s blood have decreased sufficiently so that they no longer interfere with the HIV antibody test. Therefore children above 18 months of age can be tested using the HIV antibody test in accordance with national HIV testing algorithms approved by MOHCW.

**Testing babies aged less than 18 months (antigenic tests e.g. HIV DNA or RNA PCR available)**

If the child tests **positive** with an antigenic test (e.g. HIV DNA or RNA PCR), then the child is HIV infected.

If the child tests **negative** with an antigenic test (e.g. HIV DNA or RNA PCR), then the child is not infected although he/she may still be at risk of HIV infection if still breastfeeding.

**Testing babies aged less than 18 months (antigenic test e.g. HIV DNA or RNA PCR NOT available)**

Rapid HIV tests or ELISA tests are not recommended below 18 months of age as this may simply reflect the fact that there are maternal antibodies in the child’s blood i.e. a positive result may not mean that the child is infected with HIV.

However, a clinician can request a rapid HIV test if he/she thinks it will be useful for the management of the child. Results should be interpreted as follows:

- If the test result is negative and the child stopped breastfeeding 3 or more months ago then the child is uninfected.

- If the test result is positive then the test has to be repeated at or after 18 months of age, 3 months after stopping breastfeeding.

- If the test was initially positive (earlier than 9 months of age) and then becomes negative after 9 months of age, the child is not infected with HIV if breastfeeding was stopped 3 or more months before the test.
Quality Assurance

Quality assurance is defined as the overall programme that ensures that the final HIV test results reported are correct. A false result may irrevocably damage the reputation of the HTC service and cause untold suffering to the patient or client.

Two components of quality assurance must be recognized:

1. **Internal quality control**: Internal quality control includes good laboratory practices with set standards of practice for performing HIV tests; checking rapid HIV test kits storage and expiry dates; periodic inclusion of previously tested blood samples in order to identify problems with competency of the personnel performing the HIV tests and identifying problems with the test kits.

2. **External quality assurance**: External quality assurance includes proficiency testing where all facilities providing rapid HIV testing and counselling services should receive periodic HIV proficiency blood sample panels from Zimbabwe National Quality Assurance Programme. All facilities failing the proficiency tests need to receive additional technical supervision and support from the district or local laboratory.

Laboratory Safety Rules

Strict laboratory safety precautions must be followed based on recommendations adopted by the National Microbiology Reference Laboratory (as indicated in the “Safety Module” during rapid HIV test training). Each facility must have on hand a site-appropriate guide on laboratory safety precautions. All precautions to protect against blood contamination should be observed. In case of an accident during testing, the national PEP policy should be followed.

National Standards and Protocols

Show participants the National Testing Standards and Protocols to ensure they are familiar with them.

In summary

In Zimbabwe HIV infection in children can be detected using various tests. The choice of test is dependent on:

- HIV Status of mother
- Age of the child
- Breastfeeding status of the child
- Availability and affordability of the test
Session 3: Pre Test Counselling for Children

Objectives

At the end of this session participants should be able to:

- Describe the aims of pre test counselling for children and their caregivers
- Describe the different steps involved in pre test counselling
- Establish issues of legal guardianship and informed consent and manage difficult issues
- Demonstrate skills in assessing the pre test counselling needs of children of different ages, developmental stage and level of understanding
- Demonstrate skills in providing children with appropriate information according to their age, developmental stage and level of understanding
- Be familiar with existing tools for pre test counselling children and their caregivers

Activities

- Activity 1: Discussion – *Pre Test Counselling*
- Activity 2: Presentation – *Pre Test Counselling*
- Activity 3: Demonstration – *Pre Test Counselling Tools*
- Activity 4: Case Scenarios / Role Play – *Pre Test Counselling*
Pre Test Counselling for Children

Pre test counselling for children shares many of the aims of pre test counselling for adults. However, the circumstances of each individual child and family attending for pre test counselling vary considerably. The aim and content of the counselling session is determined by the child’s age, development, current level of understanding, ability to cope with information about HIV and the caregiver’s readiness to share information with the child.

Whilst the ideal is for children to be informed that the test is to determine whether they are infected with HIV or not, it is acknowledged that some children and/or their families will not yet be ready for open discussion about HIV in front of the child. In this case, the child still requires developmentally appropriate explanations to help them understand more about the process, without directly referring to HIV.

Pre test counselling is a process which takes place in partnership with the child and the child’s parent / guardian, unless particular circumstances exclude the need for the parent / guardian to be present (e.g. 16 year olds who can consent for testing themselves).

Aims of Pre Test Counselling for Children

The aims of pre test counselling for children are to:

- Protect the best interests of the child at all times
- Review the child’s risk of infection
- Determine the most appropriate testing method (e.g. testing methods for infants or breast fed children)
- Establish who can give consent for HIV testing for the child
- Assess the child’s age, developmental stage, current level of understanding, ability to communicate their thoughts and ability to cope with new information
- Confirm with the caregiver what information will be shared with the child about HIV, the HIV test and the test results
- Equip the child and caregiver with appropriate information in a way that he/she can understand and cope with
- Assist the child, where appropriate, and the caregiver to consider the possible implications of the test result
- Prepare the child’s caregiver for any possible reactions from the child to the test results
• Inform the child where appropriate, and/or caregiver of any limitations in the test results (e.g. the ‘window period’ or rapid tests for infants)

• Assist the child, where appropriate, and the caregiver to make a decision about whether to proceed with the HIV test or not

• Obtain consent from the child / caregiver where appropriate

• Identify any legal or ethical issues that need consideration prior to proceeding with testing and to manage appropriately

• Determine any further counselling needs for children and families opting not to proceed with the test

• Identify children requiring referral for medical or social welfare assistance and to refer appropriately

Counselling Approach

In the Zimbabwean context, the recommended counselling approach is that the counsellor meets with the parent/legal guardian first before meeting with the child. This is especially applicable to children under 7 years of age.

However, various scenarios can be applied according to the counsellor’s assessment on a case by case basis. The counsellor should ensure that as far as possible, separate discussions with the child alone and with the parent/legal guardian alone take place. Three scenarios are detailed below.

Scenario 1

The counsellor meets with parent/legal guardian to find out their concern, and then meets with child and parent/legal guardian together

Scenario 2

The counsellor meets with parent/guardian first to find out their concerns. The counsellor then asks the child if he/she would like to meet you alone or with the parent/guardian and acts accordingly. The counsellor ensures that he/she meets with both the child and the parent/guardian.

Scenario 3

The parents/guardian and child may want to first meet with the counsellor, together, before meeting with the counsellor separately.
Children aged 16 to 18 years:

Counselling can be provided with or without the parent/guardian. However, the child must be encouraged to involve the parent/guardian as soon as possible as the child will usually benefit from their support if he/she is tested for HIV.

**Steps of Pre Test Counselling for Children**

The aims of pre test counselling for children are achieved through four different steps. These steps and their content are a guide to assist counsellors in the delivery of quality counselling. However, they must not be considered too rigidly at the detriment of meeting the particular needs of individual children and their families. Where necessary, counsellors should adopt a flexible approach which ensures that the specific needs of children and their caregivers are met.

<table>
<thead>
<tr>
<th>The Four Steps of Pre Test Counselling for Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Assessment</td>
</tr>
<tr>
<td>• Information Sharing</td>
</tr>
<tr>
<td>• Decision Making Process</td>
</tr>
<tr>
<td>• Implementing the Decision</td>
</tr>
</tbody>
</table>

1. **ASSESSMENT**

The Assessment step of pre test counselling for children is an opportunity for the counsellor to identify important information which is then used to direct the approach and content of the following three steps.

The quality of pre test counselling for children is determined by the counsellor’s competence in assessing a number of different questions as these will provide important information. These will now be discussed.

a) **What is the child’s age and developmental stage?**

**Assessment of the child’s understanding and communication level**

The age and development of the child will give you a broad indication of the child’s ability to understand what is happening and his ability to communicate his thoughts and feelings. This will influence the way in which information is shared and obtained.
It must be noted that age should be considered as merely a guide to the child’s level of understanding and communication ability - children of the same age have different understanding and abilities.

**Ensuring an appropriate testing method**

A child < 18 months or a child who is currently being breastfed cannot be reliably tested using a Rapid Test. The caregiver needs to be counselled about the limitations of the Rapid Test and the need for an alternative approach (i.e. PCR/P24 within your own facility, referral elsewhere or to delay Rapid testing until a later date).

**b) Why does the child think he has come to see you?**

Does the child know why he has come to see you? What has he been told? This question needs to be answered as early as possible in the counselling session - accidental disclosure of the nature of the counselling session to a child who was previously unaware can cause significant problems for both the child and the family.

The question requires careful assessment and is usually addressed by counselling the caregiver on their own before meeting with the child. This allows the counsellor and caregiver to discuss different issues freely and to clarify the way forward.

Alternatively, it is possible to establish whether the child knows the reason for the visit with both caregiver and child in the room but it must be handled sensitively - even very young children can become anxious and concerned if they hear the counsellor asking “Does the child know why he is here today?” as they will suspect that something is being withheld from them. A useful approach is to ask the caregiver and/or the child:

- *Could you explain to me what problems you have been having?*
- *Did someone suggest that you come here today? Can you tell me why?*

This approach assists the counsellor to learn more from the child and/or caregiver’s perspective and to assess what the child has been told.

**If the child knows he/she has come for an HIV test**

If the caregiver confirms that the child does know that he has come for an HIV test, then the counsellor may proceed with communication which includes naming HIV.

**If the child does not know he/she has come for an HIV test**

However, if the caregiver indicates that the child does not know, the counsellor can reassure the child with explanations like:
“Your mother has brought you here to find out why you are having problems with your skin?

“Your grandmother has brought you here because she is worried about you and wants to make sure she is doing everything possible to help you?”

If the caregiver informs you that the child does not know that he has been brought for HTC, the counsellor needs to assess the reason for this as this will determine counselling issues to be addressed:

- **Is the child not ready to be told?** Many children brought for HTC will be too young or not yet ready to be told the full details of the test. The content of pre test counselling and the approach used for such children will be discussed later in the session.

- Although HIV will not be named in the counselling, it is important to find out what these children have been told by their caregivers. Children are often given other explanations which may confuse or worry them. Alternatively, they may have been told nothing which can be equally distressing. The counsellor should clarify any misconceptions and/or fears and direct the counselling accordingly.

- **The caregiver would like the child to be told but has not done so yet.** Many caregivers are ready for the child to be told that he has been brought for HTC but do not know how to do this themselves. If the caregiver informs you that the child may be told, it is important to clarify this with the caregiver by asking “So are you asking me to name HIV and inform him that the test is to find out whether he/she has HIV?” This clarification is extremely important in order to avoid misunderstanding and accidental disclosure to the child.

- **The child may be ready to be told but the caregiver does not want him to know.** In this case, it is necessary for the counsellor to create an opportunity to counsel the caregiver alone. This provides an opportunity for the counsellor to explore the caregiver’s reasons behind not informing the child about the HIV test and to counsel about the disadvantages and advantages of involving the child fully in HTC.

- The counsellor must respect the wishes of the caregiver whilst acting in the best interests of the child at all times. The caregiver may have very valid reasons for delaying disclosure to the child about the HIV test. However, in the event that the counsellor believes it to be in the best interests of the child to be informed about the HIV test, yet the caregiver is refusing, a decision must be made to either (i) proceed with the test and provide continued counselling for the caregiver regarding disclosure of the results at a later date OR (ii) delay testing until after further counselling with the caregiver.

NB For children 16 years or over, there may not necessarily be a caregiver present as he can consent to HTC. If he has been referred for HTC, it is important to establish exactly what he knows and understands about the referral prior to proceeding. It is also important to identify what support systems are available to the child.
c) **Who has accompanied the child?**

The person accompanying the child is an important consideration for the counsellor.

*Is this person the child’s guardian?*

If the child is below 16 years, consent for HTC is required from the child’s guardian. In the event that the child does not have a guardian, it is the duty of the counsellor to clarify who has legal right to consent to testing the child prior to proceeding with HTC.

- Is the child living with the caregiver?
- Assessment of who the child lives with and existing support structures gives an indication of the support available to the child post test

*How well does the caregiver know the child?*

Counselling requires an accurate assessment of the child’s situation. This is difficult when the person accompanying the child does not know the child well. It may be necessary to re-schedule the counselling for a time when an alternative caregiver can attend.

*How is the relationship between the child and the caregiver?*

A caring, supportive relationship between the child and caregiver will assist in facilitating a caring and supportive counselling process. The counsellor needs to take into account possible tension between the child and caregiver as this may negatively influence the counselling process.

Does the caregiver need counselling themselves prior to proceeding?

The caregiver may have counselling needs themselves, relating to the child’s situation or their own.

d) **Why has the child come for testing?**

*Who decided the child should be brought for HTC?* If the child was referred by another health worker or support organisation, this can assist the counsellor with important information regarding the child’s history, risk of infection, social circumstances and specific counselling issues requiring attention. It is important to note that children and caregivers may not have been counselled fully as to the reason for the referral - their understanding of the referral requires careful assessment.

The counsellor also has a responsibility to identify potential misuse of testing i.e. “Is this test in the best interests of the child or someone else?” and to manage this situation appropriately.
e) What do the child and caregiver already understand about the child’s situation?

- A critical component of the assessment step is the provision of opportunities for the child to express what he/she understands about his current condition. The method used will depend on the child’s age, development and ability to communicate his thoughts and understanding but include open ended questions, drawing, stories and play.

- The child may already have his own thoughts and concerns about why he is sick or why he has been brought to the facility. This assessment step determines the child’s current understanding and concerns and identifies any misconceptions that the child may have.

- Useful exploratory questions include:
  - Can you tell me what has been happening to you?
  - Have you been unwell?
  - Can you tell me anything that is worrying you?
  - What sort of problems have you been having?
  - Is there anything you would like us to help you with?

It is important to remember that whilst some children may be very open about their thoughts and concerns, others may remain quiet and withdrawn. This does not necessarily mean that they do not have their own thoughts and concerns, but that they may feel unable to share these. The child should not be pressured or coerced into talking but encouraged through the use of appropriate skills and techniques as discussed in earlier modules.

Equally, counsellors should be prepared for all responses - depending on the child’s experiences, he may even state that he is concerned that he may have HIV. The counsellor must then assess why the child feels this.

f) Who will consent to HTC for the child?

The counsellor has a duty to ensure that the principles of consent to HTC are upheld.

If the child is 16 years or above, he may consent to HTC without a guardian. If the child is below 16 years, the child’s guardian must provide consent for testing. However, this should not necessarily exclude children from being involved in the discussion - children as young as 7 years can understand many of the issues if counselled appropriately.
g) How is the child’s current physical and emotional health?

Is the child sick? Is the child receiving treatment and care elsewhere? Does the child need to be referred for medical treatment? Has the child already been tested for HIV before? How is the child behaving? These questions give the counsellor a broader understanding of the child’s history and current situation. A sick child may need referring urgently for medical treatment. Also, a sick child may be less able to cope with traumatic events and this will influence the approach taken during counselling.

2. INFORMATION SHARING

The second step in pre test counselling involves a process of information sharing with the child and caregiver. The content and methods used will be determined by the information collected in the assessment step. If talking about HIV in the presence of the child is a challenge (e.g. when the parent is reluctant for HIV to be mentioned in front of the child) then the counsellor needs to ensure that the caregiver receives further sessions to assist them to come to terms with the importance of open discussion on HIV with the child. This is also an opportunity for counselling the caregiver for HIV testing.

The child and his/her caregiver need information on:

- What is HIV?
- How could an HIV test help him?
- What is involved in the test?
- What would a negative result mean?
- What would a positive result mean?
  - What would they expect? / What could be done then?

Whilst the context for each child/parent/guardian might differ, the role of the counsellor is the same – to equip the child and caregiver with appropriate information in a way that will help him/her to understand and cope with events affecting him/her. This is influenced by the counsellor’s skills in the prior assessment of the child’s age and development, understanding and ability to cope with new information.

Two scenarios will now be discussed (when HIV is to be named and when naming HIV poses a challenge) in order to give participants a guide to the type of information which should be included in the counselling session. While counsellors may develop their own approach and methods, the important issue is to ensure that the child and caregiver are equipped with all the information they require in a manner which they can understand and cope with.
Scenario 1: When HIV is to be Named

Getting Started

The counsellor can begin by informing the child in a manner which is appropriate for their age and development that he/she works with children who have different problems or difficulties in their lives. The role of a counsellor is to try to help with some of those problems.

A helpful way to start this process of information sharing is to refer to any health problems that the child has been having. This then makes the conversation real to the child and demonstrates you are interested in helping them with their problems.

What is HIV?

It is now necessary to introduce the subject of HIV. This must be done carefully and sensitively, observing the child’s verbal and non-verbal behaviour closely. The child may become distressed as he realises the implications of what you are discussing and the counsellor must respond to this.

One of the major difficulties associated with counselling children about HIV, is HOW to do it in a way that the child will understand and cope with. Consequently, children are invariably given partial information or no information at all. This makes them even more vulnerable as discussed in earlier modules.

Quality counselling empowers the child with accurate information that assists them to cope with the test and the implications of the result. The counsellor’s competence in explaining HIV to children with different needs is fundamental to the provision of quality counselling. There are various tools which have been developed in Zimbabwe to assist with this process and these will be shared with the participants later. Games and pictures are extremely powerful tools in this process as they assist the child and caregiver to understand more clearly. The following is just one approach to explaining HIV to a child:

One Approach to Explaining HIV and the HIV Test

Inform the child that normally, the body has a system for helping people to remain strong and well. This is known as the immune system. Ask the child what he knows about the immune system. Remember to encourage and praise the child for their knowledge whilst being sure to sensitively correct any misunderstandings.

Describe the function of the Immune System, using appropriate, jargon-free terminology. Many people like to use concepts such as ‘soldiers’ or ‘warriors’ to assist the child to understand the role of CD4 cells and the immune system. Explain that when the Immune System is strong, it helps the body to fight off infections. The CD4 cells (or “soldiers”/ “warriors”) have a very important role to play in this. If the Immune System or CD4 cells are weak, then the person becomes weaker and is more likely to get infections.

At this point, it is essential to assess whether the child has understood what you have said so far,
whether he has any questions to ask and whether he is demonstrating signs of difficulty coping with the information.

Now inform the child that there are times when the immune system does become weak. Ask the child whether he knows why the immune system may become weak?

Gently explain that HIV infection can make the immune system weak. Ask the child what he knows about HIV. Some children may say they know nothing yet are feeling unable to share their actual knowledge and thoughts. Other children may share considerable knowledge about HIV. A common response from children is that HIV has no cure and the person will die.

It is vital at this point in the discussion to reassure the child that this statement is both right and wrong – that there is currently no medication to cure HIV infection. However, reassure them that HIV is very different today as there is good medicine which can help children and adults living with HIV to live a normal, happy life. The counsellor must be careful not to make false promises and to be sure to give accurate, honest and reassuring information.

Returning to the way HIV affects the body, describe the way HIV damages the CD4 cells (soldiers/warriors) which then makes the immune system weak. The counsellor must be careful not to alarm the child – e.g. “the virus replicates billions of times every day and destroys your CD4 cells”.

While this may be true, this description may conjure up frightening images in a child’s mind. The same information can be given in a less threatening, yet honest way e.g. “the virus uses your body like a factory. It makes more and more virus as time goes by and this unfortunately damages your CD4 cells or soldiers which would normally help to keep you strong”.

Explain that eventually the body gets weaker and the person gets sicker and this is what is known as AIDS.

Now reassure the child in a positive, encouraging manner. Explain that whilst there used to be nothing that could be done to stop people becoming very sick and dying with AIDS, HIV is now different. Stress that it is not the illness it used to be but a chronic condition which people live with, like many other conditions. Ask the child what he knows about examples like Asthma, Diabetes and Hypertension.

Ask the child if he/she knows about Antiretroviral drugs, or ARVs. Explain that these drugs are able to make the body stronger by controlling the HIV virus – when someone is taking ARVs, the CD4 cells are protected from so much damage by the HIV virus. The CD4 cells therefore become stronger and the Immune System can become strong again. In this way, as long as the person takes the medicines regularly, then they can remain strong like other people who do not have HIV infection.

Ensure the child has understood what you have been explaining and that he is given opportunities to express any thoughts or concerns. Answer honestly, clearly and carefully.
How could an HIV test help him?

Now connect your explanation about HIV with the child’s situation. Explain that if people become sick with lots of illnesses, it is a good idea to find out what is causing this. This helps health workers to ensure that the person will get the very best treatment and care available. Otherwise the person may not get the right medicines or treatment and remain sick.

**A child who has been sick:** Carefully explain to the child that due to the illnesses he has had, it may be a good idea to find out whether these illnesses are due to HIV infection weakening his immune system. If he has HIV, this may be making him sick but health professionals could then make sure he gets the right treatment to make him strong again.

**A child who has not been sick but has been sexually abused:** Carefully explain to the child that if the perpetrator was HIV positive, there is a possibility that the virus may have been passed on to the child. Acknowledge that the child has already experienced considerable trauma but that identifying whether the child has been infected will help health workers to get the right treatment for the child.

**A child who has not been sick but has been exposed through MTCT:** It is more difficult for children who are well or asymptomatic to understand that they may have HIV. This scenario requires careful explanation about the modes of transmission of HIV. The child should be informed that although children may be well, if their mother and/or father had HIV or is HIV positive, it is a good idea to determine whether this was passed on to the child. The child needs extensive counselling to ensure they understand that their parent(s) would never have intentionally passed on HIV and that they love(d) them very much.

What is involved in the test?

Explain that it is possible to determine whether the child is living with the HIV virus by taking a blood test. The counsellor should explain the specific procedure within their own facility, including who takes the blood, where it is done, how long it takes and when the results would be available.

What would a negative result mean?

**Infants:**

- This is dependent on whether the infant continues to be exposed to HIV or not at the time of testing.
- The caregiver needs to be informed that a negative result (whether using Rapid test, PCR or P24) would indicate that the child is not currently infected with HIV.
- However, if the infant remains exposed to HIV through breastfeeding from an HIV positive mother, or has been breastfed within the previous 3 months, then the child would need to be tested again. The caregiver would also need counselling about infant feeding choices.
Children > 18 months:

- Explain that a negative result means that the child does not have HIV.
- Depending on the child’s circumstances, further counselling may be required relating to:
  - The window period (sexually abused children, sexually active teenagers, child still being breastfed and tested with a Rapid Test)
  - Safer Infant Feeding (infants still being breastfed or recently breastfed)
  - Children who are sick and require further investigation to identify the cause of their condition

What would a positive result mean?

Infants:

- This will depend on the type of test being used. If a P24 or PCR test has been used, then the child would be confirmed as being infected with HIV.
- If a Rapid test is used, the caregiver should be informed that this is not a reliable method of confirming whether the child has HIV or not but that a positive result would strongly suggest that the mother is infected. The caregiver would need counselling about the need for further testing for the child and the implications for the mother.

Children > 18 months:

- Explain that a positive result means that the child is infected with HIV

What could they expect?

- Explain to the child and caregiver that if the child is confirmed as having HIV infection, health workers would then know exactly what to do to take good care of him. The child should be informed that he would require medication but that the medication helps to make the body stronger again. The child would need to attend a clinic regularly but that this would ensure he/she was well taken care of. Reassure the child that the only people who would need to know the child’s status are their caregiver and the health workers who help to take care of them.
- Stress that there are children all over the world who were born with HIV but are now grown up and enjoying their own families. They take medication every day and they are strong.
Scenario 2: When naming HIV within pre test counselling poses a challenge

When it becomes apparent that openly discussing HIV in the presence of the child may be problematic (e.g. child is not yet ready or parental reluctance), a skilled counsellor will utilise skills and techniques for ensuring that the child is involved in the process and has an understanding of events in a way which he can cope with, whilst not naming HIV directly.

The counsellor will also ensure that the parent/guardian concerns are addressed. Areas to be discussed with the caregiver include:

- Reasons why the caregiver has brought the child for testing
- Parental / guardian concerns about open discussion of HIV with the child
- Benefits of discussing HIV openly with the child
- Strategies for assisting the parent / guardian to discuss HIV openly with the child

Why has the child come to see you?

A helpful way to start is to refer to any health problems that the child has been having. Ask the child what problems he has had? Has he been unwell? This then makes the conversation real to the child and demonstrates that the counsellor is interested in helping them with their problems.

- **A Child that has been Sick:** Explain to the child that his caregiver has brought him to find out what might be causing him to become sick and whether there is any medication that could help him.

- **A Child that has not been sick:** If the child has not been unwell, explain to the child that sometimes people seem to be well but it is a good idea to check whether they have any problems which they cannot see or do not know about. The caregiver has brought him there because she cares for him and wants to know that he is well with no problems.

- **A child that has been sexually abused:** Explain to the child that it is important to make sure that everything has been done to help him/her. One of these things is to make sure that he/she does not have any problems which cannot be seen.

- Reassure all children that they have been brought to the clinic because everybody cares about them and wants to make sure they are well taken care of.

- Ensure that the child has opportunities to express himself and that the child has understood what you have been saying.

- Explaining more without naming HIV
According to the individual child, it is often appropriate to share some of the explanation used in Scenario 1 whilst omitting content relating specifically to HIV. For example:

“The body is normally protected against infections by “soldiers” or “warriors” in the blood. They are not actually soldiers or warriors but we find it helpful to think of them like that. They are extremely small but very clever parts of the body. Unfortunately, these “warriors” sometimes become weak which means the person becomes sick. We think it might be a good idea to find out if your soldiers are weak. If they are, we can then give you medicine to help them become strong.

NB The above example does not talk about HIV directly but gives the child accurate information which can then be slowly built upon as they become closer to the time for full disclosure, if they are confirmed HIV positive.

Explain that the results of the blood test will then help to guide whether or not the child needs to take any medicines to help him.

3. DECISION MAKING PROCESS

The third step in Pre test counselling involves a discussion with the child and caregiver regarding how they feel about the test. Again, the content will depend on the age, development, understanding and specific circumstances of individual children and their caregivers.

The child should be encouraged to express themselves openly, ask questions and voice any concerns they may have. These must be responded to honestly and accurately.

The role of the counsellor is to assist the child where appropriate, and/or caregiver to make a decision about whether to proceed with the test by equipping them with the information they require. The counsellor is to remain neutral and non judgmental.

Having established whether the child and/or caregiver have any further issues they would like to consider or discuss, an informed decision regarding whether to proceed with the HIV test is required.

Legal consent for HIV testing will depend on the age of the child. For children less than 16 years, a decision to proceed with HIV testing will ultimately be made by the caregiver. However, this does not mean that a child demonstrating the ability to understand the implications of the test should not be included in discussions regarding the decision to proceed with HIV testing.

4. IMPLEMENTING THE DECISION

If the child and/or caregiver 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. Stress that the health workers, child and caregivers will miss the opportunity to plan for
the child’s optimum support and future. Encourage the child and/or caregiver to return for further counselling and review the decision at subsequent visits.

In the event that the child and/or caregiver have further counselling needs, referral for medical care or if there are legal and ethical issues to resolve, discuss this with the child and caregiver and ensure that a plan of action is agreed upon.

If the child and/or parent/guardian consent to the HIV test, proceed with the test.

**Summary**

- The circumstances of each individual child and family attending for pre test counselling vary considerably.

- The aim and content of the counselling session is determined by the child’s age, development, current level of understanding, ability to cope with information about HIV and the caregiver’s readiness to share information with the child.

- When HIV is not to be openly discussed in front of the child, a skilled counsellor will utilise skills and techniques for ensuring that the child is involved in the process and has an understanding of events in a way which he can cope with, whilst not naming HIV directly.

- There are four steps to pre-test counselling: **Assessment, Information sharing, Decision making** and **Implementing the Decision**
### Case Scenarios / Role Play – Pre Test Counselling

<table>
<thead>
<tr>
<th>Case Scenario 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rutendo is 4 months old. Her mother informs you that she is HIV positive herself so would like Rutendo to be tested for HIV. Rutendo is being breastfed.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Case Scenario 2</th>
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</thead>
<tbody>
<tr>
<td>Philipp is 10 years old. He has been brought to see you by a carer from the children’s home where he lives. The carer informs you that he has been unwell and that she has brought him for a blood test.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Case Scenario 3</th>
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</thead>
<tbody>
<tr>
<td>Anesu is 4 years old. He is brought in to see you by his Aunt. Anesu is crying and trying to leave the room. The Aunt informs you she has been looking after him since his father died 6 months ago. His father was HIV positive. She would now like Anesu tested to establish whether he is also positive.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Case Scenario 4</th>
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</thead>
<tbody>
<tr>
<td>Thandiwe is 15 years old. She is carried in to your room by her elderly grandmother who has been caring for Thandiwe for the past 2 months since her mother died. Thandiwe is emaciated, dehydrated and unable to walk. Her grandmother informs you she was told to come to you by the local clinic.</td>
</tr>
</tbody>
</table>

<table>
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<tr>
<th>Case Scenario 5</th>
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</thead>
<tbody>
<tr>
<td>Susan is 11 years old. She has been brought to see you by her 15 year old sister. Their parents are both late and they are staying alone. Susan has been coughing for three months, has recurrent diarrhoea and septic sores all over her body. Her sister is worried about her and is asking for your help.</td>
</tr>
</tbody>
</table>
Session 4: Preparing Children for Blood Tests

Objectives

At the end of this session participants should be able to:

- Demonstrate an understanding of the impact of blood tests on children
- Anticipate different emotions and behaviour in children having blood tests
- Use appropriate skills and techniques to assist children to cope with difficulties they experience as a result of having blood tests

Activities

- Activity 1: Discussion – Preparing Children for Blood Tests
- Activity 2: Presentation – Preparing Children for Blood Tests
- Activity 3: Role Play – Preparing Children for Blood Tests
Preparing Children for Blood Tests

Blood tests and HIV

Children accessing HIV testing require a blood test. Furthermore, additional blood tests may be required for repeat HIV testing where necessary or for monitoring of HIV infection and treatment. These blood tests are all essential components of appropriate HIV care, support and management.

Blood Tests for children

Very few people enjoy a blood test. Yet the majority of adults can rationalise their dislike or fear of having a test, knowing that it provides useful information regarding their health and the treatment required. Ultimately, they know it is in their best interests. However, this is not always true for children. Whilst some children may be reasonably content with having a blood test, other children experience extreme distress prior to having the test, during the test or after the test.

Response of Children to Blood Tests

The way children will respond to the need for a blood test will depend on a variety of factors, including:

- Age
- Developmental stage
- Past experience
- Level of understanding
- Environment
- Support
- Skills of person taking the blood
**Different Responses to Blood Tests**

All children are individuals and will respond to the need for a blood test differently but possible responses include:

<table>
<thead>
<tr>
<th>Positive Responses</th>
<th>Negative Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intrigue</td>
<td>Fear, terror</td>
</tr>
<tr>
<td>Curiosity, asking questions</td>
<td>Crying, shouting, screaming</td>
</tr>
<tr>
<td>Accepting</td>
<td>Struggling to get away, fighting with family and clinic staff, running away</td>
</tr>
<tr>
<td></td>
<td>Quiet, stunned, bewildered</td>
</tr>
</tbody>
</table>

**Impact on Others**

When blood tests distress a child, this can also be extremely distressing for everyone involved. The family may be upset seeing the child distressed, particularly where parents feel guilt or anger towards the child’s condition and the need for blood test. In some cases, a child’s distress over a blood test results in conflict between the child and the family due to parent’s frustration about the child’s behaviour.

**Counselling the Child for a blood test**

Counselling has a vital role to play in minimising the possible immediate, short term or long term distress which blood tests may cause in children. Effective counselling ensures that the child is counselled before, during and after the blood test. It involves:

- Understanding the possible impact of a blood test on the child
- Recognising and anticipating signs of distress in children having blood tests
- Seeing events from the child’s point of view
- Remaining non-judgmental
- A sensitive, empathic approach to the child’s fears and concerns
- Talk with the child openly and honestly
- Prepare the child for what will happen. Do not just pounce on the child with a needle!
- Use of age and developmentally appropriate explanations about why the test is important and how it can help to make decisions about how to help him/her.
• Focus on the child
• Avoid distractions which may prolong the experience
• Give the child an opportunity to ask questions
• Involve the family / carer
• Give choices where possible to empower them with a sense of control over what happens to them

**It does not involve**

• Arguing with the child
• Using negative language
• Judging the child as being difficult or rebellious
• Traumatic restraint of the child

**Ideal Outcome**

The ideal outcome is that the child is assisted to develop coping strategies which help to minimize the impact of the blood test. Whilst the child may continue to dislike the test, he/she understands that it is being done to help him/her and any trauma associated with having the test is alleviated. This outcome requires a skilled counsellor.

**Summary**

Blood tests are an essential component of care for children accessing HIV testing or for monitoring of HIV infection and treatment.

Blood tests may cause extreme distress for some children

The way children will respond to the need for a blood test will depend on a variety of factors, including age, developmental stage, past experience, level of understanding, environment, support and the skills of the person taking the blood

Counselling has a vital role to play in minimising the possible immediate, short term or long term distress which blood tests may cause in children. Effective counselling ensures that the child is counselled before, during and after the blood test.
Session 6: Post Test Counselling

Objectives

At the end of this session participants should be able to:

- Describe the aims of post test counselling for children and their caregivers
- Describe the different steps involved in post test counselling
- Demonstrate skills in providing children with appropriate information regarding their test result, according to their age, developmental stage and level of understanding
- Demonstrate skills in assessing and responding to the possible concerns and reactions of HIV positive children
- To familiarise participants with existing tools for post test counselling children and their caregivers

Activities

- Activity 1: Discussion – Post Test Counselling
- Activity 2: Presentation – Post Test Counselling
- Activity 3: Demonstration
- Activity 4: Case Scenarios / Role Play – Post Test Counselling
Post Test Counselling for Children

In the same way that pre test counselling for children shares similar aims with pre test counselling for adults, so does post test counselling. Again, the content and methods used are determined by the child’s age, developmental stage, level of understanding and ability to cope with new information.

Aims of Post Test Counselling for Children

The aims of post test counselling for children are:

- To assess whether the child and/or family are ready to receive the test results
- To inform the child and caregiver of the test results in an appropriate manner according to the child’s age, developmental stage, level of understanding and ability to cope with new information
- To help the child and caregiver understand and accept the test results as appropriate
- To assist the child and/or caregiver to cope with the implications of the test result
- To assist the child and/or caregiver to make decisions regarding appropriate follow up care and support

Steps of Post Test Counselling for Children

The aims of post test counselling for children are achieved through three different steps. These steps and their content are a guide to assist counsellors in the delivery of quality counselling. However, they must not be considered too rigidly at the detriment of meeting the particular needs of individual children and their families. Where necessary, counsellors should adopt a flexible approach which ensures that the specific needs of children and their caregivers are met.

The Three Steps of Post Test Counselling for Children

- Giving the Test Result
- Discussion
- Planning the Way Forward
1. Giving the Test Result

Take time to assess whether the child and/or caregiver have any further questions or concerns that need to be addressed. It is important to remember that although the child and/or caregiver have consented to the test and the test has been carried out, they may not be ready or willing to receive the results.

If the child has not been informed that the test is for HIV, the caregiver may need an opportunity for further counselling in the absence of the child and this need should be met.

Counsellors may have understandable fears about giving a child and/or their caregiver HIV test results. Although it is never an easy task, the counsellor requires skills and coping strategies for fulfilling this role in a manner that meets the needs of the child and caregiver.

The Child that Knows the Test is for HIV Infection

A. Giving A Positive Result

If the child and caregiver have confirmed that they are ready to receive the test results, the counsellor must state clearly:

“The test result is positive. This means that you have HIV infection”

Give the child and caregiver time to absorb the information and time to respond. It is extremely important to help the child feel that he can react as he wishes. If the child wishes to cry, reassure the child that he may do so. Be prepared for different responses. Whilst some children may remain quiet, withdrawn or shocked, others may react by crying or become angry. Whatever the response, the child is extremely vulnerable and needs immense support.

Positive body language, such as sitting next to the child, holding the child’s hand, and talking directly to him, is vital at this point as it clearly demonstrates to the child that you are there to support and care for him/her. Equally, whilst the caregiver will have his/her own emotions, the caregiver should be encouraged to support the child at this moment.

Do not rush the child by moving on with more information and discussion – give him time. When the child has had time to think about the test result and time to respond, gently move on to the third step of post test counselling, the Discussion.

B. Giving A Negative Result

If the child and caregiver have confirmed that they are ready to receive the test results, the counsellor must state clearly:

“The test result is negative. This means that you do not have HIV infection”
Inevitably, it is considerably easier to give the child and caregiver a negative test result. Inform them that the test has confirmed that the child does not have HIV infection.

Ensure that they understand what this means, provide them with an opportunity to express themselves and to ask any questions they may have.

Children in the window period (e.g. sexually abused or sexually active children)
It is essential that children in the window period for infection are aware that the test will need repeating.

Children who are sexually active need considerable counselling about the continued risks of HIV infection. Legal issues must be handled carefully and appropriately.

**When Naming HIV within Post Test Counselling poses a Challenge**

For children who have not been informed that the test was for HIV infection, the test result is usually given to the caregiver alone at first. This provides the counsellor with an opportunity to post test counsel the caregiver, informing him/her of the result and to ensure that he/she understands what this means. An important part of this discussion is to confirm with the caregiver exactly what the child should be told about the results.

When the caregiver is ready, the child can then be invited and the test result be given in an appropriate manner, as determined by their age, developmental stage and level of understanding.

**A. Giving A Positive Result:**

Remind the child of your discussion during the pre test counselling session. Use the same explanations so as not to confuse the child. Inform the child that the blood test was extremely helpful as it has helped to explain why they have been getting sick. Now the doctors will know which medicine to give in order to help to make him/her stronger again. Thank and congratulate the child for helping them to know that so they can now help him.

**B. Giving A Negative Result:**

Remind the child of your discussion during the pre test counselling session. Use the same explanations so as not to confuse the child. Inform the child that the blood test was extremely helpful as it has confirmed that there is no problem. Thank and congratulate the child for helping them to know that.
NB There are two exceptions:

When children are sick and need referral for further investigations into the cause of their illness. They will need to be counselled about the need for further investigation elsewhere.

When children are in the “window period”. They will need to be informed that the blood test has confirmed there is no problem at the moment but to be absolutely certain, it should be repeated in three months time.

2. Discussion

The third step in post test counselling involves a discussion with the child and caregiver regarding how they feel about the test result and assisting them to come to terms with the result. Again, the content will depend on the age, developmental stage, level of understanding and specific circumstances of individual children and their caregivers. When children have not been informed that the test was for HIV, this discussion may be held with the caregiver alone first.

The child and/or the caregiver should be encouraged to express themselves openly, ask questions and voice any concerns they may have. These must be responded to honestly and accurately.

The Child that now Knows his HIV Status

A Positive Result:

Ask the child whether he understands what the positive HIV test result means. Encourage him to express himself and be sure to clarify any misunderstandings. The child may now have many questions and these should all be encouraged. Common questions include:

Does this mean that I am going to die?

What will happen to me?

Who else is going to know I have HIV?

How did I get it?

Always respond openly and honestly. Be careful what you promise. Answer questions by reinforcing the explanations you used in the pre test counselling session. Remind them of what you talked about then.

In particular, reassure them that they are not alone, that they are loved and will be taken care of. Remind them that there are many other children their age who also have HIV infection and that they are strong and well because they are taking medication.
A challenge for counsellors at this stage is the time involved in meeting the child’s needs. Some children may require considerable time according to their need for immediate emotional support. This is a difficult dilemma as the counsellor will know that there are children waiting to be seen who also have considerable needs, yet do not want to turn the child away at this vulnerable time.

**A Negative Result**

Ensure the child and/or caregiver has further opportunities to discuss the meaning of the negative test. In particular, address the on-going counselling needs of exposed children, including infants and their caregivers, and those in the window period.

**3. Planning the Way Forward**

The final stage of post test counselling involves planning the way forward for the child and their caregiver. HIV negative children may not need any follow up counselling regarding HIV infection. However, counselling may have identified that the child has other significant physical, social, emotional, spiritual and mental needs. The counsellor has a responsibility to ensure that these are addressed through follow up care and support and appropriate referral.

For children testing HIV positive, this final step of post test counselling represents the first step in ensuring that the considerable follow up care and support for the child and caregiver is planned. This follow up, care and support for HIV infected children is addressed in Module 6.

**Summary**

- The circumstances of each individual child and family attending for post test counselling vary considerably.

- The aim and content of the counselling session is determined by the child’s age, development, current level of understanding, ability to cope with information about HIV and the caregiver’s readiness to share information with the child.

- When HIV is not to be openly discussed in front of the child, a skilled counsellor will utilise skills and techniques for ensuring that the child is involved in the process and has an understanding of events in a way which he can cope with, whilst not naming HIV directly.

- There are three steps to post-test counselling: **Giving the Test Result, Discussion** and **Planning the Way Forward**
<table>
<thead>
<tr>
<th>Case Scenario 1</th>
<th>Rutendo has tested HIV negative.</th>
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<tr>
<td>Case Scenario 2</td>
<td>Philipp is HIV positive.</td>
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<tr>
<td>Case Scenario 3</td>
<td>Anesu’s HIV test result is HIV positive</td>
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<tr>
<td>Case Scenario 4</td>
<td>Thandiwe is HIV positive</td>
</tr>
<tr>
<td>Case Scenario 5</td>
<td>Susan is HIV positive</td>
</tr>
</tbody>
</table>
Introduction

Whilst post test counselling concludes the process of informing a child and/or their caregiver of the HIV test result and provides immediate counselling and support, the essential role of counselling does not stop there. It is only the beginning. Whether the child has tested HIV positive or negative, the child and the family now have considerable needs. This module now addresses the follow up counselling, care and support needs of children and their caregivers following HTC and the role of the counsellor. In particular, it addresses key counselling areas of disclosure and ART counselling for children and their caregivers. It also addresses the need for strengthening of referral linkages for children requiring follow up care and support services.

Module Objectives

At the end of this module participants should be able to:

- Anticipate and recognise common challenges which children and their caregivers face following HIV testing
- Demonstrate an understanding of the role of follow up counselling, care and support for children who have accessed HIV testing
- Ensure the provision of appropriate follow up counselling, care and support through counselling and / or referral to appropriate services
- Plan and implement strengthening of referral linkages within their own facility
- Demonstrate an understanding of the key principles of disclosure for children
- Inform a child of his HIV status using appropriate counselling skills and techniques
- Demonstrate a general understanding of ARVs and adherence issues in children
- Provide ART and adherence counselling for children and their caregivers

Overview of Sessions

Session 1: Follow Up Counselling, Care and Support

Session 2: Disclosure

Session 3: ART and Adherence Counselling
Session 1: Follow Up Counselling, Care and Support

Objectives

At the end of this session participants should be able to:

- Anticipate and recognise common challenges which children and their caregivers are faced with following HIV testing
- Demonstrate an understanding of the role of follow up counselling, care and support for children who have accessed HIV testing
- Ensure the provision of appropriate follow up counselling, care and support through further counselling and / or referral to appropriate services
- Plan and implement strengthening of referral linkages within their own facility

Activities

- Activity 1: Discussion – *Follow Up Counselling, Care and Support*
- Activity 2: Presentation – *Follow Up Counselling, Care and Support*
- Activity 3: Group Work - *Planning for Strengthening of Referral Networks*
Follow Up Counselling, Care and Support

Post test counselling concludes the process of informing a child and/or family of the HIV test result and provides immediate emotional support. But the essential role of counselling does not stop there - it is only the beginning. Whether the child has tested HIV positive or negative, the child and the family now have considerable needs following the HIV test result.

Follow up counselling, Care and Support is required by three main groups of children:

1. Children who have been confirmed HIV negative
2. Children who have tested HIV negative yet remain HIV exposed or within the window period for infection
3. Children who have been confirmed HIV positive

1. Children who have been confirmed HIV negative

Children, including infants, who have been confirmed HIV negative may well have a need for follow up counselling, care and support services. For example, many children who have been brought for HIV testing live within difficult social circumstances and referral to social support services or welfare organisation is necessary. Other children may be negative but remain at potential risk of HIV infection in the future e.g. sexually active adolescents. They have a critical need for continued counselling around issues relating to HIV prevention, family planning, STIs and may need referral to reproductive and sexual health services. There will also be legal issues to address for minors.

2. Children who have tested HIV negative yet remain HIV exposed or within the window period

Counselling is extremely important for parents of infants who have tested HIV negative yet remain exposed to HIV through breastfeeding. Counselling should assist parents in understanding the results of the test, how to care for their baby including issues of cotrimoxazole prophylaxis, infant feeding choices and the need to repeat the HIV test to identify whether the baby has remained uninfected.

Children who have been sexually abused and tested for HIV within the window period will need to be counselled about the need for further testing to confirm whether they remain HIV negative or not. Importantly, the children and their caregivers must be referred to specialist child sexual abuse counsellors in order for their counselling needs to be met appropriately.
3. *Children who have been confirmed HIV positive*

The follow up counselling needs of children who have tested HIV positive vary considerably, depending on each child’s age, development, understanding, experiences and ability to cope with events in their lives. Furthermore, an individual child’s needs will evolve with time as they grow and develop through childhood and experience new challenges. Follow up counselling, care and support must therefore be adapted according to their needs at any point in time.

**This session will now focus on the follow up counselling, care and support required by children who have been confirmed as infected with HIV.**

**The Needs of Children and the Impact of HIV**

Module 2 discussed the different needs of children and the impact of HIV on the realisation of those needs.

- **Physical Needs**: to have shelter, food, physical care, clean water, clothing
- **Psychological**: to feel loved, valued and cared for; to feel accepted and respected; to be supported and understood; to be given choice; to have hopes and goals; to be able to trust; to have honest communication
- **Social Needs**: to have a supportive home environment; socialisation with peers; access to education
- **Spiritual Needs**: to have peace of mind; sense of belonging; sense of purpose

**Common Issues faced by children testing HIV positive**

The way in which a diagnosis of HIV impacts on the realisation of children’s basic needs provides an indication of the counselling, care and support required by HIV positive children and their caregivers. The issues faced can be considered in terms of physical, social, emotional, spiritual and mental issues but in reality, they all impact on one another.

Not all children will experience the same issues and the way children respond to these issues will depend on their age, development, level of understanding, sense of control, resilience and existing support networks. However, listed below are some of the more common issues requiring follow up counselling, care and support for children testing HIV positive. These issues may require immediate attention after HIV testing or they may emerge in the weeks, months or years after HIV infection has been confirmed.
**Physical Issues**

Diagnosis of a chronic, incurable condition involving recurrent illnesses

Effective management of condition depends on:

- a. Regular medical monitoring and follow up
- b. Positive living (good nutrition, hygiene, exercise)
- c. Adherence to life-long medication
- d. Recurrent medical procedures

Common association with delayed growth and development in children

Need for adequate accommodation

**Psychological Issues**

Difficulties coming to terms with knowledge of HIV status and coping with emotions (e.g. grief, sadness, fear, anger)

Fear and uncertainty about the future (e.g. fear of death, fear of ill health, uncertainty about future relationships)

Difficulties coming to terms with the mode of infection (e.g. MTCT, sexual abuse)

Difficulties coping with past and current traumatic events (e.g. loss of parents and siblings, medical procedures, change in residence, stigma and discrimination, disclosure, coping with illness)

Fear of disclosure to others

Lack of loving, supportive, accepting, caring relationships

Lack of acceptance and sense of feeling valued

Need / desire for normal physical and emotional relationships

Fear of dropping out / falling behind at school due to ill health or inadequate resources within the home

Lack of opportunities for expressing thoughts and feelings

Lack of appropriate responses which adequately address these thoughts and feelings
**Social Issues**

- Inadequate resources within the home i.e. nutrition, hygiene, clothing, schooling, transport to clinic, medication
- Frequent change of residence
- Desire to be like their peers and to socialise with peers

**Spiritual Issues**

- Fear for the future
- Feelings of abandonment by a higher power

**Follow Up Counselling, Care and Support**

Follow up Counselling, Care and Support aims to reduce the impact of stressors such as those listed above by:

- Equipping the children and caregivers with accurate, honest information in a way that he/she can understand and cope with
- Assisting the children and caregivers to develop coping strategies to reduce the impact of the challenges that they face
- Ensuring that children receive the most appropriate care and support in order to meet their complex, evolving physical, social, emotional, mental and spiritual needs.
- Protecting the best interests of the child at all times

**Psychosocial Support (PSS)**

Follow up Counselling, Care and Support is an essential component of the psychosocial support required by children with HIV.

*Psychosocial Support* is defined as an ongoing process which aims to meet the physical, emotional, social, mental and spiritual needs of children and their families.

Psychosocial Support can also be defined in the following way: (REPSSI, 2006)

- **Psycho** – about thoughts, feelings and emotions
- **Social** – about the environment in which the child live. It includes family, friends, community, school
Support – the way that children are helped to cope with problems and traumas and to build resilience

PSS = “Caring” “hanya” “ukunakekela”

PSS = the way that families, friends and communities provide care for Orphans and Vulnerable Children (OVC)

Role of the Counsellor in Follow Up Counselling, Care and Support

The role of the counsellor is to assess the different needs of the child and caregiver at any given time or point of contact and to ensure that these needs are addressed through appropriate follow up counselling or referral to other care and support services as required.

The needs of children testing HIV positive and their caregivers usually require a number of different approaches as their different physical, emotional, social, mental and spiritual needs cannot be separated from one another. For example, a 10 year old child may have delayed growth and development as a result of his HIV infection. This physical consequence of HIV infection will often lead to considerable emotional difficulties for the child who is smaller than his friends. He may be treated differently by his peers, family and community. He may even have difficulties at school when he is placed in a lower class than is appropriate for his age and mental abilities. This threatens his educational needs.

This is just one example of the way the needs of HIV positive children cannot be considered as single entities – they are all interlinked, having a ‘knock on’ effect on one another. Quality counselling for children recognises the diversity of potential issues impacting on the child and ensures that counselling addresses the specific complex, evolving needs of individual children.

The role of counsellors in follow up counselling, care and support will depend on each facility’s scope of work - some facilities may provide pre and post test counselling services and then refer all follow up counselling, care and support to other facilities. Other facilities may have integrated HTC with other services and the counsellor will therefore be involved in follow up counselling.

Children who have tested HIV positive have considerable counselling needs and it is essential that their need for follow up counselling, care and support is met. It is the role of the counsellor to ensure that follow up care is provided within their own facility or through referral elsewhere.

Follow Up Counselling, Care and Support Strategies

In order to adequately address the follow up counselling, care and support needs of children and their caregivers, a variety of strategies are required. These involve the multidisciplinary team and
depend on effective referral systems and multidisciplinary liaison. The counsellor has a pivotal role to play in each strategy.

### Follow Up Counselling, Care and Support Strategies

1. Continued counselling, throughout childhood and into adulthood
2. Referral for medical care, treatment and support
3. Referral for social welfare support and assistance
4. Peer support groups
5. Multi disciplinary liaison between different counselling, care and support networks

### 1. Continued counselling, throughout childhood and into adulthood

Continued counselling throughout childhood and into adulthood is an essential component of any HIV positive child’s comprehensive care and support. As they progress through childhood, their counselling needs will change as they face new situations and new challenges but the aims of counselling remain the same - it is intended to:

- Help children to adjust and cope with the situations they face, challenges they experience and their emotions.
- Help children to develop coping strategies to minimise the negative impact of the situations they face
- Help children to make choices and decisions that will improve their quality of life
- Equip children with accurate and appropriate information in a way that they can understand
- Empower children through involving them in their care
- Assist children to develop goals and to recognise and build on their own strengths
- Promote children’s sense of self control, self esteem and reduces anxiety

Common counselling areas are now discussed below.
**The need to equip children and their caregivers with accurate information about their condition and the implications of living with HIV**

A recurring theme throughout this training is the need for children to have access to appropriate information which they can understand and cope with as a means to assist them to adjust and eventually cope better with the implications of their HIV status. Follow up counselling continues to provide the child with greater knowledge and understanding. Children may have been told their HIV status but their need for more information at each contact remains. It is important to clarify what the children have understood each time and to identify any new questions or concerns the child may have.

**Difficulties coping with the way in which they were infected**

Mode of infection is a difficult issue for HIV positive children to cope with. Whether infected at birth or later in childhood, the child needs to be helped to understand how they were infected. Many children opt not to discuss this, finding it very difficult to come to terms with it yet it is an important part of helping them to adjust and cope with their condition. This must be handled extremely sensitively and skilfully, when the child and caregiver are ready.

**Coping with stigma and discrimination**

Unfortunately, stigma and discrimination towards people living with HIV continues and children are no exception. An HIV positive child may be subjected to stigma and discrimination at home, school, in the community or wider society. Even extremely resilient children who appear to be coping well with their HIV status experience extreme distress when faced with stigmatising behaviour from others, particularly their peers.

Counselling assists children to develop self esteem and confidence and to develop coping strategies to deal with stigma and discrimination.

**Disclosure**

**A. Disclosure of HIV status to the child:** Disclosure for children who did not previously know their HIV status is a large part of the counsellor’s role in the provision of follow up counselling care and support. This is addressed in Module 5, Session 2.

**B. Disclosure of the child’s HIV status others:** A common fear which HIV positive children have relates to the disclosure of their HIV status to other people. This can cause particular difficulties when the child lives with people who do not know his HIV status, including other household members or children in a boarding school or children’s home. Counselling assists the child to identify people to whom they may disclose to strategies for managing situations in which disclosure is not desirable.
**Grief and Bereavement Counselling**

HIV positive children are often grieving the loss of their own good health, which may be in addition to the loss of parents, siblings and their peers. They require counselling from skilled bereavement counsellors to assist them in dealing with their grief. They can also be assisted with memory work exercises which help them to reflect on positive memories and to develop coping strategies.

**Fear and uncertainty about the future**

Children with HIV infection often have fear of the future and may ask the following questions:

- What will happen to me?
- Will I die?
- Will I be able to marry?
- Will I be able to have children?
- What will happen if I cannot get my drugs anymore or my drugs stop working?

Fears such as these require that the counsellor provides honest and accurate information. Through increased understanding and continued support, the child is able to cope better. Peer support is particularly powerful here as the child will meet other HIV positive children and older role models.

**Developmental Issues**

There are developmental challenges for HIV positive children which occur at different stages. In particular, a common concern for many children with HIV infection is the realisation that they are physically smaller or less developed than their friends. This becomes particularly pertinent as the child approaches adolescence when puberty should be commencing and the child has a strong desire to feel and look like peers.

HIV positive children are repeatedly reminded of their HIV status when they compare themselves with their peers or are subjected to negative comments from other people. Children in this situation need to be counselled to assist them to develop coping strategies and to build self esteem and confidence.

**Lack of family support and love and a sense of burden on other relatives**

Children who have lost their parents to HIV infection may be living with extended family members, in children’s homes or other facilities. They may have an unstable living environment in which they are required to move frequently. This is both unsettling and emotionally demanding for the child who needs above all to feel loved, safe and secure. A consistent counsellor with whom the child has established a trusting, secure relationship can provide an important source of support for the child.
2. Referral for medical care, treatment and support

The course of HIV infection varies between different children. One child may progress very quickly and become sick with Opportunistic infections within the first few months of life. These children are sometimes known as ‘rapid progressors.’ Other children may remain relatively well for several years, only becoming unwell in early childhood or as late as 9 or ten years of age.

Where children have acquired HIV infection later in childhood (i.e. not through MTCT) they may remain well and only present with opportunistic infections in their adolescent years.

At whatever stage the child starts becoming unwell, he commonly has to endure painful and frequently debilitating illnesses. This not only has a physical impact on the child but leads to immense emotional stress on the child and their caregiver. Similarly, frequent medical procedures can cause physical and emotional stress.

All HIV positive children require referral for medical care and treatment. This includes assessment of their current condition, the need for cotrimoxazole prophylaxis, management of opportunistic infections and other illnesses, counselling and treatment with antiretroviral drugs when necessary.

Antiretroviral drugs have had a dramatic impact on the prognosis for children with HIV. However, their effectiveness is dependent on strict adherence to the drug regimen. The need to adhere to these drugs has major psychosocial implications for children and their caregivers. Children taking ARVs require extensive counselling by counsellors who have been trained in Antiretroviral Therapy for children.

When children present for HTC, they may be in varying conditions of health. Some may require urgent referral for assessment, medical investigations and treatment. Others may not require such urgent attention but will require that the counsellor follows up the referral to ensure that the child and caregiver have accessed the necessary treatment and care.

3. Referral for social welfare support and assistance

It is important that counsellors have established links with social welfare and other support services. Very commonly the HIV positive child and their family will have significant social challenges. The child’s family may lack sufficient resources to provide the care that the child needs including the costs associated with transport to clinic, medication and medical fees. Basic needs such as adequate nutrition may not be met.

Furthermore, frequent illness and hospitalisation commonly results in HIV positive children falling behind at school or dropping out of school completely. This has profound effects on the child’s educational needs but also on their emotional need to feel like their peers and to realise their own potential.

It is often very difficult to ‘solve’ the child’s social difficulties but with appropriate referral, it may be possible to alleviate some of the stressors on the children and families.
4. Peer support groups

As children grow through childhood, they develop a strong need to be like their peers. An HIV diagnosis leads children to feel that they are different, to feel isolated and afraid. Peer support groups are a powerful follow up counselling, care and support strategy for any HIV positive child. The groups provide children with an opportunity to socialise with others who share similar experiences and difficulties in life in a safe, supportive, trusting environment.

Depending on the activities of the support group, children can benefit from group and/or peer counselling and learn essential skills for living positively.

As children develop through adolescence, their natural desire for normal physical and emotional relationships starts to develop. Adolescents with HIV therefore become increasingly aware of the implications of their HIV status and begin to develop fears about the future. How will they meet a boyfriend / girlfriend? What will they tell him/her about his/her HIV status? Can they have an HIV negative partner? Will they be able to have children? At a time when the adolescent should be planning and looking forward to the future, the future is full of uncertainty and fear.

Again, peer support groups provide a safe environment in which these issues can be explored.

5. Multidisciplinary Liaison

Due to the diversity of the needs of HIV positive children, multidisciplinary teamwork is essential. Principles of confidentiality and the need to protect the child’s best interests at all times must be adhered to. However, professional, sensitive multidisciplinary teamwork has the potential to significantly impact on the child’s quality of life through addressing their different needs through a variety of approaches.
Worksheet 7

Strengthening of Referral Networks

<table>
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<tr>
<th>In your facility, what follow up care and support services exist for children testing HIV positive?</th>
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<tr>
<th>In your facility, what gaps are there in follow up care and support services for children testing HIV positive?</th>
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<th>How can these gaps be addressed?</th>
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Session 2: Disclosure

Objectives

At the end of this session participants should be able to:

- Define what is meant by “Disclosure” in relation to children and HIV
- Demonstrate an understanding of the key principles of disclosure for children
- Demonstrate skills in disclosing HIV status to a child using appropriate counselling skills and techniques

Activities

- Activity 1: Discussion – Disclosure
- Activity 2: Presentation – Disclosure
- Activity 3: Case Scenarios / Role Play - Disclosure
Acknowledgement: This presentation is based on two training manuals: 1) Paediatric HIV Home Based Care Manual (ECI, 2004) and 2) Paediatric ART Training Manual (MoHCW, 2006)

Previous modules have acknowledged that at the time of HIV testing, not all children will be ready to be informed that they are being tested for HIV or to be told that they tested HIV positive. The child will have been helped to understand more about events impacting on him / her through sharing appropriate information in an appropriate manner, but HIV will not have been discussed openly with the child.

However, for all children testing HIV positive, there will inevitably come a time when they need to be told that they are living with HIV. This process is known as “Disclosure”. Good counselling will ensure that disclosure becomes a standard of care for children with HIV infection. When disclosure is planned and structured it enhances the treatment, care and support for children and their families. On the other hand, unplanned or accidental disclosure has negative consequences.

What do we mean by disclosure?

**Disclosure is the process of informing the child of his or her own HIV status or informing someone else about the child’s HIV status. (MoHCW, 2007a)**

This module discusses the issue of informing the child of his or her own status

**Barriers to Disclosure for Children**

There are numerous barriers to disclosure for children with HIV. These relate either to adults’ lack of understanding of children’s needs or to adults’ fears and beliefs surrounding sharing sensitive information with children. They include:

- A belief that the child will not understand or be able to adjust and cope
- A desire to protect the child (e.g. fears pertaining to stigmatisation and discrimination)
- A firm belief that disclosure will take away the child’s hope and will to live
- Parental non-readiness (e.g. not yet ready to face questions, sense of fear and/or guilt)
- Inadequate skills to inform a child that they have HIV
- Fear of how the child will react
• Concern that the child will tell others

**Effects of delaying disclosure**

These barriers are all understandable concerns and beliefs. However, delaying disclosure when the child is actually ready to be told has a negative impact on that child. The child is made more vulnerable as:

• He/she is unable to understand events in his/her life
• He/she has no sense of control over things affecting him/her
• He/she may imagine things have happened/will happen and/or come up with the wrong conclusion
• He/she may blame him/herself for traumatic events
• He/she may be unable to trust adults
• He/she may learn his/Her HIV status in a manner that is not supportive
• In the unfortunate event of the parent’s death, the opportunity is lost for him/her to discuss his/her illness with the parent

**Benefits of Disclosure**

The benefits of disclosure include:

• Equipping children with accurate and appropriate information in a way that they can understand
• Assisting children to cope with the implications of their HIV status through greater knowledge and understanding
• Empowering children through involving them in their care
• Promoting children’s sense of self control, self esteem and reduce anxiety
• Assisting children to make choices and decisions about issues which affect them and improve their quality of life, including adherence to treatment
• Helping both the child and family adopt a positive attitude

Disclosure is one of the most crucial yet one of the most challenging components of counselling children with HIV. If disclosure is not handled appropriately, this could cause long term damage for the child and his family. However, if it is handled well, a skilled counsellor has the potential to equip
a child with knowledge, understanding and coping strategies which will greatly assist him and the family in coming to terms with his HIV status.

**Principles of Disclosure**

The aims of disclosure are achieved through adherence to general principles:

- Disclosure of HIV status to a child is based on the need to protect the best interests of that child at all times
- Disclosure is carried out in partnership with the family / caregiver and respects their views and wishes
- Disclosure is a process, beginning with the first contact with the child and planned together with the family/caregiver
- Age at which disclosure is carried out is based upon each child’s individual needs, understanding and maturity but the process may begin from 5-7 years
- Disclosure is honest and does not involve lies

**Partial Disclosure**

If children are not yet ready for full disclosure, (i.e. naming HIV), it remains essential that they are provided with information which helps them to understand and cope better. This is known as partial disclosure. The child is provided with accurate, honest explanations about what is happening to him/her but the complete explanation (i.e. naming HIV) is withheld until a time when deemed more appropriate.

A study in France found no differences in psychological adjustment among children who had had a full or a partial disclosure, but a poorer adjustment in those who had been deceived about the nature of their condition (Funck et al, 1997 in MoHCW 2007b).

**Preparations for Disclosure**

The first step in the disclosure process is to assess:

1. Readiness of the child for disclosure
2. Readiness of the parent/caregiver for disclosure

1. Readiness of the child for disclosure
Disclosure may begin at any age – children as young as 6 or 7 years may be informed of their HIV status. However, age alone is an unreliable indicator of the ‘right’ time to disclose. The time to disclose is dependent on:

- Family wishes and available support post-disclosure
- Age and developmental stage
- Child’s current needs and experiences
- Child’s personality
- Previous experiences (parental illness, death, own illness)
- Current knowledge and understanding
- Child’s coping mechanisms

Determining the child’s readiness for disclosure depends on the counsellor’s skills in assessing the above factors and adhering to the principle of protecting the best interests of the child at all times.

2. Readiness of the Caregiver for disclosure

As discussed above, caregivers may have significant concerns around disclosing to the child. The role of the counsellor is to be non judgmental and supportive whilst informing the caregiver of the disadvantages and advantages of disclosure to their child. The best interests of the child must be protected at all times.

If the parent/caregiver is not yet ready for disclosure, counselling should continue at each contact with the family.

If they agree to proceed with disclosure, the counsellor must then discuss and confirm with the caregiver exactly what will be said to the child. It is important to get permission from the caregiver to discuss sensitive information and to prepare him/her for possible reactions and questions from the child.

Counsellors should reassure caregivers that their wishes regarding disclosure/information sharing will be respected. Caregivers should be told that providers will not lie to the child and that if children ask direct questions, providers will give simple direct answers and/or refer the child back to the caregiver.
Who should Disclose?

Information shared with children in the wrong way or by different people in different ways can do more harm than good to the child.

Ideally the parent or caregiver should disclose in order to maintain and/or strengthen the child/parent relationship but they will need much support. This can take many forms:

Disclosure can occur at home with a follow-up visit in the clinic soon after. Where parents/carers have disclosed outside the clinic, this should be followed up with counselling to ensure the child has understood the information given to them. Also children may have lots of questions which parents/carers need help answering.

Disclosure can occur in the clinic with the physician, nurse, counsellor, clergy member present. Alternatively, Health Professionals, Counsellors, Social Workers can disclose with the parent present.

The disclosure process should be carefully planned and carried out by someone who has been trained in disclosure to children, in partnership with the family.

What Should the Child be Told?

One of the major barriers to the disclosure process is that adults commonly do not know what to say to a child or how to say it. This has been addressed throughout the training – participants will have acquired knowledge and skills for talking about HIV with children in earlier modules. The methods, skills and tools used in Pre and Post Test counselling can also be used in the disclosure process.

The challenge is to assess each individual child and provide explanations which he/she will be able to understand, remember and cope with. Conversations should be led by the child, at their own pace.

How Might the Child React?

Each child is different and the way in which they respond to being told that they have HIV infection will differ from one child to the next. It is difficult to predict the way a child will respond and counsellors must be prepared for different reactions. Different responses may include:

- Quiet and withdrawn
- Crying
- Accepting, matter of fact
- Asking lots of questions
- Relief as they can now make sense of their experiences
- Wanting to get on with other things
• Anger
• Surprise, shock

All responses are appropriate and the child must be given time to absorb what he has been told and to then express how he is feeling. The child may have already suspected his/her diagnosis or may be completely shocked.

Often, after disclosure occurs, children do not have any questions at first. Many need to process what they have been told. Ideally a clinic visit/counselling session/home visit should be scheduled shortly after the disclosure to assess how the child and family are coping.

The child should be allowed to meet privately with a member(s) of the health care team. Often children have questions that they do not feel comfortable with the parent present – this is no reflection on the quality of the relationship. Children are very protective of their parents and withhold certain questions as they fear upsetting their parent/caregiver.

Even if children have no response when disclosed to, they should be reassured that the team is there to help them stay healthy and to deal with their illness. Whenever possible, they should be given positive messages that their family and the health care team will be partners in caring for them.

Be Prepared for Questions

In the same way as for children who have been informed of their HIV status in post test counselling, the child may ask difficult questions, such as:

• Does this mean that I will die?
• How did I get it?
• Who else has got it?
• Why did no one tell me before?
• Who else knows I have HIV?

The general principles of counselling of children apply. Always respond openly and honestly.

It is important to remember that a quiet child does not mean they have no questions or have understood everything. It is the counsellor’s responsibility to ensure the child has opportunities to express himself and ask questions whilst not coercing or forcing the child.
Follow Up Counselling Post Disclosure

The act of disclosing HIV status to a child is only the beginning of the Disclosure process. Continued counselling for the child and family following disclosure is vital, particularly as the needs of children change over time.

- Provide opportunities for the child and family to gather more information, gain further understanding and express difficulties they are facing
- In partnership with the family, help the child to know who he/she can talk to
- Regularly assess the child’s understanding of his/her condition, difficulties he may be having in coping (e.g. behaviour change)
- Link in with other social and spiritual support services, including socialising with other children e.g. support groups

Summary

- Not all children will have been informed of their HIV status when they were tested for HIV. Disclosure of HIV status to children is therefore an important part of follow up counseling, care and support
- Disclosure is a gradual process of sharing appropriate information about HIV with the child in an appropriate manner
- Time of disclosure is determined by the each child’s individual needs, understanding and maturity but the process may begin from 5-7 years
- Partial disclosure assists children to understand more about events in their lives without until the time when full disclosure of HIV status is possible
- Information shared with the child in the wrong way or by different people in different ways can do more harm than good
- The act of disclosing HIV status to the child is only the beginning – continued counseling for the child and family post disclosure is vital
### Worksheet 8

**Case Scenarios / Role Play – Disclosure**

<table>
<thead>
<tr>
<th>Case Scenario 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nyaradzo is 7 years old. She tested HIV positive last year when she first moved to a children’s home near your clinic. She has been attending your HIV clinic for 6 months during which time she was commenced on ARV treatment and is doing well. She does not know her HIV status. She attends the clinic with 5 other children from the same children’s home, all of whom are older and do know their HIV status. You ask the matron from the children’s home how she feels about informing Nyaradzo that she is HIV positive. The matron agrees that Nyaradzo should be told but is worried about doing it herself.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Case Scenario 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dumisani is 14 years old. He has been attending your clinic for ARV treatment since two years ago. He lives with his mother who is also on ARV treatment but has had great difficulties coming to terms with her own HIV status and that of Dumisani. She has always made it clear she does not want anyone to know their status and Dumisani must not be told. She feels he is not yet ready as he does not ask any questions about why he comes to clinic or takes medication.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Case Scenario 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thembie is 12 years old. She was sexually abused by her father four years ago and infected with HIV. Her father is now late and Thembie lives with her mother who is HIV negative. Thembie is well and not yet on ARVs but is being monitored closely. Her mother has informed you in the past that she is terrified of the day when she has to inform her daughter of her HIV status. Today in your clinic, Thembie’s mother informs you that Thembie has started asking many questions about why she must come to clinic when she is so well.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Case Scenario 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kukhanya is 10 years old. She lives with her mother, father and younger sister. Kukhanya’s mother brings her to clinic and is also HIV positive. Her father is HIV negative. Kukhanya’s parents are extremely anxious about informing Kukhanya of her status as they are not prepared to answer questions about how she was infected with HIV. However, Kukhanya saw ARVs advertised on the television and is asking why she has to take them when she does not have HIV infection herself.</td>
</tr>
</tbody>
</table>
Session 3: Adherence Counselling

Objectives

At the end of this session participants should be able to:

- Define adherence
- Describe the role of Antiretroviral drugs in the management of children living with HIV
- Demonstrate an understanding of the importance of adherence to ART
- Describe potential challenges with adherence for children
- Provide adherence counselling for children and their caregivers

Activities

Activity 1: Discussion – Adherence

Activity 2: Presentation – Adherence Counselling

Activity 3: Case Scenarios / Role Play – Adherence Counselling
Adherence Counselling

(Acknowledgement: This presentation has been adapted from the Ministry of Health’s Paediatric ART Training Manual, 2007)

Defining Adherence

Adherence is “the act or quality of sticking to something, steady devotion; acceptance of an active role in one’s own health care”

Adherence to Care

Central to the appropriate management of children with HIV is the need for adherence to care. This includes:

- Entering into and continuing in a management and treatment program
- Attending appointments and tests as scheduled
- Taking medications as prescribed (adherence to treatment) - TB treatment, cotrimoxazole prophylaxis and ARVs

Trainers should emphasize that adherence does not just refer to medications; patients should demonstrate adherence to care even before medications are prescribed. Patients that are unable to keep clinic appointments or take cotrimoxazole prophylaxis may not be able to adhere to ARV regimens.

However, circumstances exist that may make adherence to care difficult e.g. transportation barriers, inability to miss work, distance to clinic. These barriers must be assessed and addressed. These will be discussed later in the session.

Adherence vs. compliance

Traditionally, health workers are used to the term compliance, particularly in respect to TB medication. However, it is important to stress that adherence and compliance are different concepts. The emphasis is very different and must be recognized and accepted by counsellors as it has an impact on the counsellor/child/family relationship.

Adherence: the act or quality of sticking to something, steady devotion; acceptance of an active role in one’s own health care
Compliance: the act of conforming, yielding, or acquiescing; lack of sharing in the decision making process

Adherence involves the child and family as directly involved and committed to the drugs whilst compliance suggests that the child and family are merely following orders.

Adherence in ART

What are Antiretroviral Drugs?

Antiretroviral drugs are drugs which are used to fight the virus directly, in contrast to drugs which are used to treat or manage the consequences of HIV e.g. treatment for OIs

Antiretrovirals work by interfering with the replication of HIV in the body. The primary goal of ARVs is to decrease or reverse immune system damage associated with HIV infection. In turn, the number of infections is reduced, general health improves, quality of life is restored and the length of life is increased.

At this point, the counselling approaches discussed in Module 4 should be referred to as a means of explaining the way that ARVs work. These are powerful tools for counsellors as they provide an interactive and participatory method for describing HIV and the way ARVs work in children.

Antiretrovirals

ARVs have had a dramatic impact on the prognosis for children and adults living with HIV, turning it from a terminal disease to a chronic illness which people may live with if managed appropriately.

It is important to note that not every child will need ARVs as soon as they are diagnosed with HIV. It depends on the strength of the immune system and the clinical condition of the child. If the CD4 count remains high and the child is clinically well, it is often in the best interests of the child to delay commencing ARVs until later. Meanwhile, the child is monitored closely.

Adherence to ARVs

What is meant by adherence to ARVs?

- Taking the correct ARV drugs
- In the correct dose
- At the correct time
- Under the correct circumstances (e.g. food restrictions)
It is essential that counsellors are clear on this definition in order that they are adequately equipped to counsel children and caregivers.

**Importance of Adherence**

So why is adherence so important for children taking ARVs?

Adherence is key to successful outcomes by:

- Achieving viral suppression
- Preventing drug resistance

**Consequences of Non Adherence**

- Incomplete viral suppression
- Continued destruction of the immune system and decrease of CD4 cell count
- Progression of disease
- Emergence of resistant viral strains
- Limited future therapeutic options and higher costs for individual and program

**Adherence and Suppression of HIV**

![Graph showing adherence and suppression of HIV over time](chart.png)

Factors Affecting Adherence

There are numerous factors affecting adherence and thus the outcome of care for the child. An understanding of these different factors and their impact on adherence is central to the provision of quality ART and adherence counselling for children and their caregivers.

### Factors affecting Adherence: The Medications

- Availability of drugs in palatable, liquid or mixable formulations
- Regimen complexity
- Difficult to administer drugs that have requirements to be given with or without food because of children’s (particularly infant) eating schedules
- Dosing Frequency
- Regimen

Infants and young children are dependent on others for administration of medication; thus, assessment of the capacity for adherence to a complex multi-drug regimen requires evaluation of the caregivers and their environments and the ability and willingness of the child to take the drug. Some caregivers may place too much responsibility on older children and adolescents for managing medications.

Educating families about adherence should begin before antiretroviral medications are 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 medication adherence. Strategies could include information and adherence tools, such as: written and visual materials, a daily schedule.
illustrating times and doses of medications, and demonstration on using syringes, medication cups and pill boxes.

**Difficulties taking Medication**

1. **Medication-related**
   - Taste/palatability/volume
   - Taste may cause nausea
   - Too many pills

2. **Social Issues:**
   - Fear of Disclosure
   - Visiting or going out with friends
   - Visiting relatives over the weekend
   - Visitors in the house that do not know the diagnosis
   - Alternate caregiver that does not know the diagnosis

**Factors affecting Adherence: the Child**

- Child’s dependence on caregivers for administration
- Child’s developmental level influences ability and willingness to take medications
- Toddlers may refuse based on palatability
- Adolescents have many complex issues

Adherence is usually good in small children who are supervised by a responsible, dedicated adult.

Difficulties arise when the carer is very young (e.g. child headed household) or the caregiver is constantly changing or not committed to adherence.
Factors affecting Adherence: The Family

Poor family circumstances compound the adherence difficulties including lack of disclosure or family support. A careful social assessment should always precede the commencement of therapy.

A family’s reluctance to disclose the child’s diagnosis to the child may lead to adherence difficulties in the future when the child does not understand the need for medication.

Counselling Children and Caregivers about Antiretrovirals and Adherence

As indicated above, Antiretroviral therapy is not just about drugs, clinical and laboratory markers – there are many psychosocial dimensions which influence the success of treatment and the impact of therapy on the child and family.

ART Counselling for the child and family is an essential component of Antiretroviral treatment, both:

PRIOR to commencing treatment - to ensure that the child and family are ready for ART and to assess potential barriers to adherence.

THROUGHOUT treatment, at every visit - to ensure continued adherence and identification of difficulties the child/family may be having.

Effective ART counselling is an invaluable investment and directly influences treatment outcomes but it requires:

- Time
- Commitment
- Trained counsellors in issues relating to HIV and ARVs
- Assessment and understanding of each child and family’s needs / difficulties
- Multidisciplinary team approach
- Non-judgmental, open approach

Counselling Children and their Caregivers about ARVs and Adherence

Information shared and explanations given will depend on each individual child’s:

- Parental/ caregiver readiness
- Developmental stage
Current knowledge/understanding

Previous explanations (Take time to hear and assess what they already know and understand)

Ability to absorb new information

Level of support

Be careful what you promise! Be consistent and honest with regard to what the child may expect when on treatment. He should know that this is not a ‘cure,’ the drugs do not stop in 2 weeks, there may be side effects, he may still get sick especially at the beginning

General Principles of ARV Counselling for Children

Above all, INVOLVE the child – it is he/she who has to swallow the tablets every day. Involving the child promotes the child sense of control, increases self esteem, and promotes a trusting, open relationship and ADHERENCE!

Give the Child Choices

ARV Counselling for BOTH child and caregiver together in the same room helps to promote a common understanding and shared vocabulary about the drugs and a supportive child-caregiver relationship

Don’t rush to start treatment: ensure child AND family are ready and committed

Use creative, visual strategies such as games and drawings to explain ARVs

Counselling should also address practical issues: e.g. storage of drugs, building drugs in to daily routine, Can the child swallow tablets? Can the carer accurately measure syrups? Can the drugs be mixed with food? Use of adherence charts, colour coding bottles

Remember WHO? WHAT? WHEN? HOW? – Assess each child and family prior to starting ART. Assessment and monitoring is on going

Sick children may be very much in need of treatment but if they do not fit the criteria above, ART may fail and treatment should not be commenced. This can prove very challenging for health workers who want to commence treatment yet it is in the best interests of the child

Steps in Achieving Adherence

There are various steps involved in achieving adherence and the counsellor has a vital role to play in each step.
• Assess readiness
• Education
• Preparation
• Ongoing monitoring/assessment of adherence
• Support
• Addressing Barriers

Assess Readiness

Adherence to care should be established before ARVs are prescribed. The multidisciplinary team must explore barriers to adherence to care and attempt to address them. This often poses ethical dilemmas for health workers. It is not always possible to resolve some barriers to adherence and the child may consequently not be commenced on ARVs. Common barriers include lack of dedicated caregiver, transportation difficulties and financial constraints.

Assessing readiness involves the following questions:

• Is there a consistent caregiver that can administer or supervise ARVs?
• Is the family adherent to clinic appointments?
• Has the child been adherent to cotrimoxazole prophylaxis or other regimens such as INH prophylaxis/TB treatment?
• Does the child and/or caregiver have good understanding of the child’s condition and need for treatment?
• Does the child and/or family want to commence ARVs?

Education

Ensuring that the child and/or caregiver have appropriate knowledge and understanding about the drugs is central to promoting adherence. If drugs are merely handed over without the necessary counselling, adherence will be poor and treatment will fail. Counsellors have a duty to educate the child and the family about the drugs.

In the same way that children who have not been informed that they have HIV can gain enormous benefit from partial disclosure (i.e. honest, accurate information in a way which helps them to understand more but does not involve naming HIV), non-disclosed children must have appropriate explanations regarding the need for medication. It is the role of the counsellor to assist the child to understand that the medication is to help his/her body to become strong again so that he/she can stay well.
Points to be covered include:

- Define adherence
- Never miss a dose
- Keep to specific medication times
- Method of administration
- Lifelong treatment even when feeling well
- Acknowledge difficulty of taking medicines “for life”
- Explain importance of strict adherence
- Emphasize need for communication with health care team
- Trust, partnership, honesty

Preparation

Preparing the child and family is essential. ART is rarely a medical emergency – ‘rushing in’ commonly leads to poor adherence as the child and family are not adequately prepared. Although health workers and family may be understandably eager to start treatment in order to help the child, this preparatory stage is an important ‘investment’ for the future success of treatment.

Take time to prepare the child and caregiver with the following information and assist them to formulate a plan for adherence to the drugs within their own home and personal circumstances:

- Medication administration should be done as consistently as possible – routines should be established early. Consistent routines are often reassuring for children and will aid adherence.
- What regimen is being used? The caregiver should be able to describe the medicines and doses as well as side effects to monitor for.
- When will medicines be given? Establish convenient times with the family that take into consideration family, school, and work schedules.
- Involve the child in preparation of the drugs
- Will tablets be crushed or swallowed?
- Will medicines be mixed with liquids, or be given with food?
- How will liquids be measured?
• Who will give the medications? Will they be given every day?

• Who is the "back-up" – who will give the medications if the caregiver can't? This person should be trained by clinic staff if possible.

• What should the caregiver do if problems arise? Methods for contacting clinic when closed

• Caregiver should demonstrate medication preparation (measuring accurately using syringe, crushing, mixing). Problems with administration can be identified early

• Ideally, a one week supply should be dispensed initially for four weeks to monitor for problems that can be addressed early. Visits can then be scheduled monthly

**Continued ART Counselling**

The importance of continued ART Counselling cannot be over emphasised. It does not stop once the child starts treatment.

• It is essential to re-assess the child and carers understanding of the drugs, any problems they may be experiencing, the impact of the drugs on their life

• The child’s height, weight and blood results are a powerful adherence tool when counselling the child. Height and weight are something they can visibly see changing and is a result of their own action i.e. taking the drugs. This can really encourage the child to continue

• **NB:** Like adults, when children are very sick, adherence may be good as they want to get better. However, as they get well, adherence to the drugs may not seem so important and ART counselling becomes even more vital

**Assessing Adherence**

Ask the child AND the care giver

• Can he/she describe the medicine he/she takes?

• Can he/she tell you how often he/she takes it?

• Is he/she able to swallow the tablets? / Can he tolerate the syrups?

• Why does he/she take it?

• Does he remember to take them? What does he do to help remember?
Ongoing Monitoring and Assessment of Adherence

There are no perfect measures to monitor and assess adherence. However, the following measures can be taken:

- Emphasize the importance of honest reporting
- Importance of multidisciplinary approach to monitoring
- Caregiver/Child’s reports
- Medication counts
- Biological markers
- Pharmacy records

The above are time consuming but essential

Caregiver /Child’s Report

Skilled counselling with the child can provide important information regarding the child’s adherence to ARVs.

- A series of non judgemental questions at each clinic visit (e.g. can you tell me how many doses you have missed this week? Are you having any difficulties with taking the drugs?)
- Caregiver/Child’s report using a 3 day, 1 wk, 1 month or most recent recall of missing a dose
- Has a tendency to over estimate
- The reliability of self-report relies on a trusting, non judgmental relationship between the counsellor and child/caregiver
- Easiest tool in clinic setting
- Always ask “how many doses did you miss” rather than “did you miss doses?” This gives the message that it is OK to report missing doses

Medication Counts

Providers count the remaining medication during clinic visit. Problems with this approach are that it relies on the child / caregiver bringing their remaining drugs to clinic. Furthermore, the child /caregiver can hide pills prior to the visit. Unannounced pill counts can be better.
**Biological and Clinical Markers**

- Improving clinical status – growth, developmental milestones, school performance, less illnesses
- Improved CD4 count
- A decreasing viral load implies good adherence
- But in some patients viral load may remain high even with good adherence: (? Viral resistance, ? Poor absorption of the drug)

**Pharmacy Records**

Pharmacists keep record of drugs dispensed to each child. These can inform the relevant doctor of lapses in children collecting their medicines.

The disadvantage of this approach is that it is not a measure of ingestion and it requires children to always use the same pharmacy

**Support: Promoting Adherence**

- Involve the child in a plan of care. Don’t rush to initiate ART. It is rarely a medical emergency. Both caregiver and child must be ready
- Provide ongoing counselling: Individual or group
- Information/Education/Communication on ARVs - provide simple written information (booklet, pamphlet, cartoons and bubbles)
- Warn the child and caregiver about common side effects
- Ensure the same adherence message by all health workers
- Directly observed therapy whenever possible

**Support: Family and Community Involvement**

- Identify a dedicated, consistent family caregiver or buddy for the child
- Familiarize them with ART and adherence
- Involve them during medical consultations and counselling sessions
• Home based care: Educate family caregiver to recognize side effects and refer to hospital if needed

• Community involvement and understanding of ARV therapy is important

• Recognise multiple caregivers for children in institutions

**Adherence Fatigue**

• Do not assume that once adherent, always adherent – things change!

• Children improve clinically and may feel medications are not needed

• New stressors may arise – e.g. death, change in caregiver

• Assessment is necessary at every contact

• Over time, it is very common for children to tire of taking medications

• Caregivers tire of administering/supervising medications

• Providers tire of monitoring/supporting adherence

**Support: Recognising Challenges in Adherence**

• Poor communication

• Misunderstanding/misinformation/misconceptions

• Low literacy if written materials are given

• Lack of social support

• Disclosure

• Financial barriers

• Competing priorities (Work, Child care)

• Stigma and denial

• Alcohol and drug use by the caregiver

• Mental and Physical illness on the caregiver
Testimony

“They kept handing me more and more medicine, saying take this.

So I just used to flush them down the toilet.

Then they told me why I needed them – now I take them”

(Tafadzwa, 11 years)

Summary

- Adherence is defined as the act or quality of sticking to something, steady devotion; acceptance of an active role in one's own health care
- Adherence to care is central to the appropriate management of children with HIV
- Adherence to ARVs is one of the major counselling issues in the follow up care and support for children with HIV
- Adherence to ARVs is key to successful outcomes by achieving viral suppression and preventing drug resistance
- There are many factors which make adherence to ARVs difficult for children
- Counsellors have a vital role to play in the provision of adherence counselling for children and their families
## Worksheet 9

### Case Scenarios / Role Play – Adherence Counselling

**Case Scenario 1**

Alfred is 7 years old. He is HIV positive but does not know his HIV status yet. He needs to commence ARVs as his CD4 count has fallen. His parents are also taking ARVs and they are eager for him to start treatment. You have counselled the parents alone about ARVs but you now need to counsel Alfred about the need for him to start taking medication without disclosing his HIV status to him.

**Case Scenario 2**

Buhle is 12 years old. She has known her HIV status for two years now and has been attending your clinic for regular monitoring with her aunt. Buhle now needs to commence ARVs as her CD4 count has fallen although she remains clinically well.

**Case Scenario 3**

Tenda is 14 years old and lives with his grandmother. He is aware of his HIV status and has been taking ARVs now for one year. When he commenced treatment, his CD4 count was 10 and he had been very unwell with cryptococcal meningitis and severe wasting. Initially, he made good progress on treatment – his CD4 count improved to 110 and he improved clinically. However, his last blood tests indicate that his CD4 count has started to fall.

**Case Scenario 4**

Naume is 6 years old. She is an orphan, living with her aunt since her parents passed away last year. She tested HIV positive last week at your clinic. She is extremely sick with TB, chronic diarrhoea and oral candidiasis. She is not eating and is unable to walk. Her aunt is extremely worried about her and wants her to start ARVs. Naume’s aunt is a cross border trader and is often away from home in order to earn the little income they have. Other household members include the aunt’s own children, 14 and 16 years of age.
Module 6: Counsellor Self Care, Supervision and Quality Assurance

Introduction

Counsellors have a central role to play in ensuring that children have access to high quality counselling which meets their needs. This counselling can be extremely rewarding. Yet it is a difficult, emotionally demanding task, even for highly experienced counsellors. It can be a sad, frustrating and challenging role. This can lead to physical and emotional stress, which if not addressed can result in burnout. Burnout affects counsellors on a personal level but also impacts on their ability to fulfil their role effectively.

This module reviews possible causes, signs and symptoms of stress and burnout when working with children in the context of HTC. It discusses self care and support strategies and the development of stress management plans.

It then describes the role of supervision and quality assurance in ensuring the delivery of quality counselling for children accessing HIV testing and follow up care and support services.

Module Objectives

At the end of this module participants should be able to:

- Demonstrate an understanding of stress and burnout
- Describe potential sources of stress in counselling children for HIV testing, follow up care and support
- Recognise signs and symptoms of stress and burn out
- Implement stress management strategies
- Describe the purpose of Quality Assurance and the counsellor’s role in Quality Assurance
- Describe and recognise the role of Supervision

Overview of Sessions

Session 1: Counsellor Self Care, Supervision and Quality Assurance
Session 1: Counsellor Self Care, Supervision and Quality Assurance

Objectives

At the end of this session participants should be able to:

- Demonstrate an understanding of stress and burnout
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- Recognise signs and symptoms of stress and burnout
- Implement stress management strategies
- Describe the purpose of Quality Assurance and the counsellor’s role in Quality Assurance
- Describe and recognise the role of Supervision

Activities

- Activity 1: Discussion – Stress and Burnout
- Activity 2: Presentation – Counsellor Self Care, Supervision and Quality Assurance
- Activity 3: Action Planning – Developing a Stress Management Plan
Understanding Stress and Self Care

Counsellors spend a considerable amount of time supporting other people yet they too need support. It is imperative that counsellors have the knowledge and skills required for recognising potential sources of stress, their effects and self care strategies to avoid stress that leads to burnout.

What is Stress?

Stress refers to “physical, mental or emotional strain or tension” caused by overworking the mind, body and heart. This strain or tension causes a number of physical, emotional and mental symptoms” (MoHCW, 2005).

Stress often originates from an external event or circumstance that places a demand on an individual’s inner or external resources. How stressful an event is felt depends partly on the individual’s resources. If the demands on the person (e.g. disclosing an HIV-positive test result to a child and his/her family) exceed his or her ability to cope with them, the person experiences stress (MoHCW, 2006).

“Stress is an inevitable part of life. As a positive influence, stress can help compel us to action – it can result in a new awareness and an exciting new perspective. As a negative influence, it can result in negative feelings which in turn lead to health problems. It is not possible to eliminate stress from our lives. Our goal is to learn how to better manage stress and to use it as a positive force in our lives” (MoHCW, 2006).

Signs and Symptoms of Stress (MoHCW, 2005)

Stress can present itself in different ways in different people but some of the common signs and symptoms include:

- Physical or mental exhaustion causing general body weakness
- Irritability
- Lack of concentration or forgetfulness
- Loss of appetite / eating too much
- Palpitations
- Restlessness
- Inability to sleep
Whilst stress is inevitable for HIV counsellors and needs appropriate management, burnout is not. Stress Management is important in order to prevent stress leading to burnout.

**What is Burnout?**

If the counsellor faces prolonged exposure to stress, this can result in burnout. “Burnout” has been described as “a physical, emotional, psychological and spiritual phenomenon, characterized by progressive loss of idealism, energy and purpose experienced by people working in helping professions” (MoHCW, 2006).

A person is identified as having **burnout** when the **stress** is: (MoHCW, 2005)

- **Persistent** – It does not easily go away
- **Unprovoked** – It does not have an immediate cause
- **Excessive** – It goes beyond an appropriate reaction to a particular cause
- **Disruptive** – It compromises your ability to work
- **Involuntary** – You feel it even though you don’t want to
- **Generalized** – It spills over to feelings about your personal life

**Signs and Symptoms of Burnout** (MoHCW, 2005)

When a counsellor reaches “burnout”, he/she may experience a number of the following symptoms:

- Pessimism, helplessness and hopelessness
- Anger and prejudice
- Chronic fatigue
- Emotional numbness and indifference; social withdrawal
- Emotional hypersensitivity
- Impulsiveness, acting out and addictive habits
- Chronic and non specific physical aches and pains, with no medical explanation
- Grief, sadness and depression
- Self righteous heroism and withdrawal from people outside of HIV and AIDS work
Potential Sources of Stress and Burnout when working with children and HTC

All HIV counsellors face recurrent stressful situations. This is particularly so when working with children in the context of HIV. There are numerous potential sources of stress, some of which include:

- Sense of being overwhelmed by the number of children affected by HIV infection
- Excessive workload due to number of children requiring your services
- A strong sense of commitment to the needs of children and their families in your care
- Identification with the child and their family (e.g. fears for your own children or similarities with your own family situation)
- An overwhelming desire to protect the child
- Sense of helplessness and desire to do more to assist the child
- Fear of discussing sensitive issues with the child (e.g. HIV, MTCT, death, coping with HIV)
- Powerful emotions of anger, frustration, sadness for child’s situation
- Fear of HIV infection
- Coping with the emotions and responses of both the child and their family
- The need to ‘hide’ the diagnosis from the child as the child and/or family are not ready
- Fatigue, monotony (repeatedly saying the same messages, same explanations)
- Strong emotions about teenagers’ risky behaviour
- Witnessing and responding to the strong emotions of children
- Dealing with challenging legal and ethical dilemmas
- Child’s behaviour / family’s behaviour towards you
- Not enjoying the counselling role
- Informing children of bad news
- Insufficient access to supportive and experienced supervisors
- Inadequate training to perform a counselling role
- Inadequate resources to assist in fulfilling your role
- Not being realistic about your limits, understanding and experience
• Inability to express your feelings, particularly anger and grief
• Lack of effective ways of coping with stress

**Self Care Strategies**

It is important that counsellors implement self support strategies in order to help alleviate the stress encountered in their work and to prevent it from leading to burnout. Various strategies should be implemented and these are as follows:

**1. Know Yourself**

Knowing yourself is the starting point of taking care of oneself. If counsellors are able to understand their own needs and capabilities, this can assist them in anticipating stressful situations, recognising how they respond to stress and then managing the stress.

**2. Take Care of Yourself**

In their efforts to care for others, it is important that counsellors do not neglect themselves. This includes eating a healthy diet, getting enough sleep, exercise and use of relaxation techniques.

**3. Enjoy Yourself**

Counsellors should develop boundaries between professional and personal life. This emotionally demanding role requires that counsellors take regular time out of work to relax, spend time doing the things they enjoy and socialise with family and friends outside of work.

**4. Know Your Limits**

Counselling children and their families is a challenging role, even for the most experienced counsellor. Knowing your limits involves recognising and accepting the limits of your knowledge and expertise so that you are not stressed by the feeling of being unable to cope or manage. Knowing when to ask for help and when to refer to others is an important part of preventing stress. Furthermore, children commonly have a variety of needs but be realistic and accept what you can and cannot do.

**5. Express Yourself**

Sharing your feelings, emotions and experiences with a trusted friend or colleague provides counsellors with an important opportunity to release stress.
Support Strategies

In addition to Self Care strategies, all counsellors need formal support strategies in the workplace to prevent or mitigate the effects of stress and burnout. This is especially true for child counsellors who have to deal with HIV positive children and their affected families.

Support strategies include *debriefing, support groups, training, mentorship and supervision*. These will be discussed in turn.

1. **Debriefing**

Debriefing provides an opportunity for counsellors to share challenging experiences. Counsellors provide support for one another and share management strategies.

2. **Support Groups**

Sharing of problems with other counsellors is an important strategy for minimising stress and burnout. Support groups provide an informal environment where counsellors can support and assist each other. Both social and work related issues can be discussed. This also assists in the development of a strong team in which colleagues understand and support one another.

3. **Training**

HTC for children requires specialist skills in order to fulfil this challenging role. If counsellors feel inadequately equipped to fulfil their role, this can be immensely stressful. It is essential that counsellors have opportunities for professional development, training and skills development.

4. **Mentorship**

A mentor is an experienced professional who provides support to another less experienced member of staff. An available and accessible mentor is an important source of support and training for counsellors.

5. **Supportive Supervision**

Supervision is an essential support strategy for counsellors. It is defined as “a working alliance between a supervisor and counsellor in which the counsellor gives an account or record of his/her work, reflects on it, and receives feedback and guidance”. This helps the counsellor develop ethical competence, confidence, and creativity, which enhances the quality of services offered to clients (FHI, 2005).

Supervision may be conducted either in one-on-one meetings or group sessions and should be held regularly. During these meetings the counsellor and supervisor can discuss challenging cases, share experiences and develop strategies for managing difficult situations.
Counselling supervision is neither a privilege nor a reward; it is a necessity. It is part of a legal and ethical duty of care to protect clients, and is both supportive and educational (FHI, 2005).

**Key Elements of Supportive Supervision**

The key elements of supervision are:

- Providing advice and guidance to staff
- Facilitating professional growth aimed at promoting effective counselling
- Problem solving and conflict resolution
- Building staff confidence
- Providing opportunities for debriefing

Supervisory process is characterised by flexibility and reflection

**Summary**

- Stress is inevitable when working in the field of HIV
- Counsellors need to be able to recognize potential sources of stress, their effects and self care strategies to avoid stress that leads to burnout
- Support strategies assist counsellors to prevent or mitigate the effects of stress and burnout
# Work Sheet 10

## Stress Management Plan

### Signs and Symptoms of Stress

I experience these **physical** symptoms when I am stressed ........

1.  
2.  
3.  

I **behave** this way when I am stressed.......  

1.  
2.  
3.  

I **think** this way when I am stressed........

1.  
2.  
3.  

I **feel** this way when I am stressed........

1.  
2.  
3.  

### My Stress Management Strategies are:

1.  
2.  
3.  
4.  
5.
Module 7: HIV Testing and Counselling Service Delivery for Children

Introduction

There are various models of HTC service delivery. As Zimbabwe pursues its commitment to expanding access to HTC, especially for children, the more traditional client initiated HIV testing service, (or VCT), is being complimented by Provider Initiated Testing and Counselling (PITC). This module describes the different models and their components. In addition, if HTC services are to be effective for children and their families, they must be child friendly. This module discusses why this is important and the different components of child friendly services.

Module Objectives

At the end of this module participants should be able to:

- Describe the different models of HTC service delivery in Zimbabwe
- Demonstrate an understanding of the importance of child friendly services in the delivery of quality HTC for children and their families
- Describe the different components of child friendly services
- Assess their own facility for child friendliness, identify gaps in service delivery and identify possible strategies for improving service as a means to ensuring child friendly HTC

Overview of Sessions

Session 1: HIV Testing and Counselling Service Delivery for Children
Session 1: HIV Testing and Counselling Service Delivery for Children

Objectives

At the end of this session, participants should be able to:

- Describe the different models of HTC service delivery in Zimbabwe
- Demonstrate an understanding of the importance of child friendly services in the delivery of quality HTC for children and their families
- Describe the different components of child friendly services
- Assess their own facility for child friendliness, identify gaps in service delivery and identify possible strategies for improving service as a means to ensuring child friendly HTC

Activities

Activity 1: Presentation – HTC Service Delivery for Children

Activity 2: Individual Exercise – Action Planning for Child Friendly Services
HTC Service Delivery for Children

The Vision

The Vision of the Ministry of Health and Child Welfare is:

To provide a comprehensive package for HIV and AIDS prevention, treatment and care.

Testing and Counselling is a critical component of this package

Models of HTC Service Delivery in Zimbabwe

There are currently two main models of HTC service delivery in Zimbabwe:

Stand alone provided by NGO (dedicated staff, flexible hours of operation, targets general public, easily accessible, anonymous testing, post test support group services)

Integrated into health care services e.g. district hospital, mission hospitals (ideal for rapid scaling, close links with other medical services, less expensive, low stigma but needs senior management commitment)

Approaches in HTC

There are two approaches to HTC service delivery in Zimbabwe:

Client Initiated

Voluntary Counselling and Testing

Provider Initiated

Routine (offer of) HIV testing by health care providers also referred to as “HIV screening”

Diagnostic HIV testing

Mandatory testing

These two approaches will be utilized in the provision of HTC services for children.

1. Client Initiated Approach

The client initiated approach is what is more traditionally known as VCT, or Voluntary Counselling and Testing. To date, it has usually targeted the “worried well”. The individual seeks HIV testing and
counselling services, during which he receives individual counselling to help him make an informed decision about whether to test or not. This process includes a personal risk assessment and risk reduction plan.

The primary emphasis of VCT has been on adults - identifying HIV negative individuals and encouraging behaviour change and primary prevention of HIV infection.

Conversely, VCT for children has generally been used as a means of identifying HIV infection in symptomatic children and children who have possibly been exposed to HIV through MTCT or sexual abuse. Yet the majority of VCT sites have not offered VCT services for children under the age of 16 years. This has presented a considerable barrier to access to testing for children.

2. Provider Initiated Approach (PITC)

In the provider-initiated approach, health care workers recommend HIV testing for all children attending health facilities as a standard part of medical care for children in Zimbabwe. It is aimed that this will considerably increase access for children to HTC services, facilitate earlier diagnosis of HIV infected children and early entry to treatment, care and support. It will also reduce the number of children presenting in the late stages of their illness.

However, the child or parent/legal guardian has a right to decline the test. Depending on the child’s age and special circumstances, informed consent is obtained during the normal process of consultation between the health care worker and the child or parent/guardian. The “3Cs” of consent, confidentiality and counselling are always observed.

Routine Offer of HTC

With the Provider Initiated approach, HTC is routinely offered by health care workers to all (asymptomatic) patients including children accessing:

- Antenatal, childbirth and postpartum health services
- STI services
- Health services for most-at-risk populations
- Inpatient and outpatient facilities (adults, children, surgical, medical)
- Reproductive health services
- Family and child health services (well baby clinics)
NB: A "routine" offer of HIV testing and counselling DOES NOT mean that testing is compulsory, mandatory or involuntary.

Advantages of PITC

- Normalizes HIV T&C in health care facility and the community
- HIV testing becomes the standard of care
- Provides an alternative and feasible model for delivering HTC services in a clinical setting
- Optimizes the use of human resources
- Increases uptake of HTC services
- Early identification of ARV eligible children
- Utilizes and builds on health care workers’ training, existing skills and experience
- Health care providers’ recommendations to patients for HIV testing are credible, influential and effective
- Offers services in the context of a trusted provider-patient relationship
- Facilitates patient access to and acceptance of HTC services
- Increases opportunity to provide comprehensive clinical care and to ensure continuity of care

Essential Conditions for PITC

- referral to post-test counselling services
- referral to medical and psychosocial support, for those testing positive.
- Children and their families retain the right to refuse testing

PITC is NOT

- Mandatory testing
- Testing without consent
- Testing in the absence of high quality post-test counselling
A simple way to increase numbers of people being tested – need to shift focus of resources onto good group education, rapid HIV testing, quality post-test counselling and provision/referral for other services

Key Principles of HTC are retained in ALL approaches

The Three Cs:

Confidential

Be accompanied by Counselling

Only to be conducted with informed Consent, meaning it is both informed and voluntary

Child Friendly Model of Service Delivery

When discussing models of HTC service delivery for children, it is important to address the Child Friendly model as this is central to ensuring that children have access to appropriate care and support.

Components of Child Friendly Services

Child friendly services are services that recognise the physical, emotional, social, mental and spiritual needs of individual children and their families. Services are planned and implemented in a way that addresses their different needs, minimises any potential negative impact on the child and encourages children and their families to access the service.

The components of Child Friendly Services can be considered in 4 dimensions:

a) Policies and Procedures
b) Services Provided
c) Staff Competence, Attitudes and Behaviour
d) Environment
a) Policies and Procedures

- National laws, policies and guidelines committing to child friendly services for children and their families
- Health facilities with a clear mission and strategic plan which are committed to ensuring quality service delivery for children and their families
- Established referral networks with follow up care and support facilities for children
- Ensuring adequate support and supervision for staff working with children

b) Services Provided

- HTC specifically targeting children
- HIV testing, preparation, pre and post test counselling and follow up care and support
- Peer support services on site or available through established referral networks

c) Staff Competence, Attitudes, Behaviour

- Committed staff with concern for children
- Staff trained specifically in the delivery of child friendly services
- Staff trained in counselling for children
- Staff who respect and understand the needs of individual children and their families
- Staff committed to acting in the best interests of the child
- Opportunities for staff professional development and on-going training in child friendly services

d) Environment

- Comfortable, non threatening environment for children and adolescents
- Waiting areas and consulting rooms with appropriate pictures, games, books, toys etc
- Space and privacy for talking with children and their families
- IEC materials for children and adolescents
Worksheet 11

Action Planning for Child Friendly HTC Services

What is Action Planning?

Action Planning is an important process in the overall monitoring and evaluation of services. It assists us to improve the quality of services through:

- Identifying areas which are not being addressed properly
- Identifying ways in which they could be addressed better
- Identifying time frames for doing this
- Identifying key responsible people for doing this
- Identifying what resources are needed

The process of developing and implementing an action plan also encourages the team to work together in identifying challenges and finding solutions. This promotes a shared sense of responsibility and ownership of the need to ensure that services are child friendly and thus implementation of the action plan.

Action Planning Cycle
NB: It should be noted that in order for Action Plans to be effective, participants need to take into account:

- Feasibility
- Sustainability
- Human resources
- Financial costs
- Accessibility of action plan to the whole team
- Monitoring the implementation of the action plan
- Support for the action plan

**Action Plan for Child Friendly Services**

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<th>Need</th>
<th>Goal</th>
<th>Intervention</th>
<th>Evaluation</th>
<th>Timeline</th>
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Practical

Introduction

Completion of the 5 day HTC for Children course is the first stage of training for participants. The knowledge, understanding, skills and attitudes gained in the classroom now need to be applied effectively in their workplace.

This Practical is an opportunity for participants to apply what they have learnt, to self reflect on their performance and then to receive supervision and feedback. This ensures continued learning and skills development within their role and establishes a quality assurance system within their facility.

Objectives

At the end of this Practical participants should be able to:

- Self reflect on their performance when counselling children for HIV testing and follow up care and support
- Identify areas in need of personal development and training
- Demonstrate commitment to the delivery of quality HTC for children and their families through continued professional development and quality assurance
On returning to the workplace, course participants are required to complete Self Reflection forms on five different counselling sessions which they conduct with children. This exercise is designed to assist participants in their professional development.

Each Self Reflection Form should be discussed with the participant’s supervisor and signed.

Having completed five Self Reflection forms, the participant will be joined by his/her supervisor during a further 2 counselling sessions. The participant will self reflect on each session together with the supervisor. This is an opportunity for the supervisor to provide support and feedback and to work with the counsellor to identify areas for further training and supervision.
# Worksheet 12

## Self Reflection Form

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<thead>
<tr>
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<th>Child’s Ref No:</th>
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</thead>
<tbody>
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<table>
<thead>
<tr>
<th>What could I do next time?</th>
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<table>
<thead>
<tr>
<th>Counsellor’s signature</th>
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<table>
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<tr>
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<tbody>
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</tbody>
</table>
# Worksheet 17

## Self Reflection Form

<table>
<thead>
<tr>
<th>Date:</th>
<th>Purpose of Session:</th>
<th>Child’s Ref No:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did I make the child feel comfortable, safe and welcome?</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Did I identify whether the child was aware of the purpose of the session in an appropriate, sensitive manner?</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Did I clarify issues of Consent?</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Did I accurately assess the needs of the child?</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Did I provide accurate information to the child?</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Did I provide information in a way that the child could understand?</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Did I give the child opportunities to ask questions?</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Did I respond appropriately to those questions?</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Did I manage to help the child feel involved in the counselling session?</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Did my own personal values, beliefs and attitude affect the counselling session?</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Did I manage any emotional responses from the child and/or family appropriately?</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Did I make appropriate plans for follow up?</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Did I act in the best interests of the child at all times?</td>
<td>Y</td>
<td>N</td>
</tr>
</tbody>
</table>

What did I do well?
<table>
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<tr>
<th>What could I have improved on?</th>
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## Worksheet 18
### Self Reflection Form

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<th>Date:</th>
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<td></td>
<td>What did I do well?</td>
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</tbody>
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175
What could I have improved on?

What could I do next time?

Counsellor’s signature ........................................... Date ..............................................

Supervisor’s signature ........................................... Date ..............................................
Annex 1: Technical Review Committees

Technical Review Committee One:

Hilda Bara City of Harare
Cynthia Chasokela MoHCW
O Chiakidzwa PMD Mash Central
Elizabeth Chirapa ZAPP-UZ
Mrs Derera MoHCW
G Roselyn Dete Southern African AIDS Trust
B Dupwa MoHCW
Gertrude Gamanya HAQOCI
M Hamadziripi Red Ribbon Children’s Foundation
Dr Jo Keatinge EGPAF
Viviane Keravoan SAFAIDS
Rachel Kutukwa PSI
Grace Machimre CONTACT
Anna Machiya MoHCW
L Madyara MoHCW
Rumbi Magwagwa MoHCW
Sazzy Makukumbe PACT
Alois Mandizvidza Zimbabwe Prison Services
Dr E Mbizvo MoHCW
K Mbuya MoHCW
F Mudzvova MoHCW
Dr O Mugurungi MoHCW
Constance Mujaji HAQOCI
Dr Mupambo City of Harare
Lilian Murenga MoHCW
Buhle Ncube WHO
G Ncube MoHCW
Irvinah Ndebele STI HIV Coordinator
Gina Nyamanhindi CONNECT
Chengetayi Nyamukapa Childline
Beauty Nyamwanza National AIDS Council
Rita Philip ZACF Connaught Clinic
Henry Runyowa Ingutsheni Hospital
Beula Senzanje UNICEF
Mr Siziba MoHCW
Naume Tavengwa ZVITAMBO
Alex Tigere REPSSI
S Xaba MoHCW
Technical Review Committee Two

Alfred Chingono  Department of Psychiatry, University of Zimbabwe
Beatrice Dupwa  MoHCW
Eunice Garanganga  HOSPAZ
Rachel Kutukwa  PSI
Buhle Ncube  WHO
Gertrude Ncube  MoHCW
Kukhanya Nyathi  PSI
Henry Runyowa  Ingutsheni Hospital
Naume Tavengwa  ZVITAMBO
Nicola Willis  Africaid
References


SAT (2003) *Guidelines for Counselling Children who are infected with HIV or Affected by HIV*: Southern African AIDS Training Programme, Zimbabwe


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