

Refresher Training Programme for ICTC Counsellors

(Second Edition)

TRAINEE'S HANDOUTS

April 2011



Developed by

National AIDS Control Organisation

Department of AIDS Control

Ministry of Health and Family Welfare

Government of India

New Delhi, India

List of Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ANM	Auxiliary Nurse Midwife
AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-Retroviral Treatment
ARV	Anti-Retroviral
AWW	<i>Anganwadi</i> worker
CCC	Community Care Centre
CHC	Community Health Centers
CLHIV	Child Living with HIV
COE	Centre of Excellence
CPT	Cotrimoxazole Prophylactic Treatment
CRC	UN Convention on the Rights of the Child
DIC	Drop-In Centre
DOTS	Directly Observed Treatment – Short Course
EID	Early Infant Diagnosis
FDC	Fixed Dose Combination
FSH	Follicle Stimulating Hormone
FSW	Female Sex Worker
HAART	Highly Active Antiretroviral Therapy
Hb	Haemoglobin
HIV	Human Immunodeficiency Virus
HSV 2	Herpes Simplex Virus 2
ICDS	Integrated Child Development Scheme
ICSI	Intracytoplasmic Sperm Injection
IDU	Injecting Drug User
IEC	Information Education Communication
IUI	Intra-Uterine Insemination
LAC	Link ART Centre
LH	Luteinising Hormone

LWS	Link Worker Scheme
MARP	Most-at-Risk Populations
MCP	Multiple concurrent partners
MSM	Men who have Sex with Men
NACO	National AIDS Control Organisation
NACP	National AIDS Control Programme
NFHS	National Family Health Survey
NRHM	National Rural Health Mission
NRTI	Nucleoside Reverse Transcriptase Inhibitor
NNRTI	Non-nucleoside Reverse Transcriptase Inhibitor
NREGS	National Rural Employment Guarantee Scheme
NSEP	Needle Syringe Exchange Programme
NYSK	Nehru Yuvak Seva Kendra
OI	Opportunistic Infection
ORW	Out-reach Worker
OVC	Orphans and Vulnerable Children
PI	Protease Inhibitor
PLHIV	Person Living with HIV
PPTCT	Prevention of Parent to Child Transmission
RCH	Reproductive and Child Health
RNTCP	Revised National Tuberculosis Programme
RTI	Reproductive Tract Infection
SACEP	State AIDS Clinical Experts Panel
SACS	State AIDS Control Organisation
STIs	Sexually transmitted infections
TI	Targetted Interventions
WHO	World Health Organisation
WLHIV	Women Living with HIV

List of Contributors

Ms Sanjanthi Velu
And the team
Johns Hopkins Bloomberg School of
Public Health
Centre for Communication Programs
India

Dr. Po-Lin Chan
World Health Organisation
India

Dr. Vimlesh Purohit
World Health Organisation
India

Dr. Kamaxi Bhate
PSM Dept.
KEM Hospital, Mumbai, India

Dr. Shrikala Acharya
PSM Department
KEM Hospital Mumbai, India

Mr. Sachin Mahadik
PSM Department
KEM Hospital, Mumbai, India

Dr. Raghuram Rao
National AIDS Control Organisation
New Delhi, India

Dr. Avinash Kanchar
National AIDS Control Organisation
New Delhi, India

Dr. Melita Vaz
National AIDS Control Organisation
New Delhi, India

Ms Sumitha Chalil
National AIDS Control Organisation
New Delhi, India

Ms Nisha Kadyan
National AIDS Control Organisation
New Delhi, India

Mr. Vipin Joseph (CST)
National AIDS Control Organisation
New Delhi, India

Acknowledgments

Technical Reviewers from NACO

Dr. Raghuram Rao

Dr. Melita Vaz

Mr. Sanjeev Jain

Dr. Alok Agarwal

Mr. Aditya Singh

Technical Reviewers from SACS

Ms Sudeshna Bhojia, Gujarat SACS

Dr. Christopher Nathan, Andhra Pradesh SACS

External Technical Reviewers

Dr. Rohini Ramamurthy, Independent Consultant

Dr. Po-Lin, WHO-India

Mr. Suresh Nair, JHU-CCP

Dr. Sangeeta Kaul, Centres for Disease Control

Dr. Bipasha Biswas, St. Louis University, USA

Dr. Vartika Sharma, Population Council, New Delhi

Ms Vaibhavi, AVERT Society, Mumbai

Ms Rizwana Ghadially, Mumbai

Ms Dinu Mathew, Mumbai

Prof. Veena Yardi, Nirmala Niketan College of Home Sciences

Mr. Sony Thomas, Saksham Project, GFATM R7

Ms Shweta Bajaj, Saksham Project, GFATM R7

Technical Assistance

Mr. Rajesh Singh

Mr. Vipin Joseph (BSD)

Dr. Sunny Swarnkar

Dr. Reshu Agarwal

Ms Utpalakshi Kaushik

Ms Manali Jain

Mr. Vikas Gaur

Ms Lalitha Kandpal

Ms Ratna

Mr. Santosh Wani (MSACS)

Ms Sudeshna Bhojia (GSACS)

Mr. Prashant Malaiya (MPSACS)

Permissions

For Use of Images

World Health Organisation

United Nations Office on Drugs and Crime

Dr. Suresh Shastri (Karnataka Health Promotion Trust)

FXB-India (Suraksha)

For Use of Materials

Guilford Press

INDEX

I	Introductory Modules	9
A	Follow-Up Counselling	10
B	Programmatic Linkages for the ICTC	14
C	Assistance Schemes for PLHIVs: A Special Linkage	19
II	Technical Updates	35
A	Programme Update on ART	36
B	Body Basics: Male and Female Anatomy	55
C	Basics on Family Planning Methods	72
III	Counselling Modules	81
A	Understanding Behaviour Change	82
B	Understanding Risk and Vulnerability	100
C	Working with MSMs	105
D	Working with FSWs	119
E	Working with IDUs	135
F	Counselling Children at the ICTC	155
G	Counselling Adolescents at the ICTC	192
H	Counselling Discordant Couples	231
IV	Modules related to Care and Support	280
A	Nutrition Counselling	281
B	Home-Based Care	302
V	Modules to Enhance ICTC Work	330
A	Use of IEC Materials at the ICTC	331
B	ICTC Outreach	348
C	Time Management at the ICTC	363
	Annexures	376

INTRODUCTORY INTRODUCTORY MODULES

Follow-Up Counselling

At the end of this unit, participants will be able to

- List different follow-up needs of ICTC clients

As participants in this refresher workshop, you have worked for at least one year in the ICTC and you know how to handle clients during pre-test and post-test counselling sessions. Most often you see clients only at these sessions. But a small minority will come back to you even after they transfer to the ART centre because they are familiar with you. These clients present you with an additional opportunity for counselling. Their needs are varied and your counselling must represent this variety.

What is Follow-up Counselling

HIV counselling does not end with diagnosis of the client's HIV status and informing the client about it. The client requires on-going support. Follow-up counselling refers to the counselling offered to the client after the post-test counselling session. NACO's Operational Guidelines for Integrated Counselling and Testing Centres recommend offering follow-up sessions to all clients diagnosed with HIV and those who are in the window period (2007). While pre- and post-test counselling sessions focus on test-related issues, follow-up sessions deal with the issues of living with the infection and/or risk reduction. Some clients who test negative may need to come for re-testing after the window period.

Follow-up sessions offer another opportunity to you, as the counsellor, to deepen your rapport with the client, unlike pre-test and post-test sessions which provide the scope for time-limited, brief counselling interventions. Through follow-up sessions, you can reinforce and monitor the client's behaviour change and help the client to address their issues effectively.

Some Issues to Address during Follow-up

During follow-up sessions you may need to discuss different issues based on the client's profile. The list below presents some important issues:

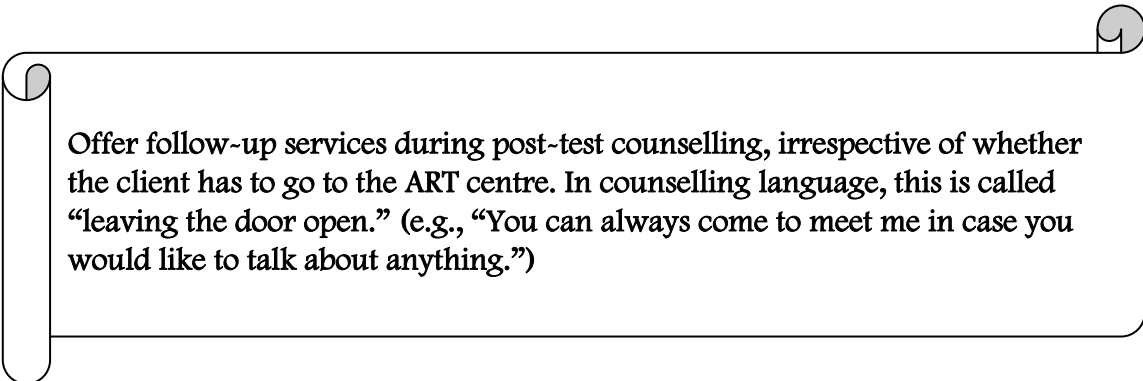
- Pre-ART care
- Registration at the ART centre
- Adherence to treatment
- Prevention of OIs
- Treatment of TB, STI and other ailments
- Uptake of PPTCT services by pregnant women
- Care of the exposed baby
- Behaviour change and risk reduction
- Partner testing and counselling
- Reproductive health issues
- Psychological issues like depression, suicidal tendency, anxiety and poor self-esteem
- Issues related to disclosure
- Stigma and discrimination including stigma
- Loss or death of family members
- Nutrition counselling
- Home-based care
- Legal issues – refer to legal aid resources or Drop-in Centres (DICs)

Follow-up counselling refers to the counselling offered to the client after the post-test counselling session. NACO's Operational Guidelines for ICTC recommend offering follow-up sessions to all clients diagnosed with HIV and those who are in the window period.

Planning for Follow-up Visits

- Offer follow-up services during post-test counselling, irrespective of whether the client has to go to the ART centre. In counselling language, this is called “leaving the door open.” (e.g., “You can always come to meet me in case you would like to talk about anything.”)
- Carefully judge how much information you can provide at the post-test counselling session. Identify issues you can address through follow-up sessions in case the client returns (e.g., checking on spouse and child, asking about stigma, asking about ability to work)
- Take the client’s contact telephone number and obtain their consent to call them.
- Plan the follow-up visit dates with the client before he/she leaves the counselling room. This is a must for pregnant, positive women. Encourage them to visit you at the end of their next hospital visit. You may also remind them in case you make an outreach visit to their home. Follow-up visits are also important for other clients whose lifestyle places them at risk such as Female Sex Workers. Invite them to come in for a six-monthly check-up.

Other clients may find it difficult to visit your centre repeatedly. But you can make arrangements, with their consent, to call them on the telephone. One instance where you should make a call is to check if the client had problems reaching the ART centre. Your line-listing will give you a reminder to call.



Offer follow-up services during post-test counselling, irrespective of whether the client has to go to the ART centre. In counselling language, this is called “leaving the door open.” (e.g., “You can always come to meet me in case you would like to talk about anything.”)

Handling Follow-up Visits

- During follow-up sessions, assess the impact of HIV status on different aspects of the client's life. Discuss how to minimize the harmful impact of HIV and OIs.
- Praise the client for the positive steps taken by him/her in coping with the diagnosis or reducing risk.
- Extend acceptance and unconditional warmth to the client during his/her visits.
- Address clients by their name as this makes them feel important.



References

National AIDS Control Organisation (2007). *Operational guidelines for Integrated Counselling and Testing Centres*. New Delhi, India: Author

National AIDS Control Organization (2006). *HIV counselling training modules for VCT, PPTCT and ART counsellors*. New Delhi, India: Author

Programmatic Linkages for the ICTC

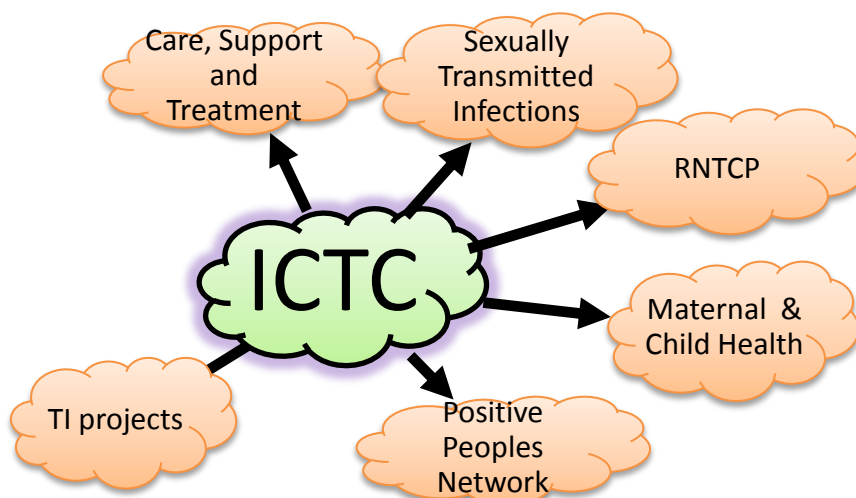
At the end of this unit, participants will be able to

- List the health services with which they should have programmatic linkages

Each ICTC must establish the following programmatic linkages with other health services. Some of these services fall under the NACP umbrella. Some are within the general health system.

The performance of the ICTC in this area is visible in completed and accurate line-lists, and good entries into the columns for in-referrals and out-referrals.

The counsellor must also be aware of the services available at each of these units and guide clients appropriately.



Care and Support



Care and support services are available through ART centres, Link ART centres, Centres of Excellence and Community Care Centres. However, the primary linkage between the ICTC and the Care and Support services will be through the ART centre whose functions are:

- ⊗ Prevention of Opportunistic Infections
- ⊗ Assessment and management of HIV-related illnesses
- ⊗ Assessment and management of other recurrent and chronic infections
- ⊗ Anti-retroviral therapy
- ⊗ Management of other recurrent and chronic infections
- ⊗ Counselling for drug adherence, nutrition, infant feeding
- ⊗ Early Infant Diagnosis and care of the child

Sexually Transmitted Infections



STI clinics are branded as Suraksha Clinics. They offer the following services:

- ⊗ Screening for presence of STI signs and symptoms
- ⊗ Early diagnosis and treatment of STIs during pregnancy including routine syphilis testing of pregnant women
- ⊗ Syndromic diagnosis and treatment where laboratory tests are not possible

RNTCP



Under the RNTCP, there are several facilities. They offer the following services:

- ⊗ Screening for TB
- ⊗ Early diagnosis & initiation of Anti-TB Treatment
- ⊗ Cotrimoxazole prophylactic treatment (CPT)

Maternal and Child Health

Linkages with Maternal and Child Health services are not just for those counsellors who are attached to Antenatal or Gynaecology units in the hospital. Every counsellor should know their services and how to link to them effectively:

- ⊗ Essential antenatal care
- ⊗ Family planning services
- ⊗ Safer delivery practices
- ⊗ Counselling and support for the infant feeding method opted by the woman
- ⊗ Maternal Care: MCH postpartum care services help protect the mother's health by providing medical and psychosocial supportive care
- ⊗ Infant care: MCH postnatal care services offer assessment of infant growth and development, nutritional support, immunizations, and early HIV testing.
- ⊗ Family care: MCH services provide social support, testing and counselling for family members; referrals to community-based support programmes; and assistance in dealing with stigma

Positive People's Networks



Positive people's networks offer:

- ⊗ Psycho-social support
- ⊗ Support groups
- ⊗ Legal support
- ⊗ Socio-economic support
- ⊗ Nutritional support

Targetted Intervention Projects

TI Projects provide:

- ⊗ Behaviour change communication
- ⊗ Referral for HIV testing
- ⊗ STI education and management
- ⊗ Condom promotion
- ⊗ Community mobilization
- ⊗ Enabling environment

Assistance Schemes for PLHIVs: A Special Linkage

At the end of this unit, participants will be able to

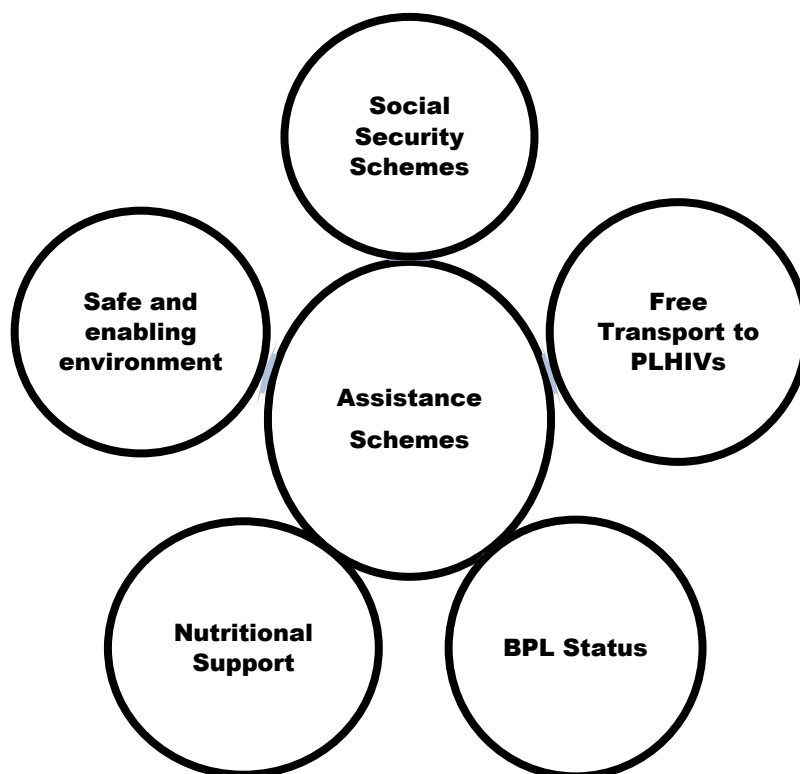
- List assistance schemes for PLHIVs for their non-health needs
- Describe how to link PLHIVs effectively to these schemes

As an ICTC counsellor, you may not always find it possible to address all the needs of your clients within the health system. The Care and Support Programme has made provisions for free treatment. But PLHIVs have other needs as well. Besides failing health, they face two problems: First, their health problems often disrupt their employment leading to breakdown in family finances. Second, they are often marginalized due to the stigma associated with HIV/AIDS. Hence there is a need to develop linkages with other government departments, non-HIV NGOs and the public sectors.

Types of Schemes

HIV/AIDS affects people of all walks of life. But its impact is greatest on members of the lower socio-economic classes. With HIV, the demand for living a healthier life is more important than ever and the additional economic burden is the biggest barrier to accessing the free care and support services.

There are various government schemes which a PLHIV can avail. These schemes differ from state to state and sometimes from district to district. The information for such schemes is available at the office of the District Collector/ District Magistrate. A partial list is provided here. But counsellors can request this information from the office of the District Collector or the District Magistrate or their State AIDS Control Society.



Social Security Schemes

Examples of such schemes are:

- ✓ Widow pension scheme
- ✓ Special pension schemes for PLHIVs
- ✓ Old age pension scheme
- ✓ Insurance schemes (government as well as private such as Star Insurance)
- ✓ Employment guarantee schemes

Free transport to PLHIVs for commuting to ART Centres

Concessions are sometimes provided for travelling to treatment centres by state transport agencies or by the Railway authorities. However in some places, this facility has been made available even with private transporters.

Below Poverty Level status for PLHIVs

Inclusion of PLHIVs in the BPL list, if eligible, helps PLHIVs to get nutritional support through subsidized rations and livelihood support through benefits under rural development and employment schemes. It also seeks to address stigma by encouraging disclosure of status.

Nutritional support for PLHIVs

Some states have provided nutritional support to PLHIVs through the ICDS scheme or Antyodaya scheme or through private donors. Chandigarh SACS has in fact developed a pooled fund through private donations like Rotary Club for providing such support. Orissa SACS has a nutrition supplement programme.

Safe environment

Some states have provisions for orphanages for CLHIVs and short-stay homes for women affected with HIV.

Additional schemes

Some states have made provisions for other schemes like animal loans, train passes, educational loan/grant, etc.

Role of the Counsellor

- Referral
- Managing Barriers
- Enhancing Linkages

Referral

An effective ICTC counsellor will gather information on the locally available schemes and seek to link people to the right resource. PLHIV networks generally are of great help in ensuring that these schemes are made available. Hence they would be your first referral link for all these activities. Various TI NGOs, Link Worker Scheme (LWS) NGOs and other non-HIV NGOs are also of great help in providing these services. You should add them to your list of referral agencies.

The ICTC counselor should ensure that the following details are displayed prominently in the ICTC:

- List of various government schemes for PLHIVs
- Name and contact details of various HIV and non-HIV NGOs providing services for PLHIVs (Services available at each NGO should be clearly written)
- A line indicating that they can ask you for more details

Managing Barriers

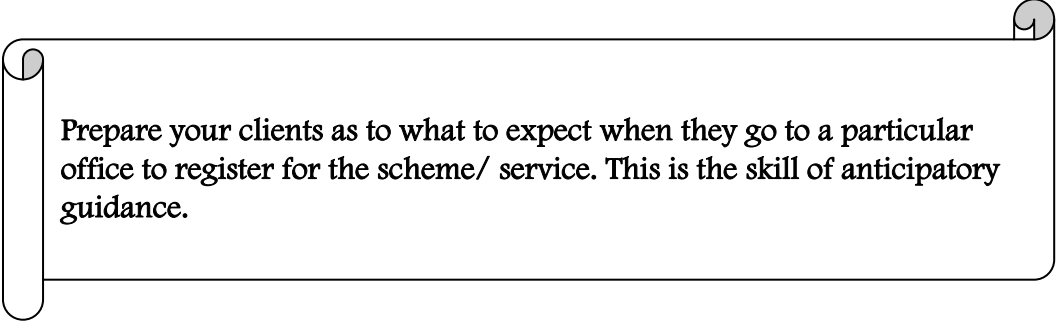
As a counsellor, you should be aware of the barriers that a PLHIV can face while trying to avail a package of services. Based on experience you should explore solutions to these barriers on a case-to-case basis. Hence it is extremely important to obtain feedback from clients for whom you have already made referrals.

Providing information that is as accurate as possible is critical. For instance, tell them how to reach there, draw a small map, etc.

Further, prepare your clients as to what to expect when they go to a particular office to register for the scheme/ service. This is the skill of anticipatory guidance.

If clients feel uncomfortable with language or with speaking with someone more educated than them, encourage them to talk with the District Level Network for a “buddy” who can accompany them the first time. Other possible advocates are workers from the Link Worker Scheme.

Be sensitive to clients’ concern about being “outed” – that is having their status disclosed. Remember it takes time for people to feel comfortable. Therefore, work with them at their pace. But always present to them the need to get registered for treatment as soon as possible as this is a life-saving measure.



Prepare your clients as to what to expect when they go to a particular office to register for the scheme/ service. This is the skill of anticipatory guidance.

Enhancing Linkages

Developing linkages with the various government departments is extremely important for the benefit of your client. A good rapport with your counterparts in these departments will ensure timely and hassle-free services to your clients. A “Thank You” note to the concerned officer will take you a long way ahead.

More Suggestions

Once you have successfully linked your client to a particular service, make a note of the relevant details in your records for future use. Share and discuss these achievements with your District ICTC supervisor and/or Nodal officers so that others can also benefit from your experience. Use your records to analyse the emerging needs of your client population, assess your success and improve your future performance.

Checklist for the ICTC counselor

Do you have the following information with you?

- ✓ List of various government schemes available in the district
- ✓ Name and contact address of the District Collector's office
- ✓ List of Tehsildars and their contact address
- ✓ Name and address of contact persons of the District PLHIV network
- ✓ Name and address of all HIV services
- ✓ Name and address of the TI NGOs in the district, their area of coverage, their typology of coverage, etc
- ✓ Name and contact details of ORWs and Peer Educators in the district and the areas covered by them in the district
- ✓ Name and address of the LWS NGOs in the district
- ✓ List of villages covered under the LWS in the district
- ✓ Name and contact details of the link workers in the villages
- ✓ Name and contact details of non-HIV NGOs in the district
- ✓ Name and contact details of short stay homes for women in the district
- ✓ Name and contact details of orphanages in the district

Assistance Schemes at the State Level

(This is a partial list that is ever-evolving)

Free baseline investigations

1. Baseline tests are provided free of cost to PLHIVs in most of the states. This includes tests like CBC, ESR, Urine Routine, Micro, Bl.UREA, S. CREATININE, LFT, X-Ray, USG, Lipid Profile, HBSAg, HCV, RBS, FBS, PPBS, etc .
2. Some states extend special services to CLHIVs. For instance, Kalawati Saran Children Hospital in Delhi provides free diagnostic tests like CT scan and Ultra Sound for HIV-positive children.

Free transport to PLHIV for commuting to ART Centers

1. The states of Assam, Gujarat, Rajasthan, West Bengal, Maharashtra, Goa and Jharkhand have provisioned travel concessions to PLHIVs for travelling to ART centers.
2. In Rajasthan some private transporters are providing concessions to PLHIVs on specific routes which cover ICTC, ART centres and TB hospitals.
3. In Gujarat, PLHIVs are receiving reimbursement of travel expenses with financial support from Clinton foundation and NRHM. This programme was implemented under the Jantan Project in October 2009. The government has earmarked Rs. 1.8 Crores for this purpose in the state health budget.
4. In Karnataka, travel assistance is provided in two high-prevalence districts.
5. In the states of Kerala, Chattisgarh and Andhra Pradesh, the proposal is under consideration with the state transport departments.

BPL status

Inclusion of PLHIVs in the BPL list helps them to get nutritional support through subsidized ration, livelihood support through benefits under rural development and employment schemes. Currently, Orissa, Rajasthan, Assam and Gujarat have given BPL status to PLHIVs.

Nutritional Support for PLHIV

1. The states of Andhra Pradesh, Bihar, Delhi, Gujarat, Orissa, Haryana, Rajasthan, West Bengal, Goa and Kerala are supporting nutritional care of PLHIVs, through ICDS, Antyodaya Anna Yojana or private donors.
2. In Gujarat, the Social Justice and Empowerment Department declared support of Rs. 500 per month to PLHIVs for nutritional support under Medical Aid Scheme for lifelong.
3. In Kerala, the Social Welfare Department has sanctioned an amount of Rs. 49.64 Lakhs for nutrition support programme for WLHIVs and CLHIVs registered in ART centres. Nutrimix powder (4 Kg p.m for WLHIVs, 2 Kg p.m for Pre ART and CLHIVs) is provided through the ICDS. Besides, multi vitamin, folic acid and iron tablets are provided to children wherever required. Free nutritional kits are also provided, through ICDS to all PLHIVs registered in DICs. This project is rolled out in 4 districts.
4. In Andhra Pradesh, CLHIVs in 4 districts are provided a special nutrition package every month under the Balasahayoga Program.

Social Security Schemes

1. Andhra Pradesh, Delhi, Gujarat, Orissa, Rajasthan, Tamil Nadu, West Bengal and Goa have incorporated social security measures through widow pension, old age pensions or special pension for PLHIV.
2. Orissa is providing Madhubabu pension scheme for PLHIVs and provides financial support of Rs 400 per month.
3. In states where widow pensions were already being provided, the SACS have advocated with the state governments to reduce the age bar for widows of PLHIV.
4. In Andhra Pradesh, PSI has launched insurance for PLHIVs through Star Health and Allied Insurance Company.
5. In Rajasthan, the Department of Social Justice and Empowerment provides monthly pension of Rs. 400 per month for all PLHIV widows.
6. In West Bengal, a one-time widow pension of Rs. 10,000/- is provided.

7. In Gujarat, all PLHIV widows are eligible for pension of Rs. 500 p/m and Rs. 60 p/m per child upto 18 years of age by the Department of Social Justice and Empowerment.
8. In Goa, the Social Welfare Department, Government of Goa gives Rs. 1000/-p/m as financial assistance for every eligible PLHIV under the Dayanand Social Security scheme.

Livelihood

1. Andhra Pradesh, Bihar, Gujarat, Rajasthan, Uttar Pradesh and West Bengal have initiated certain livelihood measures for PLHIVs through specific programmes like Jeevandeep or have integrated PLHIVs in NREGS.
2. In Haryana, PLHIVs are involved in 'Zindagi Zindabad' campaign in Haryana and they are paid an incentive of Rs. 100 per day.
3. In West Bengal, official directives have been issued by a few districts to engage PLHIV under NREGA and other schemes like AAY, GR and Widow Pension. A few other states are also moving in this direction to extend the benefit of such schemes to the PLHIV.

Legal Aid

The states of Chattisgarh, Punjab, West Bengal, Rajasthan and Uttar Pradesh have provisions of legal aid for PLHIV through different models.

1. In Gujarat, an MoU regarding free legal aid to PLHIV has been signed between GSNP+ and district legal aid authorities.
2. The Bar Associations of Durg, Korba (Chattisgarh), Alwar (Rajasthan), Itawah, Mau, Devaria (Uttar Pradesh), Alipore (West Bengal) have committed and are providing free legal aid for PLHIVs
3. DSACS' proposal with Delhi Legal aid authority is awaiting response.
4. In Punjab, free legal aid is given to PLHIVs through the District Legal Authority and the Human Right Law Network.
5. In Tamil Nadu, Legal Aid Cells are set up in 16 ART centres to address various social, legal and livelihood issues of the PLHIVs.

Safe Environment

1. Andhra Pradesh, Bihar, Delhi, Gujarat, Punjab and Rajasthan have provisions for orphanages for CLHIV as well as short stay homes for Women Living with HIV.
2. In Patna, Bihar, FXB India runs a short stay home for all PLHIVs.
3. In Gujarat, the government has planned two homes for CLHIVs in Surat and Gandhinagar respectively. The Gujarat government is extending a financial support of Rs. 65 lakhs per annum for this initiative.

Grievance Redressal Mechanism

The states of Andhra Pradesh, Bihar, Delhi, Gujarat, Orissa, Punjab, Rajasthan, Uttar Pradesh, Maharashtra Jharkhand and Kerala have Grievance Redressal mechanisms in place.

Additional Schemes

Some SACS have worked on making additional provisions for PLHIV on the basis of their needs.

1. In Rajasthan, the *Palanhar Yojana* is run by the Department of Social Justice and Empowerment for CLHIVs. Rs. 500 per month is given to children upto age 5, Rs. 650 per month to school-going children and an additional Rs. 2000 per year for expenses such as uniform and study materials.
2. In West Bengal, Ambuja Cement Foundation supports the education of children affected by HIV.
3. Jharkhand SACS has facilitated the formation of District Level Positive People's networks and the State Positive People's network.
4. Haryana SACS has facilitated the formation of seven District Level Positive People's networks.
5. In Kerala, under the Ashraya scheme, poor families are adopted by PRIs to provide housing, food, medical care etc as per the requirement of the beneficiary.
6. In Karnataka there is a special government OVC scheme in three districts worth Rs. 1 Crore
7. Government of Tamilnadu gives educational assistance to infected and affected children through the OVC Trust.

8. Gujarat has organized educational scholarships for affected and infected children of HIV-positive parents. Another support is in the form of special (and confidential) leave for the children for ART and OI treatment. The government has earmarked Rs. 60 lakhs for the parents who adopt CLHIVs.
9. The Union Territory of Chandigarh is planning to establish a school-cum-vocational training centre for CLHIVs with boarding facilities.
10. In Chandigarh, a corpus fund has been initiated by the Union Territory of Chandigarh with the help of donations from NGOs and philanthropic organizations. This money is utilized to support investigations and treatment of poor PLHIVs. Sewing and embroidery machines are provided to the DIC to develop the skills of the PLHIVs and subsequently ensure a sustainable livelihood to them.
11. In Haryana, special remuneration is given to Health Care Providers (ASHAs) for accompanying positive pregnant women for institutional delivery. Orissa also gives this kind of assistance to pregnant WLHIVs.
12. In Karnataka, under the *Yashaswini* scheme, incentives are given to the entire medical team that attends to the delivery of positive pregnant women.

Livelihood Schemes

Here is an extract of information from UN's Solution Exchange Online Community on the topic of Livelihood Programmes. They demonstrate both the diversity of such programmes as well as the teething problems to stabilize them. An ICTC counsellor cannot be expected to set up such programmes herself/ himself. But she/ he should be alert to what is happening in the district. Projects might set up and fail. New ones will arise to take their place. Clients may get discouraged. So the counsellor should encourage them in their efforts to find work and tell them that they are not responsible for the larger forces in society that cause a project to fail. Support their feelings and desires to be productive.

Himachal Pradesh

Support from Authorities Ensure Participation of PLHIV in NREGA, Kangra (*from Dr. Rajesh Sood, Department of Health and Family Welfare, Kangra*)

When a PLHIV went to the village head in order to seek work under NREGA, he was reluctant initially. However, when a higher authority issued orders that the PLHIV be included under NREGA, he complied. Support from the higher authorities to ensure livelihood security of PLHIV under NREGA has had a very positive impact on their lives. Similarly in Self Help Groups (SHGs) too, PLHIVs are members and earning livelihood through producing and marketing handicrafts items.

Uttar Pradesh

Livelihood Initiative Empowers and Contributes to Overall Health of PLHIV, Lucknow (*from Satyendra Nath Pandey, Hindustan Latex Family Planning Promotion Trust (HLFPPT), Lucknow*)

A lady was facing several challenges in life after the death of her HIV positive husband. The situation became worse when she too fell ill and tested positive for HIV. Her in-laws threw her out of house. After regaining health through treatment and support from parents, she started an NGO to organise PLHIVs for livelihood opportunities, and to fight for their rights. Playing an active role in life through livelihood activities led to their empowerment and overall improvement in health.

Kerala

Linking PLHIVs to Mainstream Livelihood Programmes Ensures Sustainability (*from D. John Packiaraj, Catholic Relief Services (CRS), Chennai*)

Upon completion of the project period, Tellicherry Social Service Society (TSSS) linked the beneficiaries of their HIV project to a Self Help Group (SHG). They were trained to produce household articles like soap and washing powder. A common facility centre provided raw material to independent units. The products of these independent units are sold in wholesale market as well as individual households. Thus, it ensured sustainability even after the project period.

Maharashtra

Livelihood Options Form Part of a Continuum of Care Project for PLHIV, Pune (*from Dr. Lalita Mahajan, Ballarpur Industries Limited, Pune*)

Ballarpur Industries started HIV interventions for their workers - initially focusing on awareness generation, education, and prevention services. Later they opened an ART Centre within the manufacturing unit. Recently they started the Continuum of Care (CoC) project that also provides jobs to PLHIVs in the project, support SHGs, link them to vocational training schemes of government, and help them start small businesses. PLHIVs find these services very helpful.

Punjab

Enterprise Development Programmes Make PLHIV Self-reliant, Ropar (*from Afzal Ahmad, Ambuja Cement Foundation (ACF), New Delhi*)

In order to provide livelihood options to PLHIV, the Ambuja Cement Foundation (ACF) is running a Paper Recycling Unit in Ropar, Punjab through the Network of PLHIV. The project has been introduced as an enterprise for PLHIVs to help them become self-reliant. At present five PLHIVs are involved in the project and are being trained for quality improvement of the product. The Foundation will provide the marketing support too.

Assam

Livelihood and Treatment Support Crucial for PLHIV, Bodoland Territorial Council (BTC) *(from Digambar Narzary, Nedan Foundation, Kokrajhar)*

Nedan Foundation started a social enterprise in the BTC which is a post-conflict area. Using the inherent weaving skill of Bodo women, the organization trains them in weaving improved designs and high quality products for income generation. It also facilitates access to antiretroviral treatment for women living with HIV and children in remote villages. This way it helps gain women economic security and reduces their vulnerability as PLHIV.

Madhya Pradesh

Societal Stigma and Discrimination Creates Barriers for PLHIV to Access Livelihood Options, Gwalior *(from B. K. Sharma, Gwalior Children's Hospital Charity (GCHC), United Kingdom)*

GCHC has been working on HIV and related issues in Gwalior since 2004. In their experience, PLHIVs often do not want to come forward identifying themselves with their HIV status. Even when they offer jobs and opportunities, many PLHIVs refuse. This is due to the prevalence of stigma and discrimination in society. In such settings, efforts to link PLHIVs to mainstream livelihood initiatives need to go hand in hand with efforts to reduce stigma and discrimination.

TECHNICAL
TECHNICAL
UPDATES

Programme Update on ART

At the end of this unit, participants will be able to

- Describe the benefits and limitations of ART.
- List the services available at different NACP care and support services: ART centre, LAC, CCC, LAC Plus, ART Plus and COE.
- List measures to ensure better follow-up of ICTC patients to the ART centre.

“The world has begun to reverse the AIDS epidemic—at least 56 countries have either stabilized or reduced new HIV infections by more than 25% in the past 10 years. New HIV infections among babies have dropped by 25%—a significant step towards achieving virtual elimination of mother-to-child transmission of HIV by 2015. More than 5 million people are on antiretroviral treatment, which has reduced AIDS-related deaths by more than 20% in the past 5 years.”

This is the good news given in a recent letter from UNAIDS (2011). This means that HIV interventions, when well-planned and efficiently executed, do make a measurable difference.

Let us examine how this applies to our country. India also has made steady progress to achieve its own goal under the NACP III to halt and reverse the HIV epidemic. The official estimate of adult HIV prevalence for 2008-09 is 0.31% and this is an overall reduction from 0.39% in 2004. In terms of actual numbers, this means there are 2.4 million People living with HIV and AIDS (PLHIV) in 2008-2009 as compared to 2.6 million PLHIV in 2004.

This progress has been possible because of the preventive, care and support services made available through the National AIDS Control Programme. The recent communication from UNAIDS also

states, “Evidence-informed programmes have helped India reach people who are at increased risk of HIV infection. The country is closing the gap on access to HIV services for those people in greatest need.”

As ICTC counsellors, you are part of this effort to halt and reverse the HIV epidemic in the country. You are part of a workforce that involves counsellors, nurses, laboratory technicians, peer workers and medical doctors. The workforce stretches to include the preventive services of Blood Banks, ICTCs and TI projects as well as the curative facilities of STI Clinics, ART centres and Community Care Centres. It is the consistent work put in collectively by all the NACP personnel that is responsible for the trends described ahead.

One caution here is that some states are doing better than others. The prevalence in some communities or groups is higher than in other groups.



Questions to ICTC Counsellors

What are the trends in your state?

Is the prevalence going up or down

The Care and Support Programme is one of the later components added to the National AIDS Control Programme to address the care and support needs of PLHIVs. NACO initiated ART centres in 2004 to provide free ART to PLHIVs. Because of this initiative, the trends show a steady decline in the estimated AIDS-related deaths per year. This means that more and more PLHIVs are surviving. This is one of our successes.

One major challenge has been to increase utilization of ART services by establishing an effective referral system between ICTCs and ART centres. Only when a PLHIV who is referred to an ART centre,

successfully reaches the centre, can he/ she enroll into the programme. Intensive efforts to strengthen the linkages, referral and feedback mechanisms between ICTCs and ART centres and HIV-TB cross-referral mechanisms have shown an increase in ICTC referrals from 68% in 2009 to 72.5% in 2010 (Internal data from NACO). But still there is a gap of 27%. This means that out of every 100 ICTC clients who are detected with the virus, 27 still do not even reach the ART Centre. This is a situation that must change and it is the ICTC counsellor who can play an important role in reducing the gap.

ICTC counsellors should emphasize the importance of registering at the ART centre during counselling sessions for newly-diagnosed HIV-positive people. To effectively refer and advise the client about the registration process at the ART centre, the ICTC counsellor should have a basic knowledge about ART and the programme. This write-up will help you to understand the importance of timely ART for a PLHIV, its benefits and limitations, linkages between ART centre and ICTC centre, services provided to PLHIVs at the ART centre, registration and treatment initiation procedures followed at the ART centre.

HIV/AIDS: Curable or Treatable?

AIDS is treatable, not curable (*rogamukt*). Once infected, the person carries the virus throughout his/her life. This is because the HIV virus hides itself in CD4 cells and forms a pool of latently HIV-infected CD4 cells during the earliest stages of acute HIV infection – the virus is present in the cells but remains inactive. Antiretroviral drugs that are currently available cannot destroy these hidden and dormant HIV viruses in the human body.

However, the emergence of Anti-retroviral therapy (ART) has made HIV treatable (*upchar*). Antiretroviral drugs interrupt and slow down the process of virus multiplication and hence reduce the number of CD4 cells that are destroyed. They delay the progression of HIV disease to AIDS.

Thus PLHIVs on ART can lead relatively normal lives while still carrying the virus.



Source: World Health Organisation SEARO, 2010

Antiretroviral Therapy (ART)

ART is a combination of drugs that reduces the ability of HIV to multiply in the body and in turn, increases the body's ability to fight disease.

Important terms:

ART- Antiretroviral Therapy

HAART- Highly Active Antiretroviral Therapy

ARVs- Anti Retro Virals

Triple Therapy- Treatment combination of three drugs

These terms are all used interchangeably!

Types of Drugs

Presently three groups of antiretroviral drugs are available:

➤ **Nucleoside Reverse Transcriptase Inhibitors (NRTI's)**

Example: Zidovudine, Stavudine, Lamivudine

➤ **Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTI's)**

Example: Nevirapine, Efavirenz

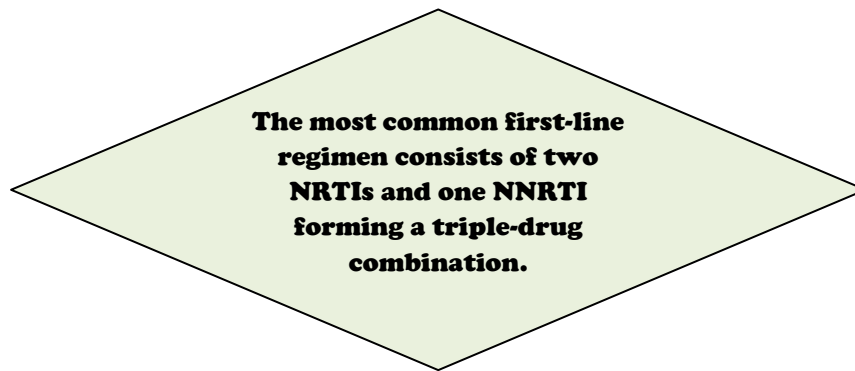
➤ **Protease inhibitors (PI's)**

Example: Ritonavir, Lopinavir

These drugs act at different steps in the process by which HIV makes new copies of itself inside CD4 cells. Regimens made up of such combinations are used to make treatment more effective as well as to overcome or delay resistance. Resistance is the ability of HIV to change its structure in ways that

make ARV drugs less effective. It is important to use drugs in a rational way so that the virus does not become immune to the treatment.

Usually, clients who have never taken ARV drugs are prescribed first-line regimens. The most common first-line regimen consists of **two NRTIs and one NNRTI** forming a triple-drug combination. To make it easy for clients to take these medicines, NACO has worked to make the basic regimens available in a single-pill format that is taken once in the morning and once at night. Clients for whom the standard first-line regimens are not suitable are prescribed the alternate first-line regimen.



Adherence to ARV Drugs

It is very important for the PLHIV on ART to be adherent to treatment - that is to take the correct dosage at the prescribed time and in the correct manner. In a person who has poor adherence to ART, HIV can change itself, causing resistance against the drugs to develop. The drugs will cease to be effective and then the PLHIV will need to change the regimen.

When the client's condition stops responding to first-line treatment, this situation is known as **Treatment failure**. In cases of treatment failure, the second-line regimen is prescribed. This usually consists of two NRTIs and a Protease inhibitor. However, second-line treatment has limitations: more drugs have to be taken and there are more side-effects. Also, at present, there is no third-line treatment available under NACP III. Thus, it is important for a PLHIV on ART to adhere to treatment as prescribed so as to prevent the development of resistance and treatment failure. From the programme perspective, it is important to ensure adherence because second-line regimens are more expensive than first-line regimens.

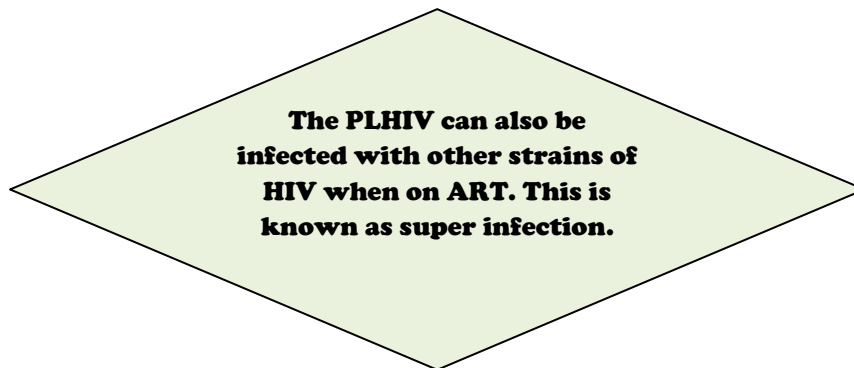
Benefits of ART

- ART helps to stabilize the immune system by increasing the CD4 cell count and reversing the progressive destruction of immune function.
- It prevents OIs which develop when there is severe damage to the immune function and a very low CD4 count. It shortens the course of any infections that are already present.
- It helps PLHIVs to live longer and have a better quality of life. Thus, they can also have the opportunity to continue earning a living and to carry out other activities such as family life.

Limitations of ART

Although ART dramatically improves the health and life expectancy of PLHIVs:

- ART is not a cure for AIDS. HIV is never entirely eliminated from the body - that is *rogamukt*.
- ART must be taken life-long. The virus can never be eradicated completely from the body. So ART has to be continued forever, even if the client is asymptomatic.
- HIV can still be transmitted to others - even when the PLHIV is healthy and taking his/her medication regularly. Thus, safe sex should be practiced even if the client is on ART.
- The PLHIV can also be infected with other strains of HIV when on ART. This is known as **super infection**. So ART does not mean relaxing one's guard and permitting unsafe sex.



ART Programme Update

Since the Government of India initiated a national programme in 2004 to provide free ART to PLHIVs, the programme has undergone scaling up in a phased manner.

- As of November 2010, there were 293 **ART Centres** serving 3,75,204 PLHIV. At the ART Centre, PLHIV clients are registered in Pre-ART Care and a baseline CD4 count is done to assess their eligibility for starting ART. All eligible clients are provided first-line antiretroviral treatment based on the CD4 count and WHO clinical staging. The criteria for eligibility are discussed later.
- **Community Care Centres (CCC)** has been set up with the mandate to support ART services. These are short-stay homes which play a critical role in providing monitoring, follow-up and counselling support to those who are initiated on ART. As of November 2010, 268 CCCs were fully functional (including 6 pediatrics CCCs).



- To expand the geographical reach of treatment services to PLHIVs, ART centres covering large geographical areas has been associated with **Link ART centres (LACs)**. These are placed at

ICTCs or CCCs. As of November 2010, there were 520 LACs serving as ART drug depots closer to the homes of PLHIV clients.

- For those PLHIVs who require second-line treatment, NACO has established **Centres of Excellence (COEs)**. COEs provide specialist care and treatment to PLHIVs. When a PLHIV client is referred to a Centre of Excellence (COE), the decision board at the COE called the SACEP (States AIDS Clinical Experts Panel) assesses the client's health status and takes the necessary decision to initiate second-line treatment. As of November 2010, there were 10 COEs and 7 Regional Paediatric ART Centres (RPC).
- The Care, Support and Treatment Programme is set to decentralize - to increase accessibility and availability of alternate first-line and second-line ART to PLHIVs, NACO plans to set up 7 **ART Plus centres**. NACO also plans to set up **LAC Plus centres** that will enroll PLHIVs, provide pre-ART management, follow up pre-ART patients who are not eligible for ART and refer eligible patients to Nodal ART Centres for ART initiation.
- NACO has initiated the Smart Card Project in Delhi and the six high-prevalence states. In this project, clients who are usually mobile can access ART treatment and care in all parts of the country. The client is issued a smart card which has his/ her basic details and the details of his/ her ARV treatment. It is hoped that this project will improve client adherence to ART.



Stored in the Chip

- Primary Data
 - Chip Serial Number
 - Unique Id No.
 - Date of Issue
 - Validity
 - Name
 - Date of Birth
 - Names of Father/Husband
 - Sex
 - Address & Phone No.
 - Fingerprint
 - Identification of Issuing Authority
- Application Data
- Reserved for Future Use

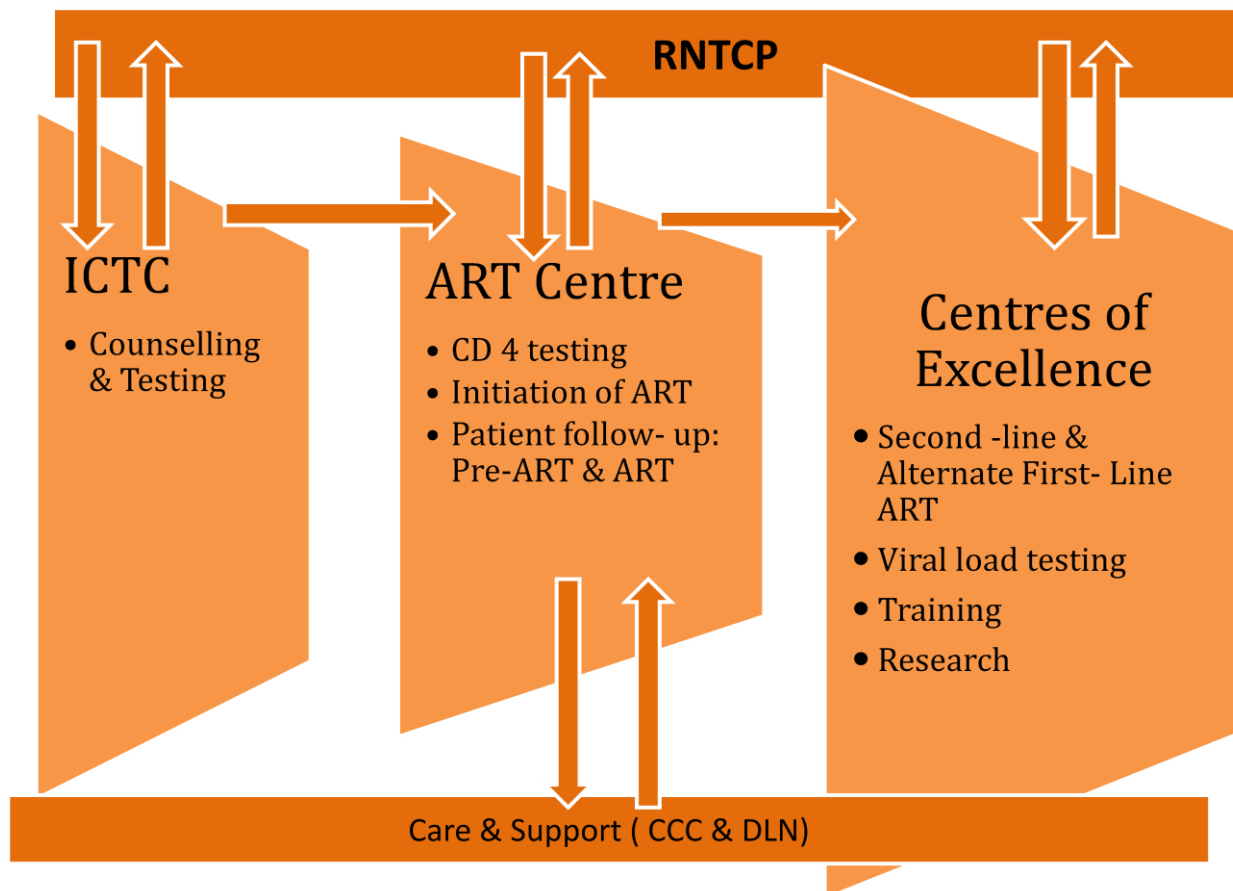
Sample of the Smart Card for ART patients along with the data it contains

Note that the National Care, Support and Treatment programme does not force patients to visit any particular centre. PLHIVs may register at any ART centre of their choice. But distant centres mean more travel and more trouble in accessing treatment. So ART counsellors do advise PLHIVs to register at centres closer to their place of stay while, at the same time, respecting their right ultimately to decide where they would like to be treated.



Continuum of Services

Entering the ICTC opens the doors to various other services for a PLHIV.



Enrollment at the ART Centre

People found to be HIV-positive at the ICTC are referred to the ART centre for registration in Pre-ART care.

ICTC-ART Centre Linkage

ICTCs are the first contact point of the client with the entire range of preventive, care and support services provided under the National AIDS Control Programme. The ICTC must link clients appropriately with the Care and Treatment services they need. However, there is a substantial loss of clients between ICTCs and ART centres.

A study of clients followed from ICTCs to ART Centres has shown that 82.9% of clients had received information about the availability of free ARV medications at government ART centers and 77.5% had been given referral slips by the ICTC counsellor. This means some clients are still not getting complete information.

The study showed that younger clients, single clients and clients working as unskilled manual labour are less likely to register for ART. Further, ICTC clients who perceive themselves as enjoying relatively good health or who fear disclosure of their HIV status are also less likely to register at ART centres.

Role of the ICTC counsellor in ensuring linkage with the ART centre

The ICTC counsellor should try to address these barriers during counselling and ensure that PLHIVs reach the ART centres. One way to do this is to check in with the ART Centre at monthly co-ordination meetings or over the telephone whether clients reached after a referral has been made. You can also periodically look over the referral forms returned from the ART centre. Matching the returned forms against the forms you wrote out will be useful to know who reached and who did not. This is a simple way of checking. Another way is line-listing.

ICTC counsellors may also use contact telephone numbers to contact clients who have not reached even 6 weeks after the test. Of course, for this, counsellors should seek permission to contact the client over the telephone and should be very discreet while making the telephone call. Your goal as an ICTC

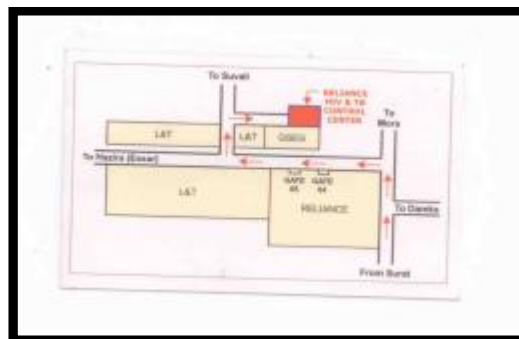
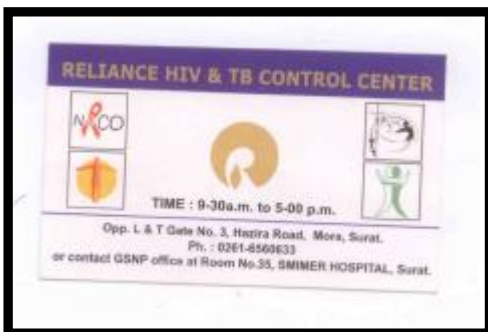
counsellor is to ensure that each and every one of your positive clients has reached and registered at the ART centre.

The ICTC counsellor must also give hope to the client by informing him/ her about ART, its importance and its free availability at the ART centre. Inform the client what he/ she can expect at the ART centre. This is called **Anticipatory Guidance**. Providing the client an idea of what happens at the ART centre will make him/ her feel less anxious about what to expect, and perhaps more tolerant of the wait-time required for the initial investigations.

Prepare your clients as to what to expect when they go to the ART Centre. This is the skill of anticipatory guidance.

Discuss with him/ her about the services available at ART centre. Inform them that at the ART centre they will be registered into Pre-ART care by the ART counsellor. For the registration they have to **carry the ICTC test result, a documentary proof of address, two passport-size photographs and the referral form**. The ART counsellor will make the patient ID card and will refer the client to the Medical Officer for the necessary investigations (including the CD4 count). The reports are usually available on the next day. Based on the reports the medical officer will prescribe treatment. The client will also interact with the counsellor and the nurse at the ART centre. After treatment has begun, he/she will have to follow up each month at the ART centre to obtain the drugs as well as to have the routine monthly check.

Provide the referral form to the clients and give them accurate instructions to reach the ART centre. It may be a good idea to display a small map on your ICTC wall.



Example of a Referral Card with location map on the reverse

Once the HIV-positive client is registered at the ART centre, all basic investigations are carried out including the CD 4 count. The ART centre counsellor will send the referral form back to the ICTC by e-mail (or by post if e-mail is not available) after filling in the necessary details.

For registration at the ART centre, clients must carry

- **ICTC test result**
- **Documentary proof of address**
- **2 passport-size photographs**
- **Referral form**

State AIDS Control Society				State AIDS Control Society				State AIDS Control Society			
Referral Form				Referral Form				Referral Form			
Name & Address of ICTC:_____				Name & Address of ICTC:_____				Name & Address of ICTC: _____			
Copy-1 (to be retained at the ICTC)				Copy-2 (to be carried by the client to the ART centre)				Copy-3 (to be sent to ART centre through e-mail or post)			
<i>Part-1 to be filled by the ICTC Counselor/Staff Nurse</i>				<i>Part-1 to be filled by the ICTC Counselor/Staff Nurse</i>				<i>Part-1 to be filled by the ICTC Counselor/Staff Nurse</i>			
Name of Counselor:				Name of Counselor:				Name of Counselor:			
PID No.		Date of referral		PID No.		Date of referral		PID No.		Date of referral	
Name of the client(optional):				Name of the client(optional):				Name of the client(optional):			
Age:		Sex:		Age:		Sex:		Age:		Sex:	
Ph. No.:				Ph. No.:				Ph. No.:			
Category of the client (Tick Mark): ANC/General/Exposed infant				Category of the client (Tick Mark): ANC/General/Exposed infant				Category of the client (Tick Mark): ANC/General/Exposed infant			
Name and address of the ART centre referred to				Name and address of the ART centre referred to				Name and address of the ART centre referred to			
Counselor's signature:				Counselor's signature:				Counselor's signature:			
<i>Part-2 to be filled by the ART centre staff</i>				<i>Part-2 to be filled by the ART centre staff</i>				<i>Part-2 to be filled by the ART centre staff</i>			
Has the patient reached ART centre: Yes/No				Has the patient reached ART centre: Yes/No				Has the patient reached ART centre: Yes/No			
If Yes				If Yes				If Yes			
<u>Pre ART Regn No.</u>	<u>CD4 Count</u>	<u>ART Initiated (Yes/No)</u>		<u>Pre ART Regn No.</u>	<u>CD4 Count</u>	<u>ART Initiated (Yes/No)</u>		<u>Pre ART Regn No.</u>	<u>CD4 Count</u>	<u>ART Initiated (Yes/No)</u>	
If ART initiated reason				If ART initiated reason				If ART initiated reason			
ART Counselor Signature				ART Counselor Signature				ART Counselor Signature			

Eligibility criteria for starting ART

It is important to start ART on time so that treatment can delay disease progression and death in a PLHIV. NACO's guidelines for initiation of ART are based on WHO's clinical staging and the CD4 count.

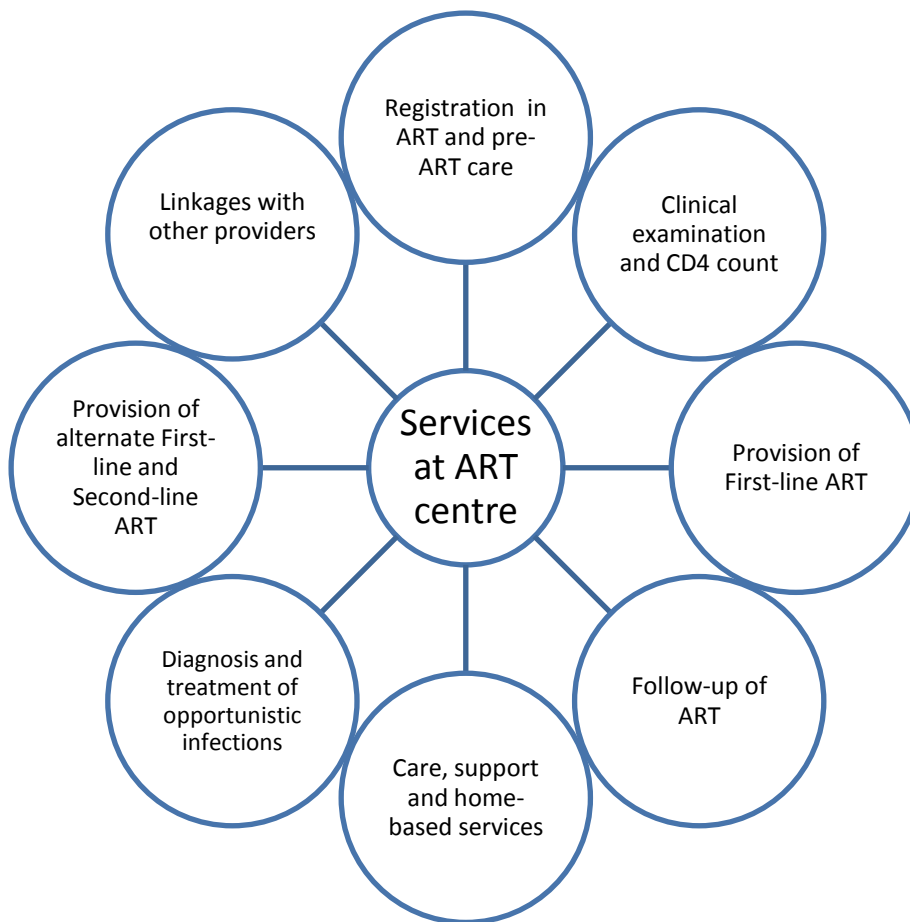
Initiation of ART based on CD4 count and WHO clinical staging

WHO Clinical Stage	CD4 Count (Cells/mm ³)
I.	Start if CD4 count less than 250
II.	
III.	Start if CD4 count less than 350
IV.	Start irrespective of CD4 count
Specific Situations 1. HIV and Tuberculosis (TB) <ul style="list-style-type: none"> • Pulmonary TB • Extra Pulmonary TB 2. HIV and Pregnancy <ul style="list-style-type: none"> • Clinical Stage III and IV • CD4 is less than 350 	<p>Start within 2 weeks of Anti-Tuberculosis Treatment (ATT) for patients with CD4 less than 350</p> <p>Start within 2 weeks of initiation of ATT irrespective of CD4 count.</p> <p>Start irrespective of CD4 count</p> <p>Start irrespective of Clinical staging</p>

Provision of services at ART Centre

The main services provided to PLHIVs through ART Centres are:

- ✓ Registration of PLHIVs for ART and pre-ART care
- ✓ Assessment of eligibility of ART based on clinical examination and CD4 count
- ✓ Provision of first-line ART to all eligible PLHIVs
- ✓ Follow-up of ART by assessing drug adherence, regularity of visits, periodic clinical examination and six-monthly CD4 count
- ✓ Care, support and home-based services (through referrals to nearby CCCs)
- ✓ Diagnosis and treatment of opportunistic infections
- ✓ Provision of alternate first-line and second-line ART to those who require it.
- ✓ Facilitating linkages with other providers.



Frequently Asked Questions



Why do clients have to provide proof of address when registering at the ART centre?

At the time of registration, the client is asked to furnish documentary proof of address for tracking patients who are lost-to-follow-up (LFU) and for ensuring good adherence.

What documents are acceptable as proof of address when registering at the ART centre?

Documentary proof of address could be

- ✓ Voter card
- ✓ Ration card
- ✓ Electricity or telephone bill
- ✓ Clients from rural areas may submit a letter from the Panchayat chief as proof of address.
- ✓ For those clients who do not have documentary address proof, a letter from a NACO-recognised NGO working for outreach activities in the area will also suffice as address proof. This includes IDU and Migrant Worker Targetted Intervention projects.

Frequently Asked Questions



Why does the ART centre repeatedly test the client?

After the client ID has been made the client is sent to the doctor for a clinical examination and baseline investigations. The baseline CD4 count is one important investigation completed at this stage. CD4 count is a blood test done to determine the number of the CD4 cells present in one cubic millimeter of blood volume (a blood drop of a size of a pea). It is measured at the time of registration of the PLHIV and once every six months for the registered PLHIV

- **Importance of CD4 count done at the time of registration:** This test is done to determine baseline CD4 count of a PLHIV. On the basis of this number the medical officer at the ART centre determines whether the PLHIV needs ART or not.
- **Importance of CD4 count done at every six months:** The pattern of CD4 count over time is more important than any single CD4 value because the values can change from day to day. The CD4 pattern over time shows the effect of the virus on the immune system. In PLHIVs who are not on ART, CD4 counts generally decrease as HIV progresses. A low CD4 count usually indicates a weakened immune system and a higher chance of getting opportunistic infections. So the regular CD4 count helps in
 - Monitoring how the HIV infection is affecting PLHIV immune system.
 - Diagnosing acquired immune deficiency syndrome (AIDS).
 - Deciding when to start antiretroviral therapy.
 - Evaluating risk for developing opportunistic infections.
 - Deciding when to start co-trimoxazole prophylaxis to prevent opportunistic infections.

Why does the ART centre not accept HIV test reports from private laboratories?

- The National AIDS Control Programme has established certain quality control standards for HIV testing. These are present at the ICTC. We cannot be confident that HIV testing in private laboratories follows similar rigorous standards of testing.



Questions to ICTC Counsellors

Are you confident you know all the documents that a client could use as proof of address at the ART centre?

If a client does not reach the ART centre, do you know how to contact him/ her?

If you plan to call a client over the telephone, are you prepared to answer the questions of someone else who might receive the call without breaking the client's confidentiality?



References

National AIDS Control Organisation, Ministry of Health and Family Welfare, Government of India (2008). *Operational guidelines for the ART centre*. New Delhi, India: Author.

National AIDS Control Organisation, Ministry of Health and Family Welfare, Government of India (2008). *Operational guidelines for Integrated Counselling and Testing Centres*. New Delhi, India: Author.

National AIDS Control Organisation, Ministry of Health and Family Welfare & Population Council (2010). *Factors affecting enrolment of PLHIV into ART services in India*. New Delhi, India: Population Council.

Body Basics: Male and Female Anatomy

At the end of this unit, participants will be able to

- Label correctly an anatomy drawing of the male and female genital organs
- Describe the structure and functioning of the male and female genital organs
- State the problems related to physical, mental and emotional changes at puberty for males and females
- Correct myths and misconceptions related to the male and female genital organs

Understanding one's own body, especially sexual organs, is essential for everyone. In our society, sadly, this information is not provided properly either in homes or schools. The major sources of information are friends, peers, books, mass media and the internet. This results in many misconceptions about sexual organs, how they function, what is normal and what conditions need help.

Social norms of not discussing sex and sexuality and one's sexual problems, make youth feel helpless. Fears due to misconceptions lead to anxiety, experimentation and irreversible consequences. Poor knowledge and lack of sanitation facilities lead to poor genital hygiene, especially in women resulting in Reproductive Tract Infections (RTIs). This increases their vulnerability to other genital infections and illnesses including STIs and HIV/AIDS.

ICTC counsellors need a thorough understanding of sexual organs and their functions. They also need to understand social norms associated with maleness and femaleness as well as the various facets of gender inequality in sexual relationships. This knowledge will provide them confidence in dealing with the sexuality issues of their clients in the context of working with HIV/AIDS.

Male Genital Organs & Functions

The male genital organs are situated externally as well as internally.

The external genital organs are

- Penis
- Scrotum
- Testes (singular testis)
- Anus

The internal organs are

- Vas deferens
- Seminal vesicles
- Urethra
- Prostate gland

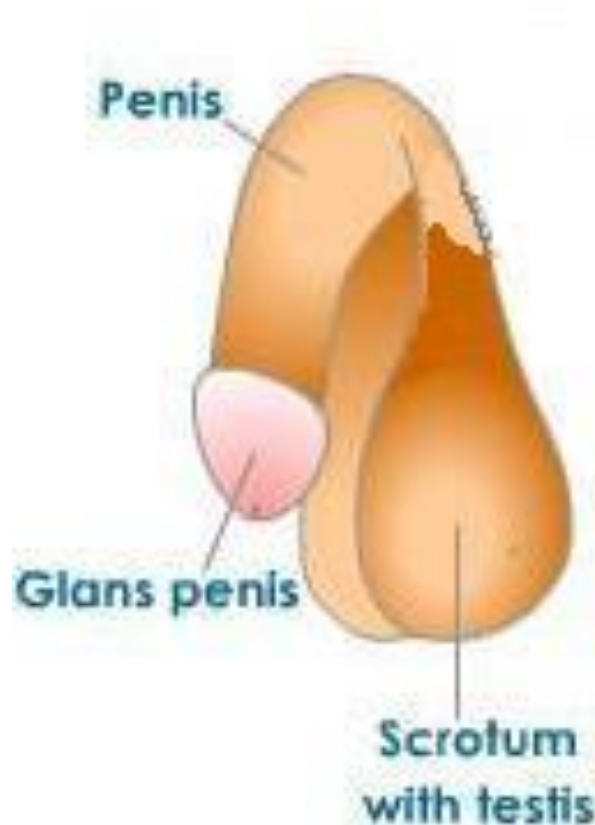


Image Courtesy of STI Division, NACO

Penis

Penis is the male organ through which the urethra opens. The front portion of the penis is slightly expanded and is called the glans penis. The skin over the glans is loose and thin and can easily be pushed back.

Scrotum

Scrotum is a sac-like organ situated behind the penis. It contains the testes.

Testes

There are two testes, one testis in each scrotal sac. They are oval shaped and small. Testes produce sperms and the hormone testosterone. The sperms are produced in millions. Sperm production begins at approximately age 12 and continues throughout a man's life.

Anus

Anus is the excretory opening from the digestive tract. This opening remains tightly closed with the help of anal ring muscles, other than at the time of passing stool (excreta).

Vas deferens

These are two tubes on either side of the penis (inside the body) which transport the sperms to the seminal vesicles.

Seminal vesicles

The seminal vesicle is a bag-like structure which is joined by a tube to the vas deferens on each side. Seminal vesicles store sperms till they mature. They also secrete a fluid for the nourishment of the sperm. This white fluid is called seminal fluid. Semen (that is seminal fluid plus sperm) is pushed out through the urethral opening. The urethral opening functions in such a way that at one time only urine or semen can flow out.

Prostate Gland

The prostate gland lies just beneath the urinary bladder. It secretes a fluid which stimulates the movement of sperms.

Urethra

The urethra is the common outlet for both urine and semen. But at one time only semen or urine can flow out.

Development of Sperm

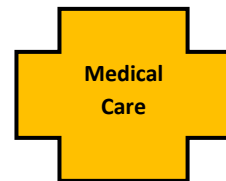
Sperms produced in the testes travel to the seminal vesicles through the vas deferens. The seminal vesicles produce seminal fluid which helps the sperms to mature. Sperms develop a tail in the seminal vesicles. Each drop of semen contains thousands of sperms. Sperms cannot be seen with eyes as they are very small

When the male is sexually excited, blood rushes into the penis which normally lies flaccid. This causes the penis to become hard and thick. We say the man has an erection. The process in which semen is expelled out of the body is called ejaculation. Sexual stimulation can happen during sexual thoughts or even by touch. Sometimes adolescent boys have an involuntary ejaculation at night. This is called a nocturnal emission.

Some additional information

A number of glands located under the skin of the glans penis produce a cheese-like secretion called smegma for keeping the area soft. If this area is not cleaned properly by pulling back the skin over the glans penis, the secretions accumulate and can get infected.

Phimosis is another condition where the skin on the glans cannot retract and is very painful. It is more painful during erection of the penis. Males might try to hide this situation as they feel ashamed. They may be advised wrongly by friends to visit a red light area to 'release' this skin. In some cases, they can bleed during such an attempt and may become more vulnerable to STIs and HIV/AIDS.



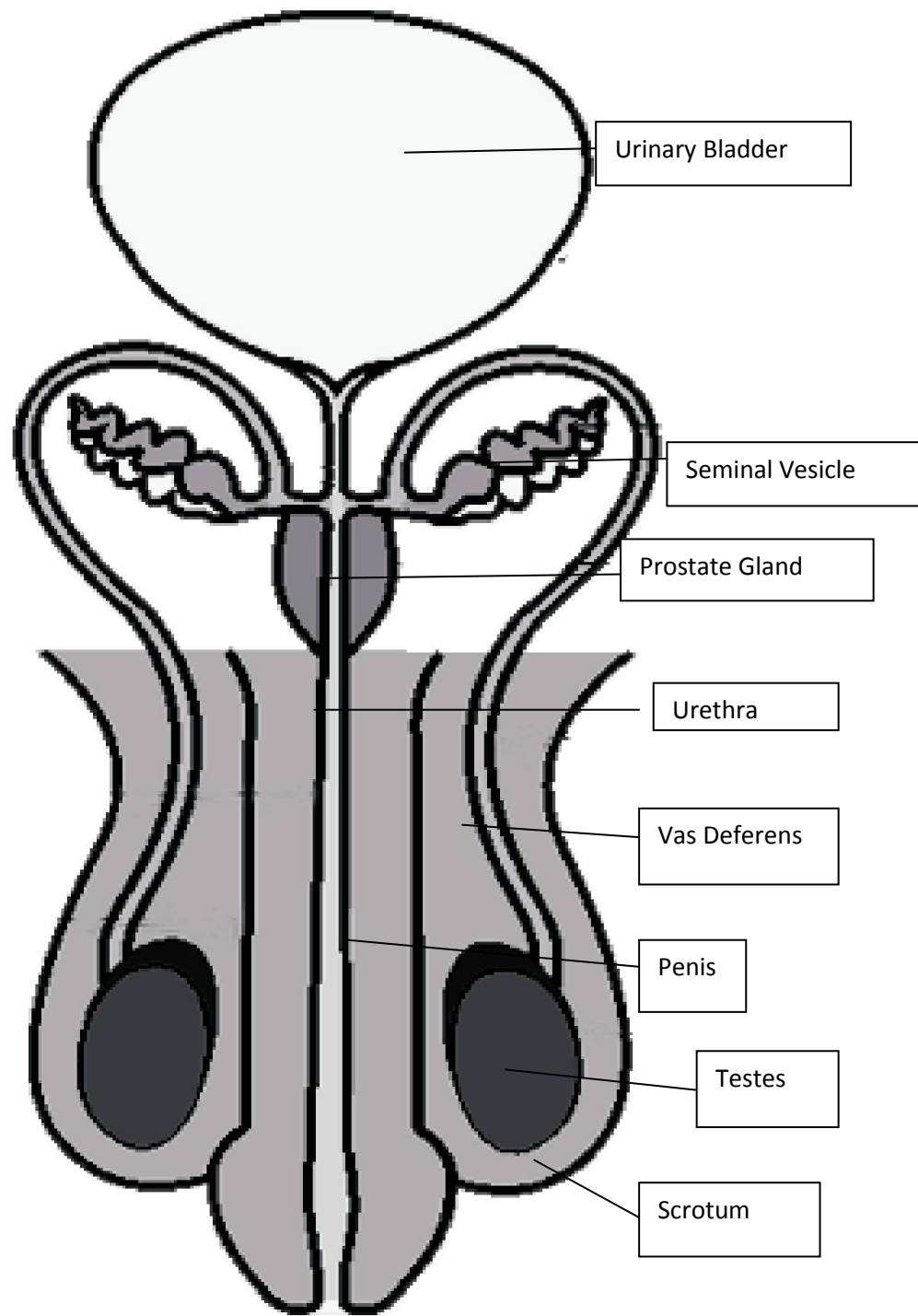


Image Courtesy of Sachin Mahadik, KEM Hospital, Mumbai

Physical Changes in Boys at Puberty

- Increase in height
- Increase in weight
- Growth of hair in the pubic area (around the genitals) and in the axillary region (under the armpits)
- Widening of shoulders
- Growth of moustache and beard
- Growth of hair on chest
- Strengthening of muscles
- Hoarseness of voice
- Acne or pimples
- Growth of external genital organs.

Mental and Emotional Changes In Boys at Puberty

Boys experience mental and emotional changes at puberty due to increased activity of hormones during adolescence. They experience:

- Anxiety about their height, beard, pimples, voice change, penis size and nocturnal emissions (involuntary ejaculations at night)
- Frequent mood changes – ranging from feeling of extreme happiness to feeling of sadness on small issues.
- Feeling awkward and self-conscious - They spend lot of time looking in the mirror, dressing up, and trying to make themselves attractive.
- Attraction towards a person of the opposite sex or the same sex
- Relations with parents - They disagree with parents, have temper outbursts, strained relations with parents and other adults.
- Rebellious attitude - They break rules, question authority, become more assertive and take risks.
- Experimentation – They may try smoking, drinking alcohol or taking drugs under the influence of peers and mass media.

Frequently Asked Questions



Why do some boys have late appearance of beard?

Adolescent period is from 10 to 19 years. Puberty is slightly different for every one as it depends on the level of testosterone hormone in the blood. So some boys show beard growth later than others.

What is masturbation? Is it bad?

Masturbation is self-stimulation of the genitals for sexual pleasure. Both males and females masturbate. During adolescence, boys/ girls want to explore sexual pleasure. This is the period when boys have intense sexual feelings. They have erections, and they may masturbate. Masturbation is not bad, nor will it do any harm.

However, there are myths associated with masturbation such as 'Masturbation causes weakness' or 'Masturbation diminishes the size of the penis.' Males should be told that masturbation does not affect health, but the feeling of guilt associated with masturbation can cause mental stress. Masturbation should not be a frequent compulsive phenomenon interfering with daily routine chores and duties.

How is Vasectomy done?

Will there be ejaculation after vasectomy?

In vasectomy, the vas deferens tubes are cut underneath the scrotum. After vasectomy, seminal vesicles continue the production of seminal fluid. Erection and ejaculation of seminal fluid continue to occur when the man is sexually stimulated but it does not contain sperms.

Frequently Asked Questions



What is Homosexuality? Why are homosexuals at greater risk?

Homosexuality means preference for persons of the same sex. Male-male preference is also called gay while lesbianism is the term used for female-female preference. Men who have sex with men generally have oral sex, mutual masturbation or anal sex. During anal sex the erect penis of the penetrative male partner enters the anal opening of the receptive partner. This can be uncomfortable and painful because the anal opening is small and not elastic like the vaginal opening. Sometimes, the skin around the anal opening may tear. The chances of HIV transmission are thus high in unprotected anal sex if one of the partners is infected. Lesbian women are at low risk of sexual transmission through female-female sexual activity as there is no exchange of body fluids.

What are eunuchs?

A eunuch is a person in whom the development of secondary male or female sexual characteristics does not occur either due to the absence of hormones or due to a castration operation. A castrated male is one who has had his testes removed. If the castration was before puberty; then the secondary male sexual characteristics do not develop. The absence of male hormone results in certain characteristics like female voice and absence of facial hair. If the testes are removed after puberty, the 'secondary male' sexual characteristics already acquired will tend to become less prominent and may diminish. Castration may also involve removal of the penis.

Frequently Asked Questions



Why do 'Night-Falls' or 'nocturnal emissions' start at the age of 14-15years?

Once the vesicles are filled with semen, it contracts and the semen flows out through urethral opening. The stimulation for the contraction of the seminal vesicles is generally sexual thoughts in the minds of young boys. Sexual thoughts are a natural part of the growing up. However, the boys feel that they will become weaker if they 'lose their vital fluid.' This is because in India, there is a common misconception - 'One drop of semen is equal to 40 drops of blood loss.' They may get embarrassed and scared about night-falls occurring at regular intervals. However they can't share these worries with anybody and may get easily misled.

Why do Nocturnal Emissions occur at night?

During the day, the adolescent boy is busy playing, travelling, studying in school, doing many other things and has strong inhibitions and control. But at night while he is sleeping and dreaming, these controls are slack and the seminal vesicles get emptied of semen automatically. Hence nocturnal emissions are also called Wet Dreams.

Will circumcision cause the penis size to increase?

No. Circumcision does not increase the size or length of the penis.

Female Genital Organs & Functions

The female genital organs are situated externally as well as internally.

The external genital organs are

- Labia Majora
- Labia Minora
- Clitoris
- Vaginal opening
- Urethral opening
- Anus

The internal genital organs are

- Vagina
- Uterus
- Fallopian tubes
- Ovaries

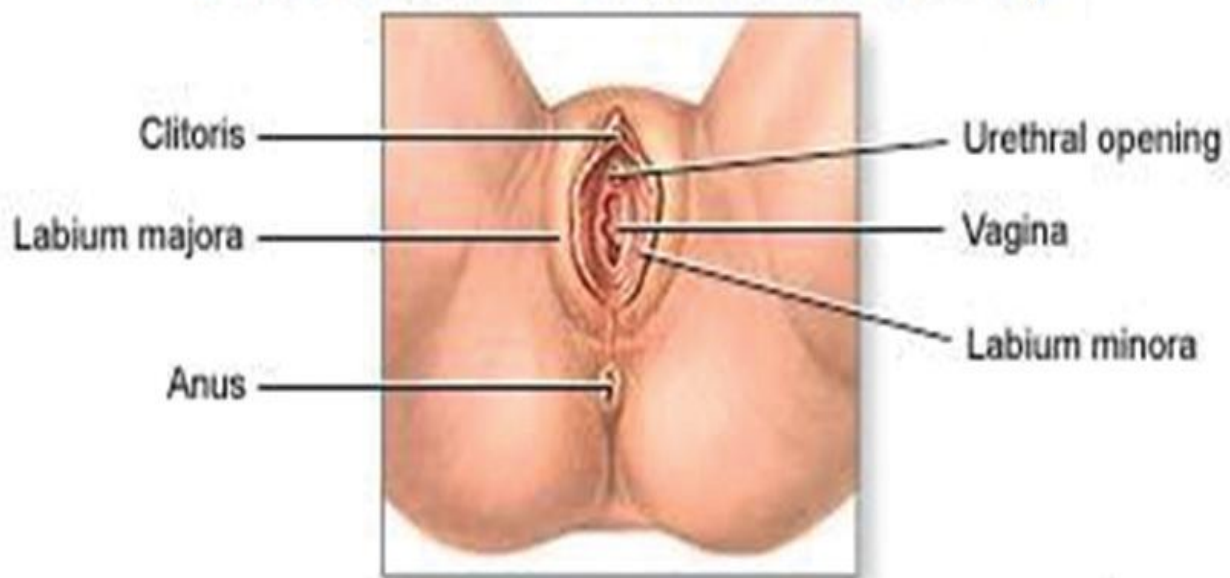


Image Courtesy of STI Division, NACO

Labia majora

Labia majora is a lip-like structure situated externally. It is covered with pubic hair.

Labia minora

Labia minora is a finer lip-like structure enclosed by the labia majora. These “lips” protect the vaginal and urethral (urinary) openings.

Clitoris

Clitoris is a pea-shaped organ. It is highly sensitive and the seat of sexual pleasure for the female. This structure corresponds to the penis in the male. The clitoris is situated between the two inner lips of the labia minora, The urethral opening and the vaginal opening are situated below the clitoris.

Uterus

Uterus is a small pear-shaped organ approximately the size of the closed fist. It is hollow and muscular, and is situated in the lower abdomen below the navel. It is sandwiched between the urinary bladder and rectum. It is capable of expanding to accommodate the foetus during pregnancy and returning to its normal size after child-birth. During periods, the menstrual blood comes from the endometrial (inner) lining of the uterus.

Fallopian Tubes

Fallopian tubes are situated on either side of the uterus and are attached to the uterus. When the ovum (egg) is released from the ovaries, the fallopian tube draws the ovum into the tube and pushes it towards the inner end of the tube and the uterus. Fertilization of the ovum takes place in the fallopian tube.

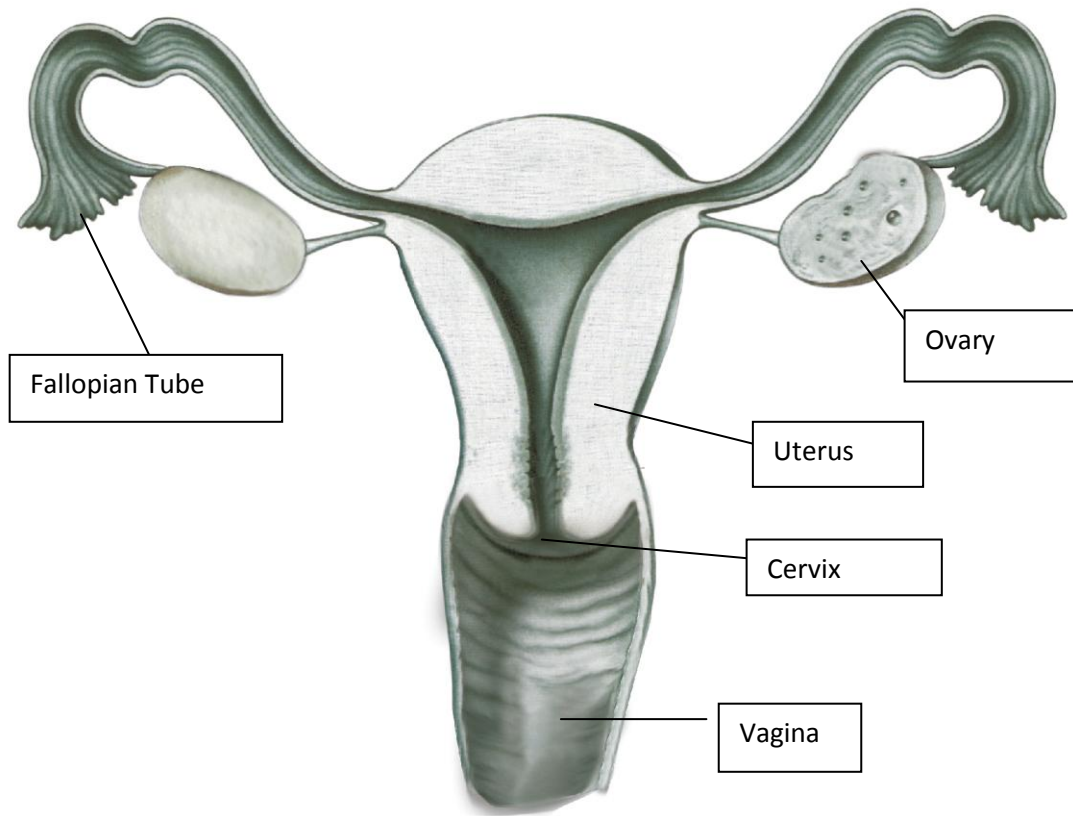


Image Courtesy of Sachin Mahadik, KEM Hospital, Mumbai

Ovaries

There are two ovaries on either side. Their size and shape is approximately that of an almond. Each ovary lies near the opening of a fallopian tube but is not attached to it. The ovaries produce ova (female egg) and secrete the female hormones – oestrogen and progesterone.

One ovum matures every month. Sometimes two or more ova may mature and be released simultaneously. In the reproductive lifespan of a woman, only about 400 mature ova are produced. After the age of 40 to 45 years, ovulation and menstruation stops.

Vagina

The uterus opens into the vagina. This is a collapsible tube that can expand to accommodate the penis during sexual intercourse and the foetus during child-birth. Menstrual blood flows out from the uterus through the vagina.

The vaginal opening is sometimes covered by a thin membrane which is called the hymen. There is a general belief that the presence of the hymen indicates virginity in the female. It is wrongly believed that the hymen ruptures only at the time of first sexual intercourse, and bleeding occurs. Actually, the hymen can be ruptured even earlier during strenuous physical activities. Further, even if the hymen ruptures during first sexual intercourse, the bleeding may not be visible except for slight spotting.

Development of Breasts

Though breasts are present in both males and females, the female breast is different because of the presence of milk glands. The size of the breast depends on the overall build of the woman. Whether small or big, breasts are able to fulfil their function - production of milk for breastfeeding the child after delivery.

Physical Changes in Girls at Puberty

- Increase in height
- Increase in weight
- Growth of pubic and axillary (armpit) hair
- Widening of hips
- Menstruation
- White mucus discharge from vagina
- Acne
- Development of reproductive organs.
- Development of breasts

Mental and Emotional Changes In Girls at Puberty

- Girls feel anxious about menstruation, pimples, breast size and general appearance
- Become moody – They experience sudden mood changes and may engage in day-dreaming
- Feel awkward and self-conscious – They may spend lot of time looking in the mirror, dressing up, trying to make themselves attractive
- Seek attention of males - They have romantic notions about love, want to be loved.
- Relations with parents – They may disagree with parents, question authority and have strained relations with parents and other adults
- Rebellious attitude – They may break rules, become more assertive and taking risks.
- Ready to take risks – Though social norms prevent girls from taking risks on the same level as boys, they also do engage in risk-taking behaviours such as sexual intercourse.

Some additional information

Menstrual Cycle

A female child is born with internal and external reproductive organs, but they are not functional in childhood. During puberty, the pituitary gland in the brain starts secreting certain hormones – Follicle Stimulating Hormone (FSH) and Luteinising Hormone (LH). These hormones are responsible for the development, maturation and functioning of the reproductive organs.

Girls start menstruating between the ages of 10 to 19 years. FSH stimulates the growth of ova in the ovary every month. Five to six ova start maturing, but the most mature ovum gets released under stimulation of LH. This released ovum is drawn inside the fallopian tube and starts moving towards the uterus. FSH and LH also stimulate the ovaries to produce oestrogen and progesterone. These hormones cause the thickening of the endometrium (inner lining of the uterus) and make it ready to receive the fertilised ovum.

Usually one mature ovum is released from the ovary during Day 8 to 18 of the menstrual cycle. This ovum is drawn into the opening of the fallopian tube from the open end and travels uterus. It is alive for 12 to 24 hours.

- If sperms are present in the uterus, the ovum can get fertilised. This fertilized ovum implants in the thickened endometrium in the uterus and grows to form a foetus.
- If the ovum is not fertilized, it will degenerate. The lining of the uterus, not being required to nurture the foetus, is shed as menstrual bleeding. This is how menstruation occurs.

After bleeding stops, a new ovum starts maturing in the ovary under the influence of FSH and LH and the same cycle repeats. Thus the menstrual cycle is a result of the coordination between the pituitary gland in the brain, the ovaries and the uterus.

In young girls, menstrual cycles may range from 15 days to 3-4 months. This continues till the coordination between pituitary and ovaries is established. In the first few months after menarche, the body slowly gets adjusted and settles into its own particular rhythm. It takes about 2 years for regular menstrual cycles to establish. Some girls get menstrual cycles at shorter intervals and others at longer intervals.

About 50 ml of blood is lost during each menstruation. The bleeding lasts normally for 3 to 7 days. The cycle gets repeated every 28 to 30 days. There is a great deal of variation in the length of the cycle, amount and duration of menstrual bleeding and regularity from one woman to another. Some women bleed a lot in a given period and for a longer period of time. Others have very scanty bleeding. One big cause for such scanty bleeding is Anaemia.

During menstruation, some girls have lower abdominal pain or gastro-intestinal disturbances that is due to congestion in the organs around the uterus under the influence of the ovarian hormone, progesterone.

The onset of menstruation indicates that a girl is physically capable of reproduction. But complete physical and psychological development takes place only by the age of 18 years. Hence it is important to postpone the first pregnancy after the age of 18. Ideally the first pregnancy should occur after the age of 21 years. Pregnancy at a young age can result in serious physical consequences and can cause complications in pregnancy and child-birth.

Fertile Period

The most important aspect of the menstrual cycle is the fertile period: **Only three days in the entire menstrual cycle of 28-30 days constitute the fertile period.** It is marked by the release of whitish mucus discharge (like raw egg-white or the fluid present when cooking brinjal).

The chances of conception are limited to a day before and two days after ovulation. This is because the life of ovum is only 24 hours after it has come out of the ovary. The life of the sperm is 72 hours after its ejaculation into the woman's genital tract. Sperm could be present in the genital tract of a woman when she ovulates from sexual interaction prior to ovulation or it could enter the genital tract within 24 hours of ovulation during sexual interaction. Persons who plan to use this method of

conception should be aware of the lifespan of both ovum and sperm, and should learn to recognise the signs of fertility in the female.

Menstrual Hygiene

1. Bathing daily during menstruation is essential. Washing the genital region daily with mild soap and lukewarm water helps prevent distinct body odour.
2. Pads and napkins - A soft cotton cloth or sanitary napkin should be used during menstruation.

Sanitary pads should be changed 3 to 4 times a day depending on the flow. The girl should always clean the genital area each time she changes the pad. She should wash her hands with soap and water.

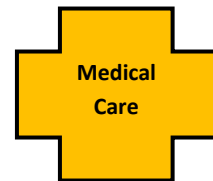
If cloth pads are used, then they should be washed in water with soap and **completely dried**. Damp cloths should not be used as they increase the chances of causing infection. Also, she should avoid sharing the same cloth pad with other female family members. Every 3 to 4 months, a new cloth should be used and the old one discarded.

If sanitary napkins are used, they should be used once and then disposed. For disposal, it is important to wrap the pad in a paper and discard it in the dustbin.

In case of females who are sero-positive, the disposable pads should be soaked in water with bleaching powder before disposal. Cloth pads should be immersed in water with bleaching powder for ten minutes before washing thoroughly with soap.

STIs/RTIs

Normally the vaginal walls and cervix secrete a watery fluid which keeps the vagina moist. A slight amount of white discharge is normal just before menses and during ovulation. However, if a woman secretes increased quantities of vaginal fluid (to the point where she needs a pad), or has a foul odour, a different colour (greenish, yellowish, curdy white, or blood-tinged), has associated pain or fever, this indicates infection and the woman needs to seek medical treatment.





Questions to ICTC Counsellors

What information about male and female anatomy should you give HIV-infected clients?

When is it most appropriate to give this information?

Basics on Family Planning Methods

At the end of this unit, participants will be able to

- List different family planning methods available in India
- Describe the effectiveness of each method in relation to preventing pregnancy as well as in relation to preventing HIV infection

All ICTC counsellors need to know the various family planning methods for two reasons:

1. Sometimes, couples come in wanting to know how to plan a family.
2. One major client group is pregnant women. The period of pregnancy is a good time for couples to reflect on their family size and decide when and whether they would like to have another child.

These are some reasons why the programmatic integration of the NACP and the NRHM emphasizes that ICTC counsellors should also be able to discuss family planning methods.

In the context of the ICTC, counselling on family planning methods discusses two aspects:

- How well the method works to regulate pregnancy
- How well the method works to prevent transmission of HIV and other STIs

In this context, the counsellor should use the skill of hierarchical counselling. Here the counsellor will discuss all methods but will stress the methods which have a higher effectiveness, or will describe the methods in order of how effective they are. To some extent you are already familiar with this idea in terms of the ABC typology of sexual risk reduction: A for Abstinence, B for Be mutually faithful and C for Condom.

How to Select a Method

Selection of a Family Planning Method should address three issues.

Effectiveness

Effectiveness refers to how reliably the method may prevent contraception. Surgical methods like vasectomy are permanent and completely prevent pregnancy. Barrier methods like condoms have slightly lower effectiveness rates because they may tear by accident.

Ease of Use

Some methods require only a one-time effort by the user. For instance, the surgical method requires the person to go to a centre once to have the procedure done. Others like the contraceptive pill or the condom require more effort by the user, such as taking a contraceptive pill consistently every day or purchasing and keeping condoms handy in anticipation of sex. Some methods like the male condom require co-operation from the person's partner.

Use by a PLHIV

Not all methods are suitable for every one. PLHIVs have a medical condition which may affect how well a family planning method will work or it may cause additional harm. In general, PLHIVs may be able to use most contraceptive methods. The exceptions are discussed below:

- ✓ Spermicides increase infection risk for uninfected women in discordant couples (M+F-). Further, spermicides or diaphragms with spermicides should not be used by women with HIV/ at high risk of HIV.
- ✓ The IUD is contradicted for an infected woman if the woman has gonorrhoea or chlamydia or is unwell with AIDS-related illness or if she is at risk of any of these.
- ✓ Rifampicin lowers effectiveness of contraceptive pills and implants.
- ✓ Some antiretrovirals such as protease inhibitors and NNRTIs may lower the effectiveness of hormonal methods.
- ✓ Female and male sterilization are not recommended for persons with advanced HIV disease.

Common Family Planning Methods

Male condom

The male condom is a rubber sheath that is worn by a man over his penis when he penetrates it into the vagina or anus or mouth of his partner. It is used to prevent contact of semen with the body surface of his partner. Each act of sex requires a fresh condom.



Female condom

The female condom is a loose plastic sheath that a woman puts into her vagina to protect her vaginal surface from coming in contact with semen. It consists of two rings – an inner ring which is place up against the cervical opening to the uterus while the outer ring remains outside the vagina. Each act of sex requires a fresh condom.



Contraceptive Pill

The contraceptive pill (*Mala D* or *Mala N*) is a set of 28 tablets which contain oestrogen and progesterone hormones to regulate pregnancy by preventing ovulation (the production of eggs in the woman). A woman who opts for this method starts taking one tablet a day – beginning on any day of her menstrual cycle. She may expect some side-effects such as mild headaches, nausea, mild bleeding in between her periods.

This method is contraindicated for women over 35, who smoke cigarettes, for women with high blood pressure, or who take rifampicin. Women who may be pregnant, or who gave birth less than 3 weeks ago, or who have been breastfeeding for 6 months or less should also avoid choosing this method.

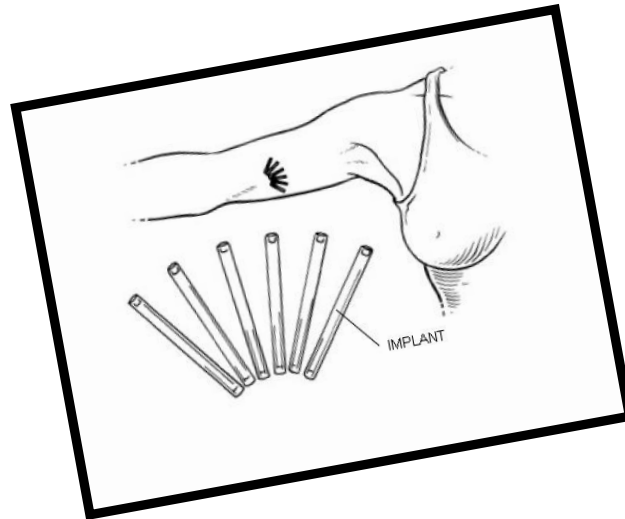


Long-acting injectable

The long-acting injectable is a progesterone injection taken by a woman every two or 3 months - beginning on any day of her menstrual cycle. It regulates pregnancy by preventing ovulation. She may expect some side-effects such as menstrual changes, no menstruation (monthly bleeding), weight gain, mild headaches, nausea and dizziness. This method is contraindicated for women with HIV or on ART who also have very high blood pressure, or who have been breastfeeding for 6 weeks or less, or who may be pregnant.

Implants

Implants are small plastic tubes that are placed under the skin of the upper arm. They are very effective for upto 4 to 7 years or till the woman wants to remove them. They usually cause changes in the menstrual pattern.



Lactational Amenorrhoea

Lactational Amenorrhoea is a method of preventing further conception based on breastfeeding. Only a woman who has opted to breastfeed exclusively can opt for this method and that too for only upto 6 months after childbirth so long as a woman's menstrual bleeding has not resumed.

Through breastfeeding there is a chance of passing HIV from an infected mother to her newly delivered child but exclusive breastfeeding is safer for the child than mixed feeding.

Fertility awareness-based methods

Fertility awareness-based methods require the woman to learn what days of her menstrual cycle fall within the ovulatory period (fertile days) and to time intercourse for days other than these fertile days in order to avoid a pregnancy.

The various methods include

- using a calendar to calculate fertile days,
- identifying changes in the cervical mucus (what many women refer to as white discharge) or
- using a basal body thermometer (not a regular thermometer).

Intra-uterine device

The intra-uterine device (*Copper T*) is a small plastic instrument which fits snugly inside the uterus and prevents pregnancy by preventing a fertilized ovum from implanting inside the uterus. It may be used effectively for upto 12 years or till the woman wants to remove it. A woman may experience increased menstrual bleeding and cramps.

It is contra-indicated for women with HIV who also have STI.



Surgical sterilization

Surgical sterilization in men involves severing the vas deferens and in women involves ligating (tying up) the fallopian tubes. Both of these are permanent methods and are highly effective.

They are not recommended for persons who already display AIDS symptoms.

Integrating Family Planning into HIV counselling

ICTC counsellors may ask how to actually integrate Family Planning into their HIV work. Here are some guidelines:

- Ask every client who is married or in a committed relationship what method they use to plan their family - Planning a family can mean delaying pregnancy as well as limiting the number of children.
- Ask every client who is married or in a committed relationship about the number of children they would like to have.
 - For clients who indicate that they already have the number of children they prefer, discuss the permanent methods such as sterilization.
 - For clients who indicate they might like to have more children in future, discuss less permanent methods such as implants or intrauterine devices.
 - Use hierarchical counselling – that is discuss all methods but stress the methods which have a higher effectiveness, or list and describe the methods in order of how effective they are.
- Be gender-sensitive – Do not discuss the female methods only.
- Address HIV prevention concerns clearly.
- Explain clearly where and when clients may access family planning services.

In hierarchical counselling, the counsellor discusses all methods of family planning but will stress the methods which have a higher effectiveness, or will describe the methods in order of how effective they are. To some extent you are already familiar with this idea in terms of the A B C typology of sexual risk reduction.

Methods in relation to HIV

<i>Method</i>	<i>Does it prevent pregnancy?</i>	<i>Does it prevent HIV transmission ?</i>	<i>Issues in relation to PLHIVs</i>
<i>Male condom</i>	YES	YES	
<i>Female condom</i>	YES	YES	
<i>Contraceptive Pill</i>	YES	NO	Contraindicated for: <ul style="list-style-type: none"> • women over 35 who smoke cigarettes • women with high blood pressure • women who take rifampicin • women who may be pregnant • women who gave birth less than 3 weeks ago • women who have been breastfeeding for 6 months or less
<i>Long-acting injectable</i>	YES	NO	Contraindicated for women with HIV or on ART who: <ul style="list-style-type: none"> • also have high blood pressure • who have been breastfeeding for 6 weeks or less • who may be pregnant.
<i>Implants</i>	YES	NO	
<i>Lactational Amenorrhoea</i>	YES	NO	Through breastfeeding there is a chance of passing HIV from an infected mother to her newly delivered child but exclusive breastfeeding is safer for the child than mixed feeding.
<i>Fertility awareness-based methods</i>	YES	NO	
<i>Intra-uterine device</i>	YES	NO	Contra-indicated for women with HIV who also have an STI.
<i>Surgical sterilization</i>	YES	NO	Not recommended for persons already displaying AIDS symptoms.



Questions to ICTC Counsellors

Using hierarchical counselling techniques, which method of family planning would you suggest for a woman who is in the fourth month of her first pregnancy?

Using hierarchical counselling techniques, which method of family planning would you suggest for a man who is HIV-infected but would still like to have children?

What methods would you recommend for a woman who is HIV-infected and is on ATT?



References

World Health Organisation (2006). *Reproductive Choices and Family Planning for People Living with HIV: Counselling Tool*. Switzerland: Author

Latka, M., Gollub, E., French, P. & Stein, Z. (2000). Male-condom and female-condom use among women after counseling in a risk-reduction hierarchy for STD prevention. *Sexually Transmitted Diseases*, 27, 431-437.

COUNSELLING COUNSELLING MODULES

Understanding Behaviour Change

At the end of this unit, participants will be able to

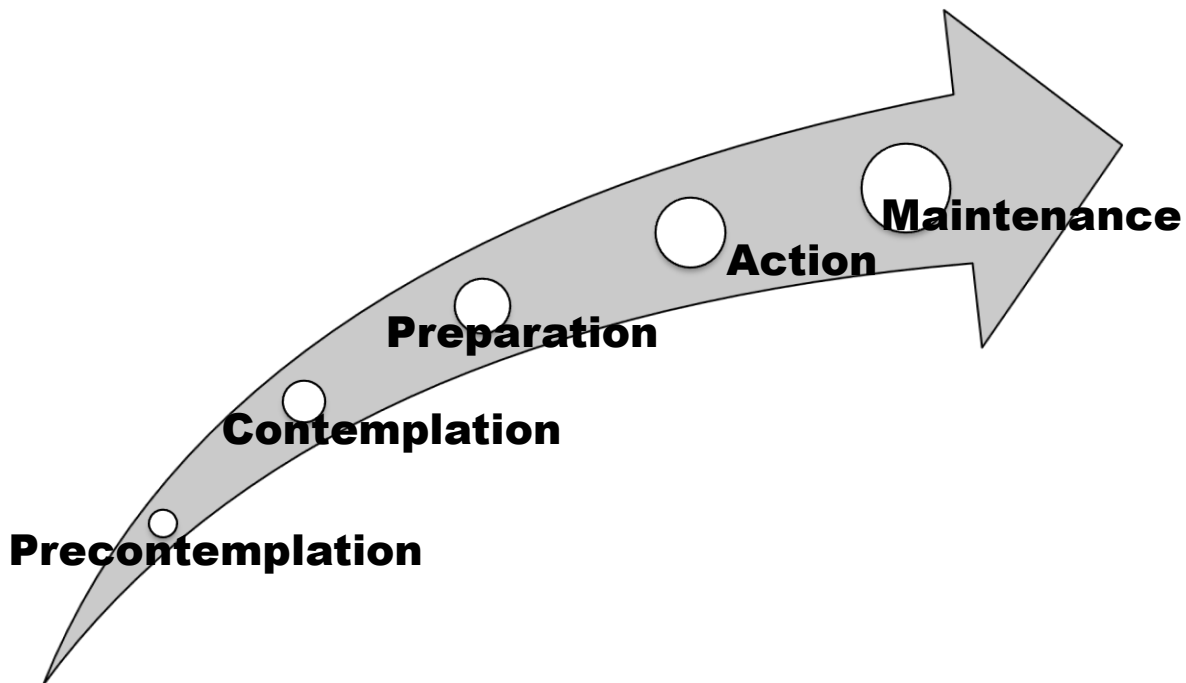
- Describe the transtheoretical model of behaviour change
- List appropriate counselling techniques for each stage of behaviour change

When working with clients at risk of HIV infection, counsellors must utilize tried and tested principles of behaviour change. The transtheoretical model of behaviour change proposed by James Prochaska is one such model that describes how individuals can move from one stage of readiness for action to actual implementation of behaviour change. This model has been applied to HIV and other health issues such as alcoholism, high-fat diets and mammography screening.

Transtheoretical Model of Behaviour Change

According to Prochaska, individuals tend to follow a common linear process from initially not being conscious of their dangerous behaviours/ their health problems. From this condition, they can be influenced to actually change their behaviour. The stages of behaviour change according to his model are:

- Precontemplation
- Contemplation
- Preparation
- Action
- Maintenance



Transtheoretical Model of Behaviour Change

Precontemplation

Most persons with a problem are often at the stage of precontemplation: They have no idea about the danger from their behaviour. Some may not even recognise that there is a problem. When asked if they are likely to change, they answer in the negative.

It is wrong to mix up pre-contemplation with denial. Denial means complete negation of a problem situation. While all persons who deny they have a problem could be said to be in the pre-contemplation stage, the reverse situation does not automatically hold true. A person may accept that they have some kind of an issue but may not feel it is significant enough to require effort to change.

Behaviour Change Techniques for this Stage

To get individuals in this stage to want to change, an effective counsellor uses the following four strategies:

➤ **Consciousness Raising**

The counsellor informs the client in detail about the dangers in continuing his/her behaviour. She/He creates awareness about the causes, consequences and corrective actions for the problem through images, feedback on personal behaviours and bibliotherapy (counselling through reading books or pamphlets on themes relevant to the client's behaviour).

➤ **Dramatic Relief**

In this technique, the emotional angle is more important than the provision of information. The counsellor provides information but also attempts to reach the client emotionally through role playing and personal testimonies of other persons. Consciousness-raising often focuses on facts such as the number of persons affected, the kinds of symptoms they display or the type of destruction in their life. Dramatic relief will focus more on an emotional appeal of how a particular course of action will help a person avoid the negative consequences of their actions/habits.

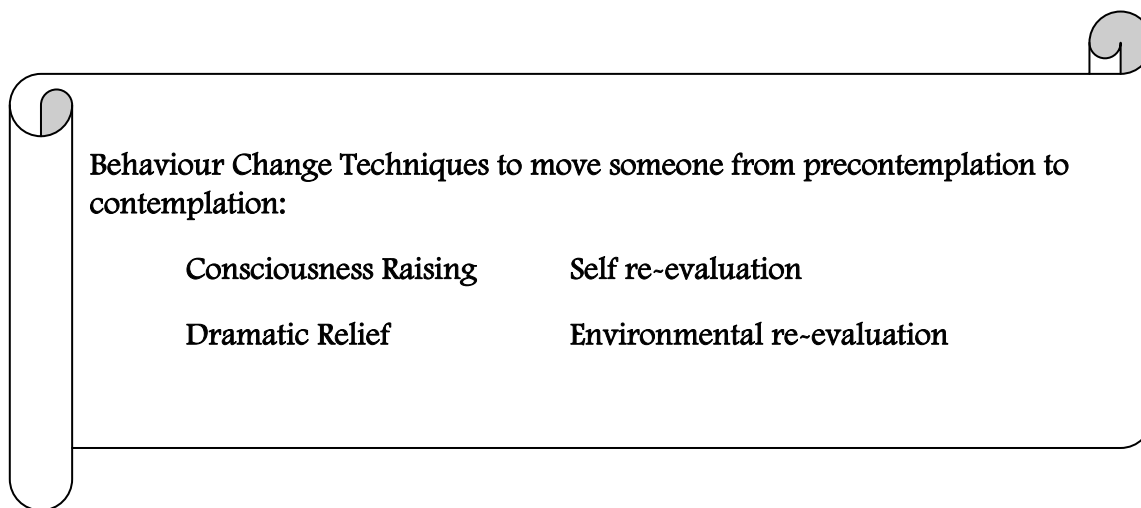
➤ **Self re-evaluation**

A counsellor using self re-evaluation invites the person to explore how his/her problematic behaviour is negatively impacting his/her life. Using the facts and figures in the previous two techniques brings awareness at a distant level whereas self re-evaluation is personal to the client. For instance, an injecting drug user may respond more deeply when shown a vision of how giving up his/her drug habit will make it less difficult for his wife to pay the child's school fees.

One common error that counsellors make here is to lay on the guilt liberally. Much more effective is to invite the client to state the negative impacts through brainstorming and asking him/her if this is a situation they would like to persist. When these issues are drawn from the client, they may cause him or her to recall how nice life was before the undesirable habit.

➤ **Environmental Re-evaluation**

Related to the above is the technique of environmental re-evaluation where the person is encouraged to explore how his/her problematic behaviour negatively impacts other persons in his/her life. Thus the IV drug user in the earlier example would be asked to brainstorm on how the drug habit is bad for the spouse or the child. Some people may respond to this technique as it tends to be guilt-producing. They may feel less concerned about spoiling their own life but may not want to do so with others. To use this technique, of course, you need to know who within the client's circle is important enough for them to show concern. As in the previous technique, it is more effective to elicit this information from the client.

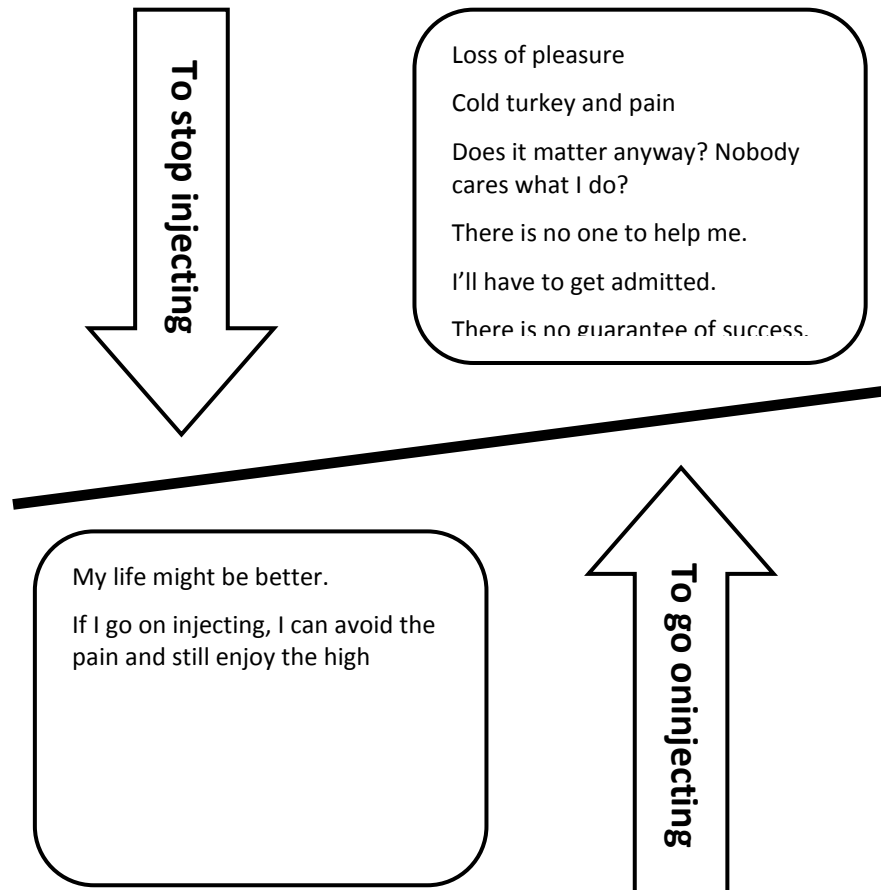


Behaviour Change Techniques to move someone from precontemplation to contemplation:

Consciousness Raising	Self re-evaluation
Dramatic Relief	Environmental re-evaluation

Contemplation

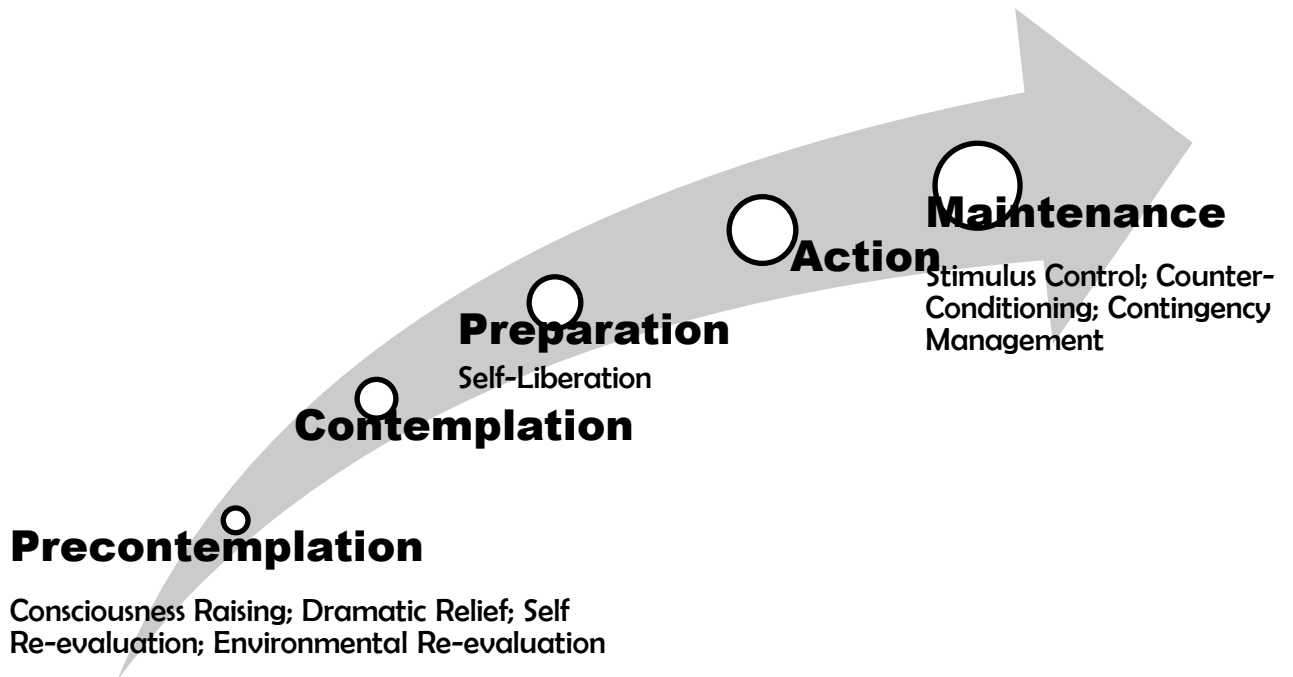
Contemplation is the second stage. While people in the precontemplation phase deny any intention to change, those in the contemplation phase will say (vaguely) that they do intend to change within the next 6 months. Such people are ambivalent about the behaviour change. They are still weighing the factors that will make the behaviour upheaval worthwhile against the disadvantages. For a drug addict in the contemplation stage, cold turkey or withdrawal symptoms are too difficult to consider. For a person wishing to lose weight, the deprivation of favourite food might not be attractive. At this point, if a counsellor or doctor were to ask such individuals to list in two columns the advantages and disadvantages respectively, the second column would outweigh the first.



Mental Ambivalence of someone in Stage of Contemplation

A counsellor who wants to move someone beyond contemplation must make the advantages of behaviour change more significant and must reduce the impact of the disadvantages. This can be done

by both techniques of re-evaluation mentioned previously. People who are in contemplation are already to some extent aware of the problems from their behaviours. But they are not yet sure that the trouble associated with change is worth it. Their behaviours are comfortable or well-entrenched habits that will take major effort to alter.



Techniques Specific to Each Stage

Preparation

People in the preparation stage are different from those in contemplation - they have worked through their indecision and ambivalence and are more likely to state an intention to change in the immediate future (e.g., next month). They are more likely to have a concrete date (e.g., New Year's day / child's birthday) and a relatively concrete plan of action (e.g., buying an exercise machine).

Behaviour Change Technique for this Stage

➤ Self Liberation

Counsellors can use the process of self-liberation to help people to move from the early stages of behaviour change to actual action. Self-liberation is both a belief that one can change as well as a strong commitment to the change process. Some ways of using this particular process of change include linking change with clear dates, ensuring a personal sense of efficacy with regard to the change process and offering the client more choices.

With regard to the last suggestion, research shows that people are more likely to be positive when presented with more than one option: For instance, counsellors can offer clients a choice of sex with condoms or non-penetrative sex or less risky penetrative sexual options. However, there is a point beyond which too much choice will paralyse the client into non-decision or non-action. For instance, offering him/ her choices between one type of test versus another or one testing facility versus another is good as this conveys a sense of being in control of the action. But presenting a long list of testing facilities in the district will be counter-productive as the client now has to take the time to sift through the data. The effective counsellor would present two or three options that are workable and manageable from the client's perspective.

Behaviour Change Techniques for someone at the Preparation stage:

Self-liberation

The first three stages of behaviour change described may confuse the first-time reader who will find it difficult to identify where one stage starts and the other ends. However, there are some clear markers that will help you to distinguish them apart – intention to change or not, and whether a person intends to change in the next month or the next six months.



Action

The person who has reached the action stage has already made specific identifiable life-style changes within the past six months or so – note that behaviour change experts do not count change for only one or two months as defining a person in the action stage. The behaviour change must appear to be significant. Here is a simple example: Just giving up smoking for the duration of a flight from Delhi to Chennai does not constitute smoking cessation. For a person to honestly say they are trying hard to give up smoking there should be a visible and significant drop in the number of cigarettes consumed, or it should be change sustained over a significant period of some months.

This statement is also important in light of the discussion on risk reduction and the validity of behaviour change goals. It may not always be possible for an individual to give up ingesting drugs. But to have them significantly reduce the dosage or to move towards a significantly safer way of ingesting the drugs is also a recognizable and significant change. Counsellors must, in a non-judgmental manner assist the client to identify actions that are manageable and achievable rather than try to insist on strict and total abstinence. This is the principle that underlies both risk reduction and harm reduction.

Maintenance

In the stage of maintenance the client displays the success of a behaviour change strategy. People in the maintenance stage have been successful in sustaining their changed behaviours for a period of 6 months. They become less susceptible to thoughts of relapsing – of returning to the earlier behaviour.

Behaviour Change Techniques for this Stage

➤ **Stimulus Control**

Counsellors teach clients to manage the cues in their environment that remind them of the earlier unhealthy behaviour. This is similar to why an alcoholic who wishes to recover from alcohol addiction is asked to make new friends, avoid drinking buddies and to find a new way home that avoids old temptations such as a convenient liquor shop on the way home. Some ways to achieve this are through environmental re-engineering (placing condoms near the bedside to ensure safer sex, throwing out alcohol bottles to avoid succumbing to temptation at home), avoidance (staying in the controlled environment of a drug rehabilitation facility) and support groups (for instance, Alcoholics Anonymous which is quite active in India).

➤ **Counter-conditioning**

In counter-conditioning, counsellors encourage people seeking to maintain behaviour change to learn healthier behaviours that can substitute for earlier problem behaviours. We see this strategy in the suggestion to replace invasive sexual behaviours with non-invasive ones (such as mutual masturbation), or to replace higher-risk behaviours with lower-risk ones (such as encouraging the replacement of anal sex by oral sex), or permitting drug addicts in recovery the use of cigarettes to control their cravings. While the last suggestion may not appear to be healthy, it should be noted that the alternative behavioural action is one that places the individual at severe risk of damage.

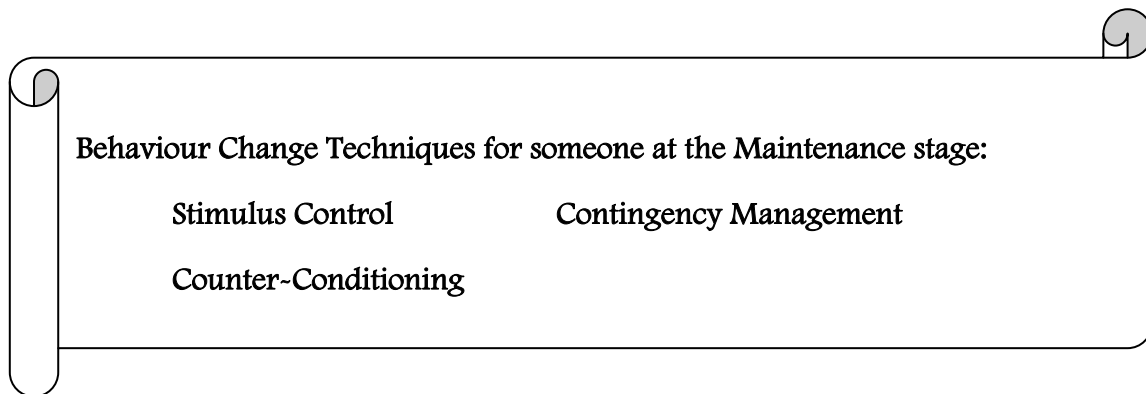
For counter-conditioning to be successful, the counsellor helps the client to explore the pressure points that might cause him/ her to fail in successfully maintaining behaviour change. Together, they examine strategies used in the past to manage this pressure in terms of their potential for risk and

harm, they list the least harmful strategies and explore other potentially helpful strategies (e.g., picking up the telephone to speak with a friend at the end of a stressful day instead of picking up a bottle of alcohol). The counsellor must focus on strategies that the client finds useful because not everything will work for everyone. Further, the counsellor should recognise that some behaviours provide in-built reinforcement to the client because their use answers a need within the person (e.g., release of tension, experience of pleasure or a “high”) and, therefore, substitute behaviours should provide and answer those needs as well.

The Opioid Substitution Treatment strategy in the National AIDS Control Organisation is one concrete example of such a behaviour change strategy through counter-conditioning. Here the drug user who injects drugs is permitted to continue the drug habit through the oral consumption of buprenorphine. This reduces the chance of HIV and Hepatitis transmission through sharing of infected needles but drug consumption carries on in a safe manner.

➤ **Contingency Management**

Contingency management is simply the process of reward and punishment to ensure the successful maintenance of the behaviour change. Research shows that rewards (positive contingencies) are usually more effective than punishments (negative contingencies). Effective counsellors take time to explore contingencies that are effective for individual clients.

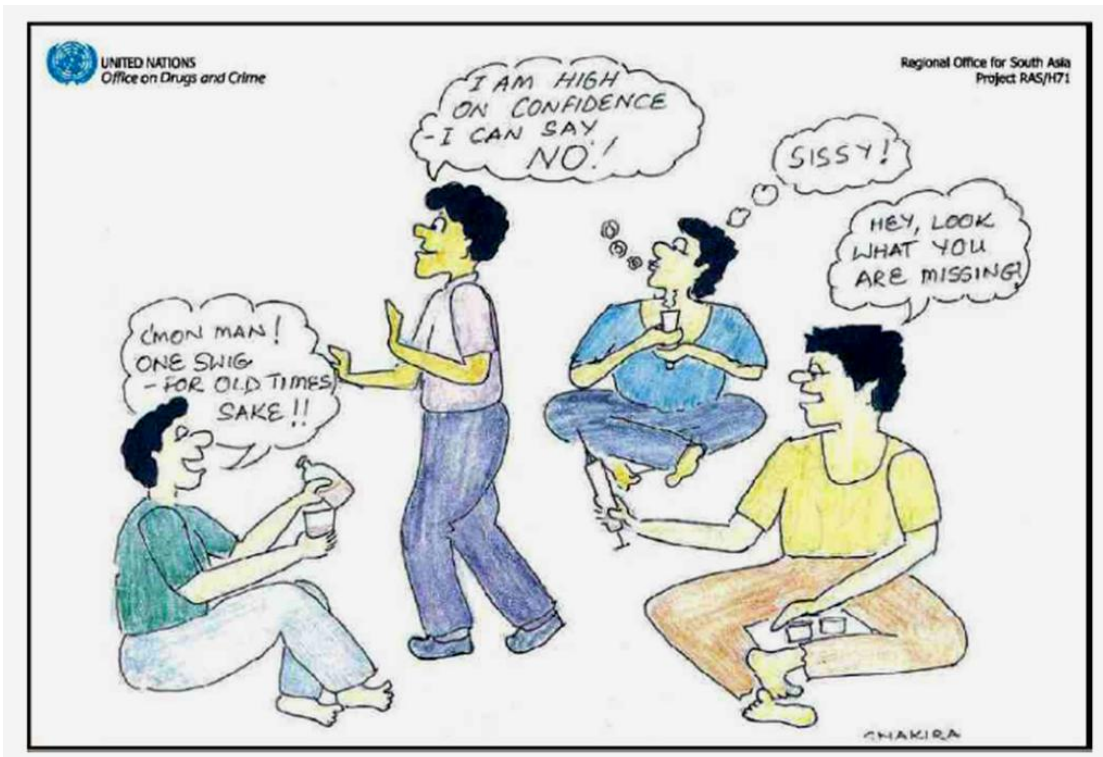


Behaviour Change Techniques for someone at the Maintenance stage:

Stimulus Control	Contingency Management
Counter-Conditioning	

Relapse

Prochaska included relapse in recognition of the fact that some people do not succeed in maintaining their behaviour in the long-run. Rather they may fail and return to one of the earlier phases. Unfortunately for counsellors working with behaviour change relapse is very common. However, the client will never return to pre-contemplation.



Example of cues for which Stimulus Control is important

Source: United Nations Office on Drugs and Crime

To reduce the possibility of relapse, counsellors must work with clients to identify and avoid potential pitfalls. This is termed relapse maintenance. It involves the skill of anticipatory guidance where the counsellor informs the client about potential dangers ahead (e.g., based on experience with other clients). For those clients who have tried but failed in changing their behaviour, counsellors can highlight the good news that they were able to make some progress in planning their behaviour change, and are now further along in the process. This positive message avoids further discouraging the client with blame and guilt and it encourages him/ her to look forward to trying again. Some other strategies for relapse prevention are counter-conditioning and social liberation which give the client maximum opportunities for successful practice.

To reduce the possibility of relapse, counsellors must work with clients to identify and avoid potential pitfalls. This is termed relapse prevention. It involves the skill of anticipatory guidance where the counsellor informs the client about potential dangers ahead



Questions to ICTC Counsellors

Which techniques of behaviour change have you used till date in your counselling practice?

Behaviour Change Story 1

This is an exercise to apply the Transtheoretical Model. Read the story and identify statements which show the different stages of change the person is at:

Precontemplation

Contemplation

Preparation

Action

Maintenance

'I have been gaining weight for some 10 years now ever since the age of 28. Then I was slim. But the weight gain began very slowly. At first my family would tell me that I was putting on weight. But I would ignore their comments. Once I actually threw and broke a china cup when my father went on and on about how he could not distinguish between my mother and me in the dark as we were the same size. When professional colleagues mentioned my weight, I would joke, "I usually skip meals when I am depressed. Therefore, the fact that I am getting fat means that I am happy," or simply "Now there is more of me for you to appreciate." I would dismiss their comments by saying that I was eating healthy.'

'But a lot of this changed three years ago. My father passed away from a heart condition. He had been a little on the stout side. I began to realise just how out-of-shape I was. As he also had diabetes, I began to worry about family history issues. I even took a blood sugar test and breathed with relief when I was found to be in the normal range. I noticed how breathless I would become after climbing a few stairs. I noticed that a favourite sari could not be worn till I made a new blouse as I had already altered the seams once. Whereas before I did not mind people clicking my photographs, I suddenly became conscious that certain angles made me look fat. I began to dislike having my photograph taken.'

'Still I did not do much. But then I met with a colleague who had experienced good outcomes with a brand new diet. I was impressed. I thought wistfully about how nice it would be if I could also do so. I began to read about the diet. I liked the book so much that I went out and bought it. I even began experimenting with the recipes.'

'When I felt ready to make the change, I went out and brought some of the foods necessary for my new diet. I opened my diary and measured my weight. I was 78 kilos at that time. I started my new diet from the first of January. I would weigh myself every Monday morning and note it on the calendar. I felt really happy when I had dropped 10 kilos at three weeks of dieting. At this point my clothes began to hang on my body. So I went out and bought a new suit. I felt lighter and more energetic. I began to walk about more. This was something I had lost the habit for as I used to get breathless. The more I walked of course, the more I lost weight.'

'Now it is August. I am 18 kilos lighter. I have had to buy new clothes. But I feel good.'

Comments on the Story

1. Identify the different stages

- a. Stage of pre-contemplation: *But I would ignore their comments... I would dismiss their comments by saying that I was eating healthy.'*

Here the person displays a complete lack of readiness to change her behaviour or lifestyle. Well-meaning comments from friends are ignored.

- b. Stage of preparation: *I began to read about the diet. I liked the book so much that I went out and bought it. I even began experimenting with the recipes.*

Here the individual begins making tentative steps towards changing the behaviour but has not yet made a full commitment.

- c. Stage of maintenance: *Now it is August. I am 18 kilos lighter.*

Here the individual has lost weight and has managed to maintain it for more than 6 months.

2. Some ways to help the person move from pre-contemplation to contemplation of behaviour change

- a. **Consciousness-raising:** Presenting facts and figures linking over-weight with heart disease and other health problems
- b. **Dramatic relief:** Presenting stories about how good people feel after they have managed to lose weight, how their personal well-being improves; Role-playing during counselling about how other people might respond to the "new and reduced You."
- c. **Self-re-evaluation:** Encouraging the client to think of how being fat negatively impacts her life (e.g., she has to endure nicknames, she is no longer comfortable to have her photo taken, she has difficulty finding clothes that fit, she does not have energy to play with her children, she tires easily, she is at greater risk of heart disease, her boss has overlooked her for a promotion as he/ she prefers a smart looking employee)
- d. **Environmental-re-evaluation:** Encouraging the client to think about how her fat stature negatively impacts other people in her life (e.g., her children miss playing with her, her family is embarrassed)

3. An example of counter-conditioning for this individual

One example of counter-conditioning for this individual is to substitute unhealthy eating with healthy eating, that is green salads in place of high-cholesterol foods which are deep fried. As the person may enjoy deep fried items, the replacement foods should provide comparable enjoyment to her. Another example is to bake or steam food items instead of frying them.

4. An example of contingency management for this individual

The individual mentions: *I would weigh myself every Monday morning and note it on the calendar. I felt really happy when I had dropped 10 kilos at three weeks of dieting. At this point my clothes began to hang on my body. So I went out and bought a new suit.*

Here the individual is using the technique of contingency management on herself. She rewards herself when she has reached a level of behaviour change that is meaningful to her. She also uses a calendar to track her progress.

Behaviour Change Story 2

Practice Time

I began smoking when I was 14 years old. I used to steal cigarettes from my father's pocket. Later I began to also "borrow" money from my mother's purse to buy cigarettes. In college I found out that for the same money I could buy a small 'puḍi' of stuff that was better. I enjoyed myself.

My best friend warned me that I was going down the wrong track. I laughed at him. I told him that I was not like those "druggies," "smackiyas" or "charasis". I could stop at any time. Yes! I could stop. I had tried to stay away from the stuff during exams. The longest I could do was 7 days. But soon I was back to taking the "stuff" again.

When I began working at the age of 21, I had already begun taking a cocktail of pharmaceutical stuff. You crush it together, dissolve it and inject it. This was clean stuff, not like those "charasis." I worked in sales. It was difficult to keep my focus. But I managed. More than half my salary would disappear.

My mother started to notice my behaviour patterns. She would grumble that I was not the good child she had known before. Then one day she found me injecting myself in the bathroom. The whole family started harassing me. By now I knew I was hooked. The family tried many things. They took me to a "baba" who prayed over me. They began accompanying me to work but I would find a way to escape. They locked me in the house one day. But my withdrawal pain was very great. I started screaming and cursing. This frightened them and they let me out.

A friend came over to talk to me. She tried to make me see the light. But all I could think of was how to avoid the withdrawal pain. I looked forward to my "nasha," my "intoxication."

My family left me alone. But they would leave pamphlets about drug NGOs around the house. I would throw them in the waste-paper basket.

Then one day my mother came to me and in tears asked me if I could give her a birthday gift. She said I could afford this one. I loved my mother. So I said, "Yes." She took me to a support group meeting. I did not like the idea of being in Narcotics Anonymous. But I had promised my mother. So I decided to wait for 20 minutes. There were two speakers who had to speak. I kept looking at my watch.

Five minutes before I was ready to walk out, an older man got up to speak. He had a soothing voice. I began to listen to his testimony. His words were very familiar to me. He could have been saying my life story. He described his own trouble with drugs. I realized how much I had sunk down. My mother looked over at me and held my hand. I had no thought now to leave.

After the meeting she requested that man to speak to me. I was now starting to get twitchy. I needed my fix. But I spoke to that man a little. He took my telephone number. He would call me every week and speak to me gently about turning my life around. His message slowly sunk in.

One day, I decided that I would go to a drug agency to get straight. I told my friend from Narcotics Anonymous. He told me that he would go along with me as a support. I agreed. I knew that if I was alone, I would be tempted to give up.

My first week at the drug centre was like sitting in a fire. There are no words to describe it for you. But later it got better. I learned to control my need for the drugs through yoga prayer and hard work. I was allowed to smoke cigarettes because I still got twitchy. When I went out, I was encouraged to go with another addict friend so we could support each other to remain sober. I still have the certificate that the centre gave me for remaining sober for 50 days. Even Sachin's half-century could not be better!

It has been 8 months since I have taken drugs. I am with my family now. We spend a lot of time together because I still worry about meeting my old friends who would lead me back to my bad habits. I still think about the drugs. So I began learning how to paint as a distraction. This works sometimes.

I look forward to the future. The centre has warned me about sliding back, about relapse. I go to Narcotics Anonymous meetings. Being around other ex-addicts helps.

Read the story and identify sentences in the story which show the person passing through the different stages of behaviour change according to the Transtheoretical Model: Precontemplation, Contemplation, Preparation, Action, Maintenance.

Identify the different types of techniques used in this story

Comments on Behaviour Change Story 2

1. Identify the different stages

a. Stage of pre-contemplation:

b. Stage of contemplation

c. Stage of preparation:

d. Stage of action

e. Stage of maintenance:

Understanding Risk and Vulnerability

At the end of this unit, participants will be able to

- Describe the concepts of risk and vulnerability

Please note: This is a non-instructional unit.

As ICTC counsellors, you play a key role in linking members of Most-At-Risk Populations with testing services and with targeted intervention projects that are designed to address their needs. Counselling is focused on helping such clients to assess their susceptibility to HIV infection, to recognize ways to reduce their susceptibility, and to encourage them to know their HIV status through the HIV Rapid test.

However, as counsellors, you may also experience a sense of frustration that even though you advise clients about the advantages of learning their HIV status, or about the need to change their behaviours, clients continue to resist behaviour change. It is important here to understand that counselling operates against a background of various societal factors such as community norms. These may prevent clients from changing their behaviours. It is important for you to recognize these factors that limit behaviour change in clients and to facilitate ways to overcome them. Behaviour change is a process, and like every process, it takes time to unfold and to stabilize. One counselling session is not sufficient.

In this context it is important to understand some key concepts: Risk and vulnerability. Besides these, stigma and discrimination are other factors that are common to all Most-At-Risk groups.

Risk

Risk is the “probability that a person may acquire HIV infection” (UNAIDS, 1998). Any person has high risk of HIV infection if they have unprotected sex with a partner of unknown HIV status or if they inject drugs with shared needles and syringes. People may be at risk for many reasons:

- poor or incomplete information on HIV,
- being unable to negotiate safer sex,
- being unable to get hold of condoms,
- belief that HIV affects people who are richer/ poorer than themselves.

Initially, most HIV programmes aimed at reducing risk behaviours by targetting individuals and groups. For instance, they provided information and education, free condoms and clean syringes. However, this approach is not sufficient. People do not always act the way we expect them to act. For instance, an injecting drug user may share needles as a sign of solidarity with her/ his friend even if there is easy access to clean syringes. Similarly, a sex worker or MSM may use condoms with every one except a special partner – they may perceive the use of condoms as a sign of lack of trust, or as an expression of love and confidence.

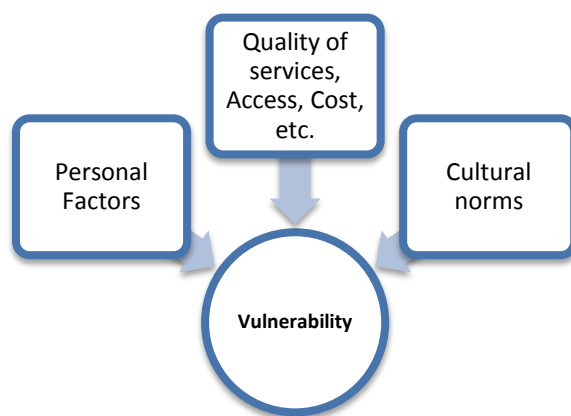
In addition to individual factors, behaviour of people and their personal risks are also influenced by environmental and societal factors. For instance, a child who is settled within her family may be far from HIV risk. But a sudden family crisis such as a poor harvest or the death of the earning family member can change this and make the person vulnerable to risk through trafficking.

Vulnerability

Vulnerability is the result of “societal factors that affect adversely one’s ability to exert control over one’s health” (UNAIDS, 1998). Vulnerability could be due to various factors:

- Personal factors such as sexual history, personal knowledge, and membership of specific social networks may increase vulnerability.
- Factors such as quality of services offered to individuals in need, geographical access, and cost will also increase or decrease vulnerability.
- Finally, there are societal factors such as cultural norms which influence a person’s behaviour. For instance, Indian men and women are expected to marry and have children. So it is almost impossible for men and women who have a sexual attraction for a person of their own sex to avoid getting married to a person of the opposite sex. Gender norms and poverty are other societal factors that increase vulnerability.

The next three modules focus on risk and vulnerability of three Most-At-Risk Populations. Risks and vulnerability related to HIV infection are different for these various communities. Moreover, these are not isolated communities. Instead they may overlap with other sub-groups. For instance, many drug users may also sell and buy sex. Men who have sex with men may also be married and have sexual relations with spouses and sometimes with female sex workers. It is not possible to put the behaviours of people into neat boxes. It is important for ICTC counsellors to recognize this. It is also important to recognize that while counsellors work with clients to reduce their personal risk behaviours, clients live and work within contexts where they are vulnerable for reasons beyond their immediate control, and they may not be able to easily implement measures to change their behaviours.



Stigma and Discrimination

HIV/AIDS is typically viewed by common people as a disease that affects “others,” that is people who are different from them, people whose lifestyles are seen as “perverted” and “immoral.” In the case of the three high-risk groups that this module describes, their behaviours and activities appear to be very different from what is familiar to general communities. Hence they are treated with rejection. Sometimes even counsellors struggle with these attitudes.

Anyone who sets aside certain persons or groups from the normal social order because they believe them to have some negative characteristic is basically placing a **stigma** on those persons or groups. UNAIDS defines HIV-related stigma as a ‘process of devaluation’ of people either living with or associated with HIV and AIDS.

Anyone who treats an individual unfairly and unjustly based on his or her real or perceived HIV status is guilty of practising **discrimination**. Discrimination is the result of the social separation or devaluation. It is also sometimes called enacted stigma.

We can think of stigma as attitudes and thoughts, and discrimination as the behaviour based on stigmatizing attitudes and thoughts. However, it is important for counsellors to note that even if a person feels stigma towards another, she/ he can decide not to act in a way that is unfair or discriminatory.

HIV/AIDS stigma and discrimination violate human rights and arise from 3 factors:

- Lack of awareness of how stigma affects People Living with HIV/AIDS
- Common fear of people of being infected from ordinary contact with people already infected with HIV – In this case, it is fear of being tainted/ damaged by associating with people whose sexual behaviours or drug-related behaviours we cannot understand
- Linking all PLHIVs with behaviours that are immoral

HIV/AIDS stigma and discrimination is one of the structural factors that create barriers for people in accessing health care and protective measures such as condoms. When counsellors and other health care personnel reflect such stigma and discrimination, they are guilty of becoming barriers themselves.



References

- Busza, J. (1999). *Challenging HIV-related stigma and discrimination in Southeast Asia: Past successes and future priorities. (Horizons literature review)*. Washington, DC: Population Council.
- Joint United Nations Programme on HIV/AIDS (1998). *Expanding the global response to HIV/AIDS through focused action: Reducing risk and vulnerability: Definitions, rationale and pathways*. Geneva, Switzerland: Author.
- Joint United Nations Programme on HIV/AIDS (2005). *Reducing HIV- related stigma, discrimination and human rights violations: Case studies of successful programmes*. Geneva, Switzerland: Author.
- Joint United Nations Programme on HIV/AIDS (2007). *Reducing HIV stigma and discrimination: A critical part of national AIDS programmes*. Geneva, Switzerland: Author.
- Mahendra, V.S.L., George, G. L., Samson, L., Jadav, M.S., Bharat, S. & Daly, C. (2006). *Horizons final report: Reducing AIDS-related stigma and discrimination in Indian hospitals*. New Delhi, India: Population Council.

Working with MSMs

At the end of this unit, participants will be able to

- Describe the type of sexual behaviours that are visible among MSMs
- List the reasons which increase vulnerability in MSMs
- Demonstrate skills of risk assessment and risk reduction for MSMs

The reason for a special focus on the HRG communities and the general population is because sero-prevalence in these two groups is different. For instance, while annual sentinel surveillance shows that 0.31% of the general population is infected with HIV, the sero-prevalence among the MSM community is as high as 11.8% (HSS, 2008).

Who are MSMs?

Though this section begins with some terms commonly used in the context of Men who have Sex with Men, you, the ICTC counsellor should realize that it is important not to try to fit an MSM client into a neat box based on the terms discussed below. Similarly, it is also important to avoid replacing one label with another one. Awareness of these terms is useful in becoming more effective in working with clients with MSM behaviours. Earlier labelled homosexual, today we refer to members of the community as MSM partly to differentiate same-sex behaviour among women, and partly to place emphasis on the sexual behaviour practices of Men who have Sex with Men.

Kothis

Kothis are more recognizable among the MSM community because of their visible feminine mannerisms. They may or may not adopt feminine clothing. They are generally receptive partners in the sex encounter (Chakrapani, 2007). Their partners appear to be more masculine and *kothis* usually address them as *panthis*. *Kothi*-identified MSM tend not engage in sex with one another.

Kothis generally come from a lower socioeconomic background. Some of them engage in survival-based sex work. They often present very differently from middle-class, educated, gay-identified MSM with whom we may be familiar, from say television or popular films like *Dostana*.

However, among *kothis*, there are a significant number who may identify themselves as *kothi* but who also penetrate their male partners. In North India, these individuals may be identified by the term '*Khada Kothi*.' Further, many *kothi* men also engage in sex with women and may get married to a woman. Behavioural surveillance shows that MSMs who report marrying a female could range anywhere from 10% to 56% (NACO, 2006).

We repeat the earlier caution about not putting people into boxes while counselling. To do so means you may fail to ask all the questions necessary for a complete risk assessment.

Panthis

Panthis is the term used by *kothi* men and by *hijras* to refer to their sexual partners (Chakrapani, 2005). They are also sometimes called *Kowriya* or *Giriya* or *Gadiyo* or *Parikh*. However, men who are designated as *panthis* rarely refer to themselves by this label. These are simply the men who “penetrate” during the act of sex. They may or may not appear to be more tough and masculine-looking. However, even *panthis* may have sex where they are the receptive partners who are penetrated. MSMs who engage in both insertive and receptive anal sex are sometimes labelled within the community as “double-deckers” (Chakrapani, 2007). They are also called *Dupli-kothi* or *Do-paratha*.

Hijras/Transgendered People

Hijras or eunuchs – also known as *Aravanis* or *Alis* or *Bhand* - are a traditional Indian sexual minority community. They are born biologically as males but they reject their ‘masculine’ identity and self-identify as women or as non-men (Chakrapani, n.d.). They tend to live in *gharanas* - communities of hijras (NACO, 2006). They are equivalent to transgendered people or transsexuals of modern times though they have existed as a strong, cultural group for hundreds of years in India and are feared for their power to curse or bless a person.

It is important to note that among *Hijras* there are differentiations. For instance, those who have removed their penis and testes in order to complete the transformation from male to female are said to have undergone “*Nirvana*” and are addressed as *Nirvana Kothi*. Achieving “*nirvana*” status is a costly affair and many *Hijras* resort to services from quack doctors (Chakrapani, 2005). Some of them face complications from botched operations. Not all *Hijras* undergo this operation to remove their reproductive organs. Some live as *Ackwa* or *khada-kothi* – that is they may only adopt female attire and may learn to adopt a feminine manner from a *Guru*. They may also penetrate their male partners. One type of *Hijra* is the male temple prostitute - also called *jogta* or *jogappas*. These are mostly male children who are dedicated to a goddess. Later, they ritually cross-dress for religious purposes (NACO, 2006).

Many *Hijras* provide sexual services in exchange for money because of a paucity of other work opportunities. In a study in 4 high-prevalence states, upto 63.5% of *Hijras* reported selling sex (Brahman et al, 2008). They may also have a steady partner with whom they co-habit. Some *Hijras* get

married to a female before joining the community, and may also have children from this union (Chakrapani, 2005).

However, we repeat the message of not slotting people into boxes. A community consultation in Mumbai with members of the *hijra* community brought out the fact that *hijras* may practise different professions: While some sell sex, a second group begs for money at traffic signals and a third group sings and performs at the homes of people, say when children are born (AVERT, 2010). Even among these other two professional groups, some *hijras* may engage in sex with one partner or many.

While originally ascribed a cultural role in Indian society, *Hijras* today tend to be stigmatized because of both their non-normal appearance of “men dressed as women.” They also are looked down on because of their presumed occupation, namely sex work (Chakrapani, n.d.). Indian mores have changed drastically from the time when *hijras* were referred to as *tritika laingik* or the third sex (NACO, 2006). They face much stigma and discrimination today.

Bisexuals

Bisexuals are people (male or female) who have sex with other people of their own sex as well as with people of the opposite sex. Many married MSMs may fall into this category as they may sexually active with their wives as well as with male partners.

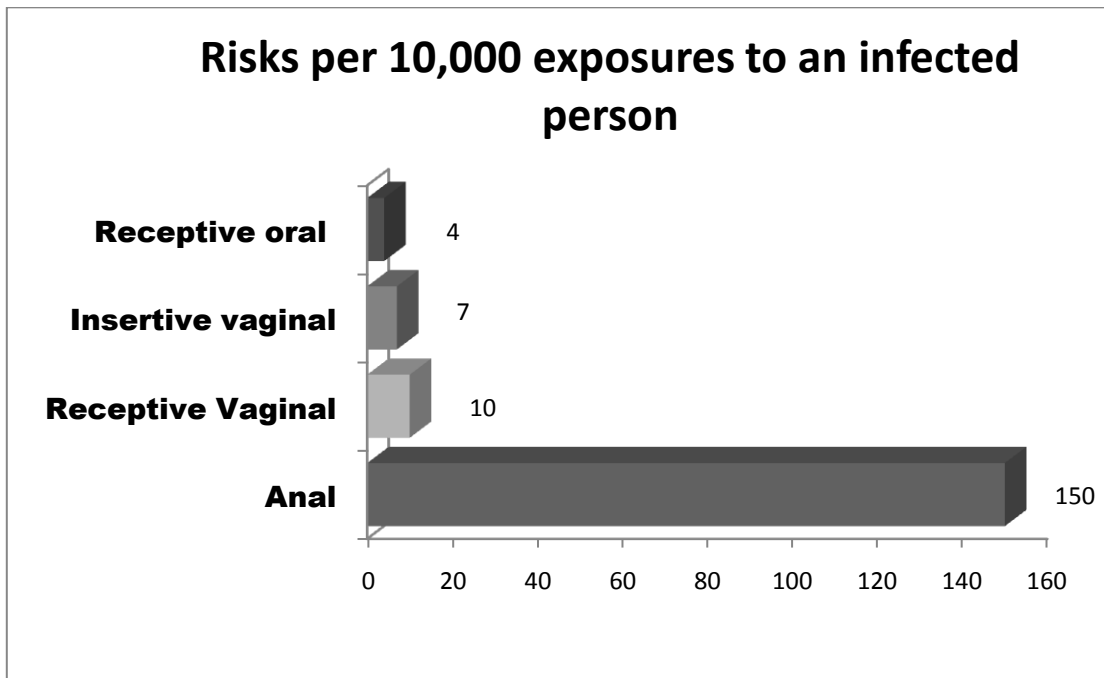
While it is important to know the common terms that are used to label Men who have Sex with Men, it is possible that these terms may cause the counsellor to slot the client into a particular category. The counsellor should learn to look past the appearance or mannerisms of the client and work to reduce their risk and vulnerability.

Understanding Vulnerability of MSMs

Vulnerability due to Anal Sex

One reason for the high prevalence of HIV is the fact that MSMs frequently practise anal sex. This carries a higher possibility of transmission of HIV because of the increased risk of physical trauma (damage). It is estimated that relative HIV risks from anal sex is higher than that posed by other sexual acts. For instance, transmission through anal sex may occur in 15 out of 1000 sexual acts compared with 1 out of 1000 acts of receptive vaginal sex, 7 out of 10,000 incidents of insertive vaginal sex, and 4 out of 10,000 incidents of receptive oral sex (as reported by Dandona et al., 2006).

Besides anal sex, MSM sexual practices also include mutual masturbation, oral sex and other non-penetrative sex options. However, of these, anal sex is most risky. It is also very common. When asked to report their first sexual experience with any male partner, in 6 out of 10 surveillance sites of NACO, the highest number of respondents reported that their first sexual activity was anal sex (NACO, 2006).



Vulnerability due to Other Sexual Factors

Other factors that increase vulnerability are the high number of sexual partners (NACO, 2006) as well as the co-existence of sexually transmitted infections (Dandona et al., 2006). For instance, MSMs surveyed through NACO's (2006) behavioural surveillance report a mean number of commercial sex partners in one month ranging from 25.2 to 3.1 (Bangalore and Delhi respectively). Further, 45.6% of MSMs surveyed in New Delhi, 29.4% in Gujarat, and 28.9% in Kolkata reported suffering from burning pain during urination – sign of STIs. In addition, *Kothi* men experience heightened vulnerability on account of violence, including sexual violence (Chakrapani, 2007).

It is important to note that a person who practises MSM activity may be both a receptive sex partner as well as the insertive or penetrative partner. Also note that many MSMs may also practise sex with a woman. For instance, the proportion of MSM respondents who reported being married and living with their wives ranged from 8.5% (Chennai) to 52.1% (Gujarat) (NACO, 2006). When asked about sex with any female partners in the last 6 months, the percentage of those disclosing such behaviour was as high as 69.9% and 30.4% in some sites, and the highest average number of female partners was 3.7 (NACO). These figures once again remind us not to slot clients in boxes.

Vulnerability in MSMs who Sell Sex

Risk of HIV (and other sexually transmitted infections) is higher among men who sell sex to other men. They may also be more vulnerable than female sex workers. For instance, one study in Andhra Pradesh found that while female sex workers had a 1.7 to 2.7% chance of being infected, male sex workers were at greater risk – 11.6 to 17.9% chance of being infected (Dandona et al., 2006). The same study also estimated that male sex workers might have had a higher number of sexual contacts to whom HIV might be transmitted than the female sex workers. This, however, is only one study and its findings should be treated cautiously.

Vulnerability due to Early Sexual Initiation

It is important for counsellors to ask about MSM behaviour in all clients irrespective of age. NACO's annual sentinel surveillance shows that people often initiate their sexual life early: 50% of all MSMs first had sex with a woman anywhere from the age of 17 (Uttar Pradesh) to 23 years (Kerala); 50% first had sex with a man between the ages of 16 and 21. Sex with a male partner before the age of 15 was reported by 28% of MSMs in Kolkatta and 29% in Uttar Pradesh. Early sexual initiation means a longer sexual life. It also means that these individuals might be particularly vulnerable because of inability to negotiate condom use, or to comfortably access condoms.

Vulnerability through Inconsistent or Infrequent Condom Use

Using a condom consistently can reduce risk of sexual transmission but not eliminate it completely. However, this is an important behaviour change for MSM clients to adopt. Further, through NACO-supported Targetted Interventions, sachets of lubricants are available for MSM clients for use during anal sex.

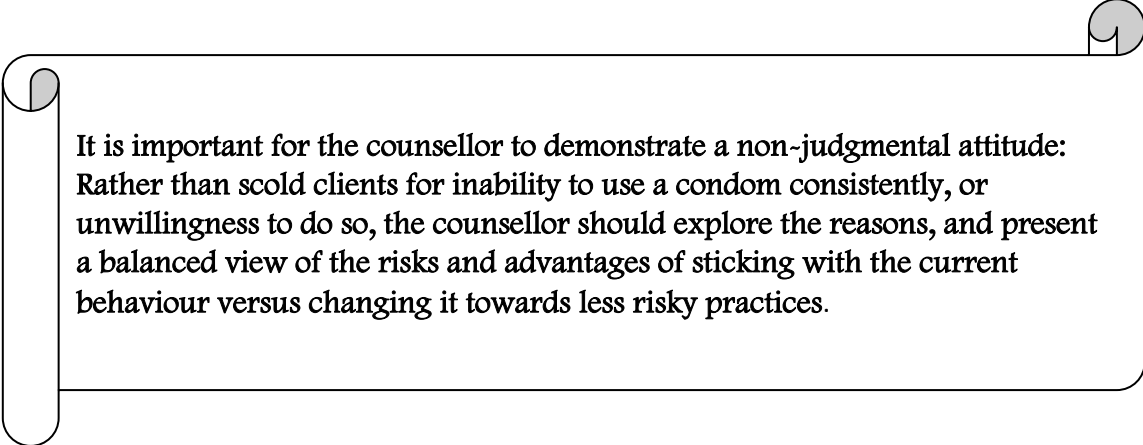
While using a condom consistently and correctly will reduce risk of HIV transmission, such behaviour is rarely adopted consistently. MSM community members are no different in this respect from non-MSM clients. Low consistent condom use is observed among all categories of MSM: *kothi*, *panthi*, *hijra* and double-decker/ bisexual (Brahman et al.). Figures of MSMs who report using a condom consistently are as low as 8.8% (Chennai) to 50.8% (Gujarat) (NACO, 2006). These figures indicate risk to both the male partners and female partners.

There are many reasons why MSMs may not use condoms consistently. For instance, there is a perception that using the condom may reduce sexual pleasure for self or the sexual partner (Chakrapani et al, 2008). Some MSM suffer from misconceptions about the role of the condom: They prefer to use a condom for oral sex over anal sex because of the perception that the mouth is used for eating or to protect self from the smell associated with the penis. Rather, they do not see the risks associated with anal sex. Other reasons include lack of access to condoms and risks of being identified and mistreated if caught by the police with a condom in their pocket.

Among MSMs with steady partners, the motivation to wear a condom may decrease as an expression of love, or an assumption that the partner is also HIV-free. MSM who are married (or have a steady female partner) may find it difficult to explain to their female partner why they want to use a

condom. Male sex workers may experience difficulties negotiating condom use with clients: They may wish to avoid the disease connotation associated with use of a condom, as well as may be tempted to have sex without a condom for more money. Some MSMs may be forced by policemen or criminals to have sex without a condom.

These are all practical difficulties which a counsellor should elicit during the counselling session. **It is important for the counsellor to demonstrate a non-judgmental attitude:** Rather than scold clients for inability to use a condom consistently, or unwillingness to do so, the counsellor should explore the reasons, and present a balanced view of the risks and advantages of sticking with the current behaviour versus changing it towards less risky practices. Ultimately, it is the client who will make these decisions.



It is important for the counsellor to demonstrate a non-judgmental attitude: Rather than scold clients for inability to use a condom consistently, or unwillingness to do so, the counsellor should explore the reasons, and present a balanced view of the risks and advantages of sticking with the current behaviour versus changing it towards less risky practices.

Vulnerability due to Stigma and Discrimination

Stigma and discrimination is a very real problem with MSMs that contribute to their vulnerability and affect their well-being. Chakrapani and others (2007) describe MSM as facing “multiple contexts of stigma, discrimination and violence.” In their research with a small group of *Kothi*-identified MSMs, they noted violence (overt and hidden) from the police ranging from verbal harassment, blackmail and extortion to sexual assault and rape. Since some policemen themselves perpetrate such violence against MSMs, the latter are even more vulnerable to being targeted by criminal elements. Within the general community, they experience an inability to openly state their sexual preference to their heterosexual friends for fear of rejection. Among their homosexual friends, married *kothis* may face teasing. HIV-infected *kothis* may face HIV-related stigmatization. Many *kothi* men do not experience support from their families either. Some prefer to leave the family home rather than face family pressure to marry.

Transgendered people often cannot find alternate employment from their traditional occupations. This is because of the stigma attached to them. This causes some of them to fall back on selling sex for survival. Similarly, other groups who are forced to engage in survival sex include film extras, gym boys, hotel servers, truck cleaners and workers in beer parlours. These males have a poor ability to say “No,” to their employers or clients.

On the health front, they face discrimination from health providers and so conceal their sexual behaviours and practices from health care personnel. It is only when directly asked that some might feel comfortable in opening up. Even a direct question may not produce an honest disclosure if asked in a disrespectful way, or if asked in a situation where privacy is missing. Counsellors can introspect and ask what they can do to make their own practice area more MSM-friendly, and how they can make MSMs feel comfortable in discussing their issues.

Trying to reform MSMs or cure them of their “gay nature” IS NOT counselling.



Assessing Behaviour & Risk in MSM Clients

For ICTC counsellors an important part of pre-test counselling involves assessing behavioural practices of clients. It is important to assess each and every male client in terms of risk from both heterosexual behaviour as well as homosexual behaviour. Such questions should not be put only to those who appear feminine in their mannerisms, or who fit our personal conception of being gay or “homo.”

Some barriers that hold counsellors back are embarrassment related to asking such intimate questions, perceived “strangeness” of MSM behaviour, or lack of knowledge of proper terminology or language to ask the question.

You could use simple, nonjudgmental, questioning techniques:

- “HIV is passed on from male to male through sex. Have you ever had sex with another man?” If the client responds to this closed question with a Yes, follow up with an open-ended question: “Can you please tell me how?”
- “One way that HIV is transmitted is through anal sex. This could be between a man and a woman, or between two men. Have you ever had anal sex?” This closed question would then be followed by the open-ended question, “What are the situations in which you had anal sex?”
- “Anal sex is sometimes called sex through the back passage. Have you ever had such sex through the back passage or the rectum?” If the client responds with a Yes, ask for more details politely.
- “Sometimes men who are married (or who have a female partner) have also had physical or sexual relationships with other men. Has this ever happened to you?” If the client responds positively, follow up with a polite question about the details of the behaviour.
- Ask about oral sex and vaginal sex as well as about anal sex. It is safer not to assume that a person enjoys or prefers sex in only one type of way.
- Ask about condom use in all sexual encounters. Asking “How often do you use a condom?” requires the person to estimate the answer rather than “Do you use a condom every time you have sex?” which may draw a socially desirable answer which the client hopes will make him look good in the eyes of the counsellor. It is important to probe further: “Do you use a condom each time you have sex with a man and/or woman?”
- Ask about problems with use of a condom during sex with another man as well as with a female partner. This includes the condom breaking or the partner refusing to wear it.

- Ask all clients about symptoms of sexually transmitted infections: “Have you experienced any problems such as burning sensation while urinating, yellow or green discharge from the penis, or boils or open sores on the penis?” “Do you have pain or bleeding in your anal area when you pass a stool (defecate)?” If they report these, explore further and refer them to the STI unit after counselling them on the possibility of an STI. Also, alert them to the possibility of passing on this infection to their sexual partners through sex without a condom.

Use simple, nonjudgmental, questioning techniques which involve a suitable mixture of open-ended questions and closed questions.

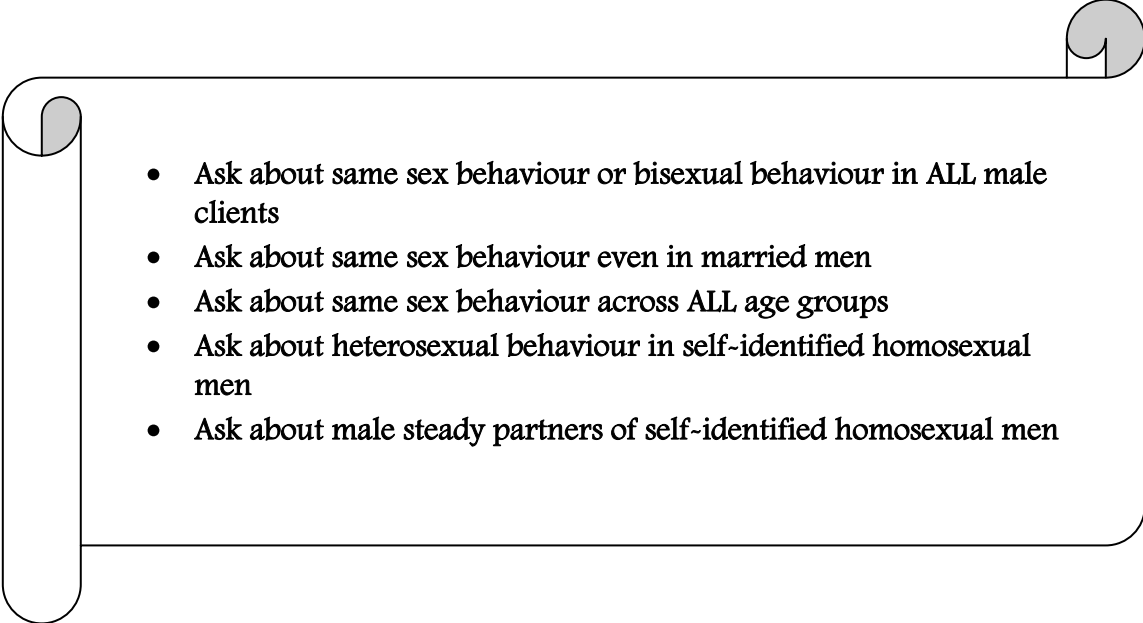
For instance, you may launch the conversation with a closed question: “HIV is passed on from male to male through sex. Have you ever had sex with another man?” If the client responds Yes, follow up with an open-ended question: “Can you please tell me how?”

Sometimes it is better to use an open-ended question. For instance, asking the closed question: “Do you use a condom every time you have sex?” may draw a socially desirable answer which the client hopes will make him look good in the eyes of the counsellor. But asking “How often do you use a condom?” requires the person to estimate the answer.

Some men who have sex with other men may not identify themselves as MSM. For instance, some truckers who are married and who also occasionally have sex with their truck cleaners may view this as '*masti*' (mischief) rather than sex. It is important to help them recognize that even this is a sexual act that can carry risk.

Chakrapani (2005) suggests that it is important to:

- ✓ Ask about same sex behaviour or bisexual behaviour in ALL male clients
- ✓ Ask about same sex behaviour even in married men
- ✓ Ask about same sex behaviour across ALL age groups
- ✓ Ask about heterosexual behaviour in self-identified homosexual men
- ✓ Ask about male steady partners of self-identified homosexual men

- 
- **Ask about same sex behaviour or bisexual behaviour in ALL male clients**
 - **Ask about same sex behaviour even in married men**
 - **Ask about same sex behaviour across ALL age groups**
 - **Ask about heterosexual behaviour in self-identified homosexual men**
 - **Ask about male steady partners of self-identified homosexual men**

Working to Reduce Risk faced by MSMs

Behavioural risk reduction measures for MSMs involve:

- ✓ Reducing the number of sexual partners.
- ✓ Using a fresh condom consistently during every act of sex.
- ✓ Moving from more risky sexual acts to less risky acts – for instance, reducing anal sex.
- ✓ Engaging in non-penetrative sex options – e.g., mutual masturbation, hugging, kissing, licking, fingering (using a finger in the anus to stimulate sexual pleasure)

At the post-test session, an ICTC counsellor will have a chance to reinforce any risk reduction measures suggested at the pre-test session.

Working to Reduce Social Disadvantages of MSMs

While it is not likely that an ICTC counsellor can directly influence the stigma and discrimination displayed by the police, the family, or the general community, she/ he can attempt to create an MSM-friendly environment within the ICTC and the health institution where the ICTC is located. For instance, when counselling a *hijra*, the counsellor could check how the person would like to be addressed – as he or as she. The counsellor can educate her/ his colleagues in the health institution about MSM issues. She/ he can visit MSM-specific Targetted Interventions to create awareness of ICTC services. She/ he can make case presentations of MSM-specific counselling to colleagues to build their professional capacity. Though it is important to ensure audio and visual privacy for all clients (that is counselling should neither be visible nor audible to other clients), it is particularly important for counsellors to be sensitive to male concerns about disclosure. For instance, male clients are unlikely to disclose their MSM behaviours in front of their female partners. In terms of the larger context of discrimination, the counsellor should build up knowledge of other services in the community from where MSM clients can receive support. These could include gay support groups and legal aid cells. Suitable referrals should be made for social problems that the client may report facing.

Things to avoid doing are: making jokes about MSMs, calling them names and breaking confidentiality about their sexual identity. Sometimes, people resist having labels placed on them. So it is best to avoid titles such as a kothi client or a panthi man unless the client uses it first. It is safer and more respectful to address the behaviour of the person. Under no circumstance is an MSM client to be turned away from the ICTC.





References

- AVERT (2010). *Thane transgender meet*. Mumbai, India: Author
- Brahmam, G.N.V., Kodavalla, V., Rajkumar, H., Rachakulla, H., Kallam, S., Myakala, et al. (2008). Sexual practices, HIV and sexually transmitted infections among self-identified men who have sex with men in four high HIV prevalence states of India. *AIDS*, 22, S45-S57
- Dandona, L., Dandona, R., Kumar, G. A., Gutierrez, J.P., McPherson, S., Bertozzi, S.M., et al. (2006). How much attention is needed towards men who sell sex to men for HIV prevention in India? *BMC Public Health*, 6, 31-40.
- Chakrapani, V., Newman, P.A., Shunmugam, M., McLuckie, A. & Melwin, F. (2007). Structural violence against Kothi-identified Men who have Sex with Men in Chennai, India: A qualitative investigation. *AIDS Education and Prevention*, 19(4), 346-364.
- Government of India (2006). *National Behavioural Surveillance Survey (BSS) 2006*. New Delhi, India: Author.
- Government of India (2007). *Annual HIV Sentinel Surveillance Country Report 2006*. New Delhi, India: National Institute of Health and Family Welfare & National AIDS Control Organisation.
- National AIDS Control Organisation (2006). *HIV counselling training modules for VCT, PPTCT and ART counsellors*. New Delhi, India: Author.
- Newman, P. A., V. Chakrapani, Cook, C., Shunmugam, M. & Kakinami, L.(2008). Correlates of paid sex among men who have sex with men in Chennai, India. *Sexually Transmitted Infections*, 84,434-438.
- Newman, P. A., V. Chakrapani, Cook, C., Shunmugam, M. & Kakinami, L. (2008) Determinants of sexual risk behavior among Men Who Have Sex with Men accessing public sex environments in Chennai, India. *Journal of LGBT Health Research*, 4, 2-3.

Working with FSWs

At the end of this unit, participants will be able to

- Describe the type of sexual behaviours that are visible among FSWs
- List the reasons which increase vulnerability in FSWs
- Demonstrate skills of risk assessment and risk reduction for FSWs

Understanding Key Issues related to FSWs

According to the National AIDS Control Programme a female sex worker (FSW) is “an adult woman, who engages in consensual sex for money or payment in kind, as her principal means of livelihood.” She is at a high risk of HIV. As a result of interventions among FSWs to control HIV infection, prevalence in this community is declining (from 10.3 in 2003 to 5.1% in 2007). However it is still five times higher than that among the general population. More over the scenario differs from state to state (0.4 % in Chandigarh to 17.91% in Maharashtra).

HIV counselling and testing are important services required for FSWs. NACO recommends that all FSWs undergo HIV testing once in six months. This is to enable them to know their own HIV status and to make necessary changes in their behaviour with support from the ICTC counsellor. The counsellor has a very important role in supporting behaviour change among FSWs and linking them with various services required. Counsellors must know how to provide appropriate counselling to them as well as to exhibit non-judgmental attitudes.

Types of Sex Workers

Sex workers are not a homogeneous group. Under the National AIDS Control Programme they are categorized to 6 main typologies, based on where they work and more specifically on where they recruit or solicit clients (NACO, 2006).

Street-based sex workers

These are sex workers who **solicit clients** on the street or in public places such as parks, railway stations, bus stands, markets, cinema halls. They may live in a brothel and may entertain their clients in a lodge, car, truck, hotel room, the home of a client, a cinema or a public place.

Brothel-based sex workers

These are sex workers whose clients contact them in recognisable brothels. Typically, a brothel is a place where a small group of sex workers is managed by a Madam (*gharwali*) or an agent. It can be located in a building or a residential home where people from outside the sex trade know that sex workers live and work. Usually the sex worker pays a part of her earnings to the *gharwali*. Sex workers in Kamathipura in Bombay and Sonagachi in Calcutta and also in smaller brothels in districts such as Sangli, Bagalkot and Guntur fall into this category. Usually sex workers stay for longer durations in brothels.

Lodge-based sex workers

These are sex workers who reside in what is known as a lodge (a small hotel) and their clients are contracted by the lodge owner, manager or any other employee of the lodge on the basis of sharing the profits. These sex workers do not publicly solicit for clients. Clients usually approach the manager or lodge owner or any other middle person who gives them information about the sex services in the lodge. The women may be kept in the lodge only for those periods when she is available to customers. These service periods at any particular lodge may vary from days to months.

Dhaba-based sex workers

These are sex workers who are based at *dhabas* (roadside resting places for truckers and other long distance motorists) or roadside country motels. Like lodge-based sex workers, these sex workers do not publicly solicit clients, but rather are accessed by clients who come to these locations. In some cases, dhaba-based sex workers are also contracted by the *dhaba* owners and could move from *dhaba* to *dhaba* based on their contracts. It may be difficult for the dhaba-based sex workers to access prevention services, especially when they are moved from one place to another. They also require help from the *dhaba* owners to find out services like STI treatment and condom supply.

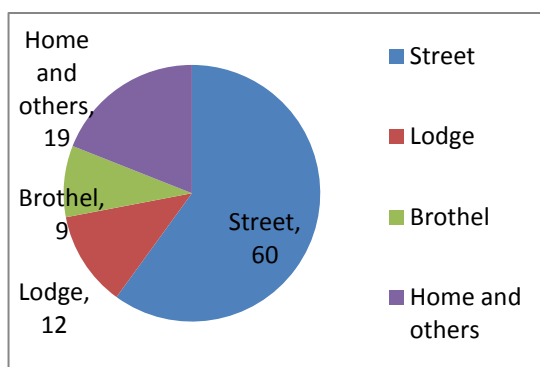
Home-based or “secret” sex workers

These sex workers operate usually from their homes, contacting their clients on the phone, through word-of-mouth or through middlemen (e.g. *autorickshaw* drivers). Generally, they are not known as sex workers by their family or their neighbours. In fact, they could have an entirely different “public” identity – e.g. housewife, student.

Many sex workers operate “secretly” due to the fear of harassment, violence and stigmatization from the police, criminals and the general public. They may come to ICTC with their spouse or any family member. They may not be willing to disclose that they engage in multi-partner sex. They may open up only when privacy and confidentiality is assured by the counsellor. Further, it is better not to use labels such as sex work and sex workers unless they label themselves so.

Highway-based sex workers

These sex workers recruit their clients from highways, usually from among long-distance truck drivers. Their primary occupational identity may vary and may include bar girls, *Tamasha* artistes and *Mujra* dancers. A large proportion of them often engage in commercial sex regularly and in significant volumes. However, it is important to note that not all bar girls, *Tamasha* artistes and *Mujra* dancers are commercial sex workers.



Source: NACO Operational Guidelines for Core Target Groups

The above categories are often overlapping and fluid. For example, a sex worker may be street-based for some time and then may go into a contract with a lodge owner to become lodge-based. Or a brothel-based sex worker may move to another town or city temporarily and work as a street-based sex worker. Their vulnerability patterns change with the change in soliciting area, however they remain as vulnerable to HIV. The chart above shows the distribution of these typologies among sex workers in southern India.

Counsellors need to understand that the risk of an FSW depends on her specific situation and backgrounds. Sex workers in brothels, lodges and *dhabhas* tend to have higher client volumes than home-based sex workers, and therefore may have a higher risk profile. At the same time, the home based sex workers are also vulnerable to infection because of the hidden nature of their work and their inability or unwillingness to disclose the same in health context.

NEW WAYS OF SOLICITING

Research in South India tells us that sex workers are finding new ways of soliciting clients – The internet and “mobiles” are one way that technology is being used to reach new markets of clients.

Why do women become sex workers?

Women become sex workers due to various reasons.

- Most of them are pushed into the sex trade through trafficking.
- Many others enter the sex trade because of lack of other options to look after themselves and their families.
- A few sex workers enter sex work due to the traditions they follow in their religion, community or society, like *Devadasis* in Karnataka.

Once in this “flesh trade” most women are forced to remain as sex workers as they do not have any other source of income (Banadakoppa M Ramesh et al and other studies). Ironically, most of the sex workers feel that the work they are engaged in is immoral and promiscuous. This lowers their self esteem and self respect.

Pimps or Agents

Pimps are an important part of the sex trade. They act as procurers or agents as well as watchmen. Some persons such as *paan* shopkeepers, *autorickshaw* and taxi drivers also serve as pimps. Pimps are constantly watching for the police, pressure groups and other elements that can obstruct the operation of their sex trade. They are important for HIV prevention services because sex workers require their cooperation to reach services such as HIV counselling and condom supply. Sex workers may be concerned about pimps knowing about their visit to ICTC or finding out about their HIV status.

Understanding Risks & Vulnerabilities of FSWs

Counselling FSWs requires ICTC counsellors to have knowledge about the risks associated with sex work and the vulnerabilities faced by the female sex workers. This will help counsellors to assess the different levels of risk and to tailor the contents of the counselling session.

Risks associated with sexual practices

All FSWs engage in penetrative sex including vaginal and anal. Different sexual practices have different levels of risk.

- FSWs sometimes engage in anal sex which poses high risk, particularly when it is forceful. In a small study in Karnataka 27% of FSWs reported that they do offer anal sex to their clients regularly. (Anand, 2009). They also reported that clients demand anal sex due to misconceptions that there is no HIV risk through anal sex, interest in sexual experimentation and for increased pleasure (because the anal passage may be tighter).
- Sex workers report being unable to refuse clients: “In this type of work, our primary concern is to avoid the loss of customers, to entertain the men. We have to engage in different types of sex- whether we like it or not. They want to perform all types of sex which they cannot experiment with their wives or girl friends”- A quote from an FSW in Manipur (Assessment of Situation and Response on CSWs in Manipur, Population Health Institute, 2005)
- Sexual intercourse through the vagina places women at risk of HIV.
- Oral and thigh sex are the other two major sexual practices followed by FSWs. In oral sex, client puts his penis in the mouth of the FSW and in thigh sex he puts his penis between her thighs. He may or may not ejaculate. Oral sex is a comparatively low risk activity while thigh sex poses only slight risk.

Risk & vulnerability related to sexual partners

Risk of infection of HIV and other sexually transmitted infections increases with the number of sexual partners. Behavioural Surveillance by NACO reports that on an average a FSW engages in sex

with 10 clients a week. She is at risk of exposure to HIV if condom is not consistently used. In almost all categories FSWs have limited or no power to refuse clients or to insist of using a condom.

FSWs may have sexual partners who pay for the sex and those do not pay. They have different risks and vulnerabilities associated with their paying and non-paying partners. Some FSWs do not use a condom with their regular clients or with partners to whom they are emotionally attached. They may develop emotional attachment to a man who visits them frequently. They may claim that they are their boyfriends or lovers and they may not charge them for every sexual act. Rather, they ask for money or other items when they are in need. The faith or dependency on the client/partner often prevents them from adopting safe sex measures.

Risk associated with poor use of condoms

FSWs use condoms for two purposes - prevention of pregnancy and prevention of STIs and HIV. Those who access HIV prevention programmes report that they use condoms with their paying clients. However, consistent use of condom with all types of sexual partners- whether paying or non paying, regular or not regular is still not visible among FSWs.

Some reasons FSWs offer for not using condoms are:

- Objections by partner/client to use condoms during sex saying that condoms reduce pleasure.
- Inability to negotiate condom use with regular partners. The primary reason for low condom use with regular partners is the faith FSWs place in their partners having sexual relationships with them only, or with them and their spouses only (Srinivas et al, 2006)
- Non-availability of condoms when it is required. Availability of condoms depends on the willingness of the lodge managers, brothel owners, pimps, etc to provide condoms.
- Perception that condom is not necessary for them.
- Forced sex by clients etc

This highlights that even if counsellors offer condom education and demonstration to FSWs, they may still not be able to alter their behaviour without support.

Risks associated with presence of STIs

Presence of STIs increases the risk of HIV transmission. STIs are common among FSWs (NACO BSS-50%). The high prevalence of STIs and their recurrence are associated with lack of proper understanding about STI and poor health-seeking behaviour. Some FSWs are more concerned with the illnesses like fever, pain etc which make them unable to work. They show less concern for STIs and thus do not go to health care providers for such problems. Very often, FSWs do not identify the symptoms they suffer as related with STIs. For example vaginal discharge, menstrual disorders and lower abdominal pain are most commonly regarded as women's health problems and not as results of infections transmitted through sex. As they do not identify their symptoms as those from infections transmitted through sex, they engage in sex even when the symptoms are present. Symptoms such as ulcers increase the possibility of HIV transmission.

FSWs, out of embarrassment or shame, may refuse to seek treatment from a medical professional. They may either wait for the symptoms to abate on their own, or they may seek "easy" remedies from pharmacists or traditional healers or they may self-medicate. None of these remedies are effective. In fact, some medications may actually make them health worse. Even among FSWs who do reach a doctor for treatment, there is a problem related to poor adherence to treatment – especially when symptoms disappear. This leads to recurrent episodes of STI among FSWs and places them at greater risk of HIV infection.

Counsellors can assess risk to STIs through simple screening questions :

- *Are you suffering from any discharge from your vagina?*
- *If discharge is present, does it have a bad smell? Is there a change in colour?*
- *Do you feel burning or itching in your vagina?*
- *Do you have any ulcers, blisters or boils in the genital area or anus or area surrounding anus or mouth or lips?*
- *Is your monthly bleeding abnormal or more heavy than normal?*
- *Do you suffer from pain during sexual intercourse?*
- *Do you have pain below the waist (below the navel)?*

If the answer is Yes, address the reasons and refer the client to STI services after appropriate counselling. The counsellor should have the names of preferred providers and other referrals handy.

Vulnerability associated with age & duration in sex work

Many women enter into sex work at early ages. The BSS (NACO, 2006) found that most of FSWs started sex work in the age range from 16 to 21 years. Early initiation into sex work means women spend a longer span of their life in this profession and have greater sexual exposure in terms of number of clients. This increases vulnerability to HIV. Chances of developing habits like consumption of alcohol or drugs also increase with a long duration in sex work. Young girls are highly vulnerable as they have to engage in sex with many partners due to the higher demand for young girls. They are also vulnerable as they lack the power to negotiate for safer sex or demand health services when they are sick. Children in sex work face higher risk due to injuries during sex and due to lack of proper knowledge about HIV (Louise Brown, Sex Work in Asia, WHO, 2001).

Vulnerability associated with alcohol and drug use

Alcohol consumption adds to the vulnerability of FSWs to HIV. Nearly 50% of FSWs report that they have consumed alcohol some time in their life and that too before sex (NACO, 2006). Many clients also report that they consume alcohol. Use of alcohol by themselves or their clients makes it difficult for FSWs to negotiate condom use. FSWs also find it difficult to refuse clients' demands for higher risk behaviours, or to resist forced sex. FSWs also use their professional earnings to pay for purchasing alcohol, heroin or other substances. (Banerjee et al, 2002) This makes it more difficult for them to reduce their risk behaviours.

Risks and vulnerability associated with mobility

Many FSWs move from place to place to protect their identity. They also travel to places where they expect to find more clients such as places which host religious functions and fair (eg: Jatara in Maharashtra). In a study by Population Council (2008) 60% of FSWs in Karnataka, Maharashtra, Andhra Pradesh and Tamil Nadu were observed as moving a minimum of two times in the 2 years

preceding the study. For instance, FSWs in Kanyakumari District in Tamil Nadu moved to other states like Kerala while FSWs in Madurai moved within the district. FSWs from Mumbai moved to and from different states of the country such as West Bengal, Karnataka, Andhra Pradesh and Gujarat. When FSWs move to new locations, they have poor or no access to HIV-related information and prevention services including condoms. Hence they tend not to use condoms with clients. This places them at greater risk of infection of all STIs including HIV.

Violence & vulnerability

Female sex workers are often subject to violence - from clients, from intimate partners, from police and pimps. Some sex workers report '*sex with force*' is the most "*preferred type of sex*" after conventional sex (FGD conducted in Manipur as part of a situational assessment). (Assessment of Situation and Response on CSWs in Manipur, Population Health Institute, 2005). Forced sex causes mental and physical trauma. It also adds to the risk of transmission of HIV due to the chances of injury in vagina or anus.

Other social disadvantages for FSWs

Since sex work is considered as immoral and promiscuous, FSWs face different forms of reactions from the society. The perceived lower level of women in the society and her sublime status adds to this. The mental trauma and humiliation they suffer from the family is also a threat to their well being. Lack of support from any family member or nearby people adds to their vulnerability and feeling of insecurity

Counselling FSWs in the ICTC

How FSWs reach the ICTC

- Referral by a peer educator, Out Reach Worker (ORW) or counsellor of a Targetted Intervention (TI) programme.
- Referral by health care providers, including STI treatment providers
- Referral by friends, clients, police etc
- Referral by other agencies like NGOs working for social causes
- Voluntarily walk-in after hearing about HIV

It may be difficult to identify those female clients who are practicing sex work out of their homes. They would wish very strongly to maintain their secrecy. So it is important to address counselling questions and messages in terms of number of sexual partners (instead of customers or sexual clients), and to be specific about the types of sexual behaviours and their consequences. Although all clients require privacy, it is doubly important to reassure female clients on this score, and to explain to them about confidentiality. This might make them open up more.

Simple conversation openers

- ✓ *“HIV is spread through sex with more than one person. Have you had sex? If yes, have you had sex with more than one person?”*
- ✓ *“Sex takes many forms. Some people have sex through the vagina, some have sex through the mouth, or through the anus/back passage. Can you tell me if you are aware of these different ways of having sex?”*

- ✓ *“HIV can be avoided through using a condom each and every time one has sex. Could you tell me if you know what a condom is? Could you tell me if you use a condom? Could you tell me how frequently/ infrequently, you use a condom?”*
- ✓ *“Sometimes, people take alcohol before sex either to increase their pleasure, or because they are accustomed to it. Could you tell me if you are in the habit of taking alcohol? If yes, how does this affect your sexual behaviour?”*

The attitude and approach of the counsellor towards FSW clients is important in creating a friendly and comfortable environment for the FSW in the ICTC. Considering her as somebody with low status may hinder counselling while accepting her as a woman with dignity like other women will build trust. Ensuring the same from the colleagues in the ICTC and hospital is also the responsibility of ICTC counsellors. Counsellors should be aware of their own thoughts, language and non verbal behaviour. Words which communicate negative/double meanings, labels (e.g., bad behaviour); questions which appear to blame the client like “Couldn’t you get any other job?” should be strictly avoided.

While counselling FSWs it is important to use simple language and communication tools like flipcharts and posters. This is because upto 40 % of the FSWs do not know to read and write (NACO, 2006). The rest have limited schooling. Their ability to comprehend technical material may be limited. Counsellors can also use local terms to refer to anal sex, thigh sex etc. It is important to frequently check how much the client has understood, and to use techniques like summarizing and paraphrasing.

The following messages are important for FSWs in order to address the risks and vulnerabilities associated with their work. Counsellors should include all of them in the counselling session

- ✓ Risk of HIV associated with sex work
- ✓ Importance of regular HIV testing
- ✓ Importance of safer sex practices
- ✓ Correct and consistent condom usage with all clients
- ✓ Condom negotiation skills
- ✓ Identifying health problems and seeking treatment
- ✓ Completing treatment

Helping the FSW to decide on the HIV test

Enabling the FSW to take a personal decision on the HIV test is important in ICTC settings. Risk assessment can be followed with an offer for HIV testing. Some FSWs may refuse to undergo HIV testing due to reasons such as

- Fear of their test result becoming known to their partner, their clients, their pimp/ brothel owner, or their family. Here the counsellor needs to explain procedures for confidentiality.
- Low risk perception of HIV and STIs. The counsellor needs to do a thorough risk assessment and show her how various behaviours enhance her risk.
- Having already done an HIV test before. Here the counsellor should check when she was last tested, explain about the need to test every six months, and explore all types of risk behaviours since the time of the last test.

Risk reduction & condom use

➤ Difficulties in accessing condom

During risk reduction counselling, all FSWs should be asked about their knowledge about accessible sources of condom supply. It can be mentioned to them that condoms are available at petty shops, medical stores, etc and also with their own peers who act as Peer Educators with TI projects.

➤ Limited negotiation power for condom and safer sex practices

Practical suggestions and practice sessions on condom negotiation may be required. The following strategies may be helpful

- The FSW may be directed to TI projects and encouraged to access the services here.

- If possible, group counselling sessions may be arranged to help her develop negotiation skills through sharing problems and experiences. This can be done in collaboration with the TI projects.
- When a FSW spends money for alcohol on herself as well as the client, she should be taught to include condom negotiation in this transaction.
- The female condom is another female-controlled option. ICTC counsellors should demonstrate these to the client. She should be provided with details of female condom availability such as sources and approximate cost.

➤ **Condom availability and mobility**

FSWs who move to different places may find it difficult to access condoms. Here it is important for the counsellor to check how recently she moved and whether she knows of available sources of condoms, such as local TI projects. The counsellor can also help her to implement practical solutions like keeping enough stock of condom and referring her to STI clinic services if she needs it.



➤ **Condom use with regular partner/spouse**

One sensitive area in counselling FSWs might be use of a condom with a regular partner or a spouse. As mentioned earlier, FSWs may choose not to use a condom because they feel safe from infection with a particular partner, or because they would like to express their love for the person. It is important to elicit the reasons underlying the decision not to use a condom, and to address these respectfully.

Risk reduction & TI projects

HIV risk is mainly associated with behaviour and can be addressed through behaviour change interventions. FSWs require a comprehensive set of services to understand the risk associated with their work, to change the behaviours so that their risk reduces and to continue with the new safe behaviours in their work environment. TI projects designed by NACO provide a set of services directly to the FSWs and also links them with required services and support structures. These community-based programmes include behaviour-change communication interventions, awareness programmes, STI treatment services, risk reduction services and support for empowering the FSWs so that they are able to address different vulnerabilities associated with sex work.

Even in case of FSWs referred from TI projects, it is important for the counsellor to check their awareness and understanding of the TI services.

Addressing Vulnerabilities of FSWs at the ICTC

It may not be possible for the ICTC counsellors to address different vulnerability issues of FSWs. However, counsellors can provide information on where an FSW can receive support.

- ✓ Support groups of FSWs
- ✓ Schemes or services available for women to improve their financial status such as self-help groups and saving schemes.
- ✓ Services available for rehabilitating women in sex work (eg: Rehabilitation programme by department of Social Welfare, Government of Kerala)
- ✓ Projects which address human trafficking
- ✓ Institutions like juvenile homes, adolescent and adult female care institutions where their daughters can be placed safely.
- ✓ Different education support schemes for children through governmental and non governmental agencies.
- ✓ Doctors who are Preferred Providers and who provide stigma-free treatment
- ✓ Legal support cells
- ✓ Other social support interventions like National Rural Employee Guarantee Scheme.



References

- Dandona, R, et al. (2005). High risk of HIV in non-brothel based female sex workers in India. *BMC Public Health*, 5, 87.
- Dandona, R, et al. (2006). Demography and sex work characteristics of female sex workers in India. *BMC International Health and Human Rights*, 6, 5.
- Evans, C., & Lambert, H. (1997). Health-seeking strategies and sexual health among female sex workers in urban India: Implications for research and service provision. *Social Science and Medicine*. 44, 1791- 1803.
- National AIDS Control Organization. (2006). *National AIDS Control Programme phase III - Strategy and implementation plan*. New Delhi, India: Author
- National AIDS Control Organization. (2007). *Targeted Interventions under NACP III - Operational guidelines. Volume 1 - Core high risk groups*. New Delhi, India: Author
- Matheou, A. (2009): *A blind spot in HIV prevention: Female Anal Sex*. New Delhi, India.
- Population Health Institute. (2006). *Assessment of situation and response on CSWs in Manipur, 2005*. Imphal, India: Author.

Working with IDUs

At the end of this unit, participants will be able to

- Describe the type of drug-use behaviours that are visible among IDUs
- Describe the type of sexual behaviours that are visible among IDUs
- Demonstrate skills of risk assessment and risk reduction for IDUs

Understanding Injecting Drug Use in India

HIV infection in India mostly occurs through the heterosexual route – about 85 from every 100 HIV positive people got HIV through sex. In comparison only 2 out of every 100 HIV positive people are Injecting Drug users (IDUs). However, almost 10 out of every 100 IDUs are infected with HIV. This high prevalence of HIV infection among this group ensures a high chance of the spread of HIV from one injecting drug user to another through infected syringes as well as from IDUs to members of the general community through sexual contact. Thus, identified as a critical group in HIV/AIDS transmission, IDUs are one of the key target groups for HIV/AIDS intervention projects. ICTC counsellors may have the opportunity to interact with clients who are both regular users of drugs as well as those who have just begun their experiments with substance use. They must understand this particular group and its behaviour patterns in order to work more effectively on behaviour change.

Why do people take drugs?

People take drugs, both legal and illegal, for a variety of reasons that will differ from person to person and from drug to drug. Individuals may enjoy the sense of detachment or euphoria that drugs

create, their relaxing or energy-inducing properties, the heightened alertness or sensitivity they produce, and their medicinal qualities. Peer pressure or habit may be other reasons, and if they are chemically dependent drug users may continue to use drugs to avoid troublesome withdrawals symptoms. The individual's background and socio-economic circumstances also influence the situation.

Why do people inject drugs?

Route of consumption of a substance may depend on a number of factors. Most frequently, it is a function of the type of substance itself: e.g. some substances have only one route of consumption (alcohol is consumed only orally), while others may have multiple routes (tobacco may be chewed, smoked, inhaled or sniffed depending on the preparation). Similarly, some substances may be injectable while others may not. Substances which may be injected include opioids (heroin or brown sugar, buprenorphine, pentazocine, dextropropoxyphene), stimulants (cocaine, amphetamine-type substances), sedatives (diazepam, lorazepam, chlorpheniramine) and anaesthetics (ketamine). Some of these substances have other routes of consumption as well for e.g. heroin (smoked, chased or injected), cocaine (smoked, snuffed or injected). A person who is habituated to any of these substances or substances may prefer a particular route of drug consumption over the other. For a substance which can be taken from other routes, a drug user may prefer the injecting route because of:

- ✓ Perceived faster onset of action of the drug and the resultant euphoria
- ✓ More economical route of consumption as the entire quantity of drug consumed enters the bloodstream and is available to produce a high (maximum use of the available "stuff"). In contrast, the use of same drug orally or by smoking is associated with wastage of a proportion of the available stuff.
- ✓ Peer group influence (everybody else is also injecting the drug)
- ✓ Habit (person has always used the substance through the injecting route)
- ✓ Cheaper (some drugs are cheaper than others producing similar effects but can only be injected, e.g. pharmaceutical opioids and heroin)
- ✓ Personal preference (Client may like it through the injecting route only.)

A client may choose the injecting route despite understanding some or most of the harmful consequences of the same. Others may use these practices due to lack of awareness regarding the risks. A counselor needs to first understand the reasons behind a person's choice and assess risks and vulnerabilities before initiating a discussion on behavior change and risk reduction.

Key terms related to IDUs

Use

Use is defined as the ingestion of drugs (alcohol etc) without the experience of any negative consequences (A person consumes alcohol on social occasions like a marriage but is able to control the amount of drinking).

Abuse

Abuse occurs when a person experiences negative consequences from the use of drugs (A person consumes alcohol excessively and engages in a fight with his neighbour under the influence of alcohol).

Harmful use

Harmful use is defined as a “maladaptive pattern of use resulting in physical, social and legal harm and the person continues using the drugs in spite of negative consequences.” (A person indulges in heavy drinking repeatedly and meets with an accident while under the influence which of alcohol results in arrest).

Dependence

Dependence on drugs is defined as drugs taken in large amounts or over a long period with a persistent desire or unsuccessful attempts to cut down. In this severest form, use of substances becomes the most important activity for the person which may result in neglect of other social, familial and occupational responsibilities as well as other avenues of pleasure and recreation. A person dependent on a substance experiences intense craving and physical withdrawal symptoms when trying to stop or cut-down substance use which make it nearly impossible to give up drugs without medical intervention. The person spends a great deal of time in obtaining the drug, using the drug and recovering from its effects.



Stages of drug use: Drug use typically begins when a person has friends who use drugs. They may first try drugs just as an experiment. They enjoy the sense of feeling 'high' or 'stoned' and begin to use the drug more and more, until they reach a stage when they feel sick every time they do not take the drug or are late in having their 'fix'. At this stage they must take the drug regularly to avoid feeling sick. They have crossed from recreational use to the stage of dependence and will feel that they cannot operate without drugs.

Frequency and the modes of drug used also change with the stage of drug use. The drug user moves from 'softer' drugs to 'harder' ones. For instance, they move from alcohol/tobacco to *charas/ganja*, from *charas* to heroin/smack and then to the injection.

Sometimes other societal factors cause change in drug use patterns. For instance, in 1991, there was a street scarcity of heroin following the crackdown on Tamil militants in Tamil Nadu. This caused heroin users to shift to the easily-available injectable preparation called Buprenorphine. When heroin was available in the illicit market again, many preferred to use heroin by injecting.

This process of movement from one stage to another has implications for counselling. Many people who inject drugs do not inject regularly or do not identify with being IDUs. Young, new and occasional injecting drug users are particularly at risk of HIV infection. Often it can be difficult to reach them and convince them that they are at risk. So, counsellors have to take care to ask specific and non-judgmental questions to allow people space to open up.

Understanding Vulnerability of IDUs

Injecting drug users are more vulnerable to HIV as compared to the general population because of factors such as exposure to high risk behaviour as a result of their drug taking behaviour, discriminatory laws against them/their practices, decreased access to health services and increased stigma and marginalization by society.

Illustration of Dipping the Needle into the Ampule



Vulnerability due to sharing of needles

Drugs can be taken in a variety of ways including drinking, smoking, snorting and rubbing, but in the context of HIV, it is the injection of drugs that creates the biggest risk of HIV transmission. HIV is effectively transmitted from one person to another when they share injecting equipment without sterilizing it. Sharing of a needle contaminated with HIV-infected blood is one of the most efficient vehicle for HIV transmission. The risk with a single act of sharing a used needle is 5 times that of the risk associated with heterosexual intercourse. This efficiency of transmission is one of the reasons for such high prevalence of HIV infection (9.2%) amongst IDUs.

Also due to this high efficiency of transmission, HIV spreads very rapidly amongst a network of IDUs and then to their sex partners. The re-use of contaminated needles and syringes is common amongst IDUs. In the National Behaviour Surveillance Survey (NBSS, 2006) a relatively high proportion of respondents report injecting drugs with a used needle or syringe. The proportion of the

respondents who report injecting drugs with a previously used needle/syringe has significantly increased in some places like Delhi and Mumbai. In addition, 22.8 % of respondents in Punjab report that they never clean previously used needles or syringes. These behaviour patterns of IDUs are dangerous for their health, as injecting drug use through unclean syringes fuels the rapid spread of injection-related diseases such as HIV and Hepatitis.

Many factors specific to individual IDUs as well as government policies/laws influence or cause needle sharing. For many users, sterile syringes are not readily available and drug laws in some areas make it an offence to distribute or possess syringes for non-medical purposes. For example, the sharing of contaminated injecting equipment may arise because IDUs fear that, while carrying needles and syringes, they will be stopped by police who will use possession of drug paraphernalia as evidence of a drug-related crime. Instead of purchasing or obtaining a new needle and syringe, users prefer to use the specific needle and syringe in use where the drugs are purchased or consumed. Thus they are able to leave the scene without carrying any equipment. One IDU in the state of Manipur – where police can stop and search any suspected drug user – describes fear of the law as a factor in needle sharing: *“When we [inject] drugs we need to be quick. Police might come at any time. For that reason... we don't mind sharing with others.”*

These situations give rise to ‘shooting galleries’: locations where the needles and syringes provided by a dealer are used in rapid succession, without adequate (if any) sterilisation between use, by a number of different users. For a fee, professional injectors administer to ‘clients’ the drugs which they have purchased, and in so doing, provide a potential hazard for transmitting HIV and other blood-borne viruses.

A lack of awareness or education about safe injecting can also lead to needle sharing. For example, according to BSS 2006, just 76.2% of the respondents in Punjab and 86.4% in Delhi are aware that needle sharing is one of the major modes of HIV transmission as compared to the 98.9% in Manipur.

Besides actual needle sharing, indirect sharing such as the use of common spoons, solutions, and cotton swabs as well as dipping the needles into the ampules could also be another, important factor in the spread of HIV among IDUs (Kumar, 1998). Other possible reasons for reuse of the injecting equipment could be poverty, socio-psychological and cultural factors such as a sense of camaraderie, connection and of solidarity.

Thus, needle sharing is a simple term that covers a very complex reality. It presents scope for an ICTC counsellor to give suitable education to injecting drug users who present at the ICTC.

Vulnerability due to Unsafe Sex

ICTC counsellors must not restrict themselves to questions about drug use with drug users. They must also ask about sexual practices. IDUs are at risk of HIV infection through sexual transmission, particularly when they have unsafe sex while intoxicated. In such situations, they are less likely to practice safer sex. Some IDUs especially female injecting drug users engage in selling sex for money to buy drugs. This puts them at much greater risk of acquiring HIV infection. Also, their sex partners may be part of other sexual networks which means that infection may get transmitted to other at-risk populations. This has been confirmed through the BSS.

Moreover, when comparing the results of the BSS done in 2006 to 2001, a worrying increase is noticeable in the proportions of IDUs who have sex with commercial sex partners. Thus, injecting drug users constitute a risk group in themselves. Also there is an overlap between drug addiction and those involved in sex work. Individuals who fall into both categories are therefore particularly vulnerable to HIV and are perhaps doubly stigmatised.



Source: United Nations Office on Drug and Crimes

The following factors link injecting drug use to sexual transmission of HIV:

- Male to male and heterosexual transmission involving IDUs
- Commercial sex among partners of IDUs and amongst female IDUs
- STIs are common among IDUs but they have poor access to STI prevention services
- Intoxication during intercourse is common

Oral sex may also be risky for heavy crack-cocaine smokers who have open oral sores due to the potential for blood transfer through frequent fellatio. The intense heat from the vapourising smoke being conducted through poorly constructed smoking devices may cause burns, blisters and cuts on the lips and inside the mouth. Blood from these wounds can contaminate the 'stem' - usually a small metal pipe - and be passed along to the next smoker. If two smokers both have open sores then there is a risk of HIV transmission.

It has been observed that services for drug users produce significant changes in injecting risk behaviour but sexual risk behaviour is difficult to change. So, counsellors need to emphasize the importance of safe sex practices. They have to make sure that IDUs identify the problems that they could face in practicing safe sex and are able to find solutions for the same.

Vulnerability due to Gender

When women who use drugs are also involved in sex work, the risk of acquiring HIV infection through unprotected sex increases the existing risk of transmission through the reuse of needles and syringes.

Women are increasingly involved in all forms of drug-related problems and are likely to suffer more severe consequences than men. They face more risk of HIV infection than males because of their generally subordinate status in society. Women IDUs, who are dependent on men, may fear rejection by their partners if they do not inject drugs. ICTC Counsellors can empower female clients with a clear message that they need not use drugs just to retain their partners, that doing so increases their own personal risk and that the use of drugs only deteriorates their family life.

Vulnerability due to Socio-economic Conditions

Illicit and licit drugs are injected in many parts of the world, especially in regions where poverty, homelessness, migration and other socio-economic problems are common. Drug users may live under

extremely poor conditions, coupled with the fact that they face widespread stigma and discrimination. IDUs often reside in slums or are homeless.

IDUs are usually involved in occupations where they do not get enough money to support their drug intake. For instance, the majority of the IDUs respondents in the BSS were local transport workers, truck drivers, cleaners or were unemployed (NACO, 2006). To pay for the drugs they may also indulge in commercial sex or illegal activities like thefts which in turn increases their vulnerability to HIV transmission. Other problems which become more apparent as the person's drug use increases are absenteeism from the job, frequent job changes, and job loss. An IDU with limited resources to sustain his/her drug habit is more likely to utilize them on purchasing drugs than on buying new needles and syringes for each injecting act.

Vulnerability due to Lack of Access to Support Services

In urban settings, drug users are often uneducated, homeless or living in slum conditions. In rural areas, injecting drug users may be located in remote regions where drugs are produced and trafficked. In both instances, drug users have little access to the support, information and services necessary to protect them from becoming infected with HIV.

Vulnerability due to Early Age of Initiation

Often drug abuse starts in youth. Most of the respondents in the BSS, started injecting drugs between the age of 21 and 25 years. Almost 40% of the respondents in Delhi and Sikkim reported started using injecting drugs even before the age of 20 years (NACO, 2006).

One of the main reasons why youth begin using drugs is peer pressure. Curiosity and easy availability may also be important for early initiation. Young IDUs are at higher risk of HIV infection than older IDUs because they:

- Are less likely to be aware of HIV risks.
- Are more likely to engage in risky drug-using behavior, particularly sharing of injecting equipment; and have less access to HIV information, sterile needles, syringes and condoms.
- Are less likely to seek out and use drug treatment and other health services.

Vulnerability due to Marginalisation

People with drug dependence problems are marginalized as drug use is highly stigmatized, both within the general community and among health care workers. Because this is an illegal activity (and also sometimes related to commercial sex), it creates barriers to accessing adequate treatment and prevention services making IDUs more vulnerable to HIV and its effects. IDUs are generally stigmatised, discriminated against or excluded from access to health services. As they have less access to information services, they are often subject to human rights violations. Despite their numbers and vulnerability they constitute a low priority in terms of their health and welfare. This means that HIV interventions may not be available to them, or that they are unable or unwilling to access services for fear of recrimination.

Vulnerability due to Criminalization of IDUs

As injecting drug use is an illegal and covert activity, it adds to the marginalization of IDUs by increasing their risk of imprisonment. This, in turn, makes it more difficult for them to access HIV prevention and treatment services. IDUs often experience that they are on the wrong side of the law and after encounters with the police, they may be mistrustful of the authorities in general and may hesitate to seek treatment or to take advantage of any prevention initiatives.

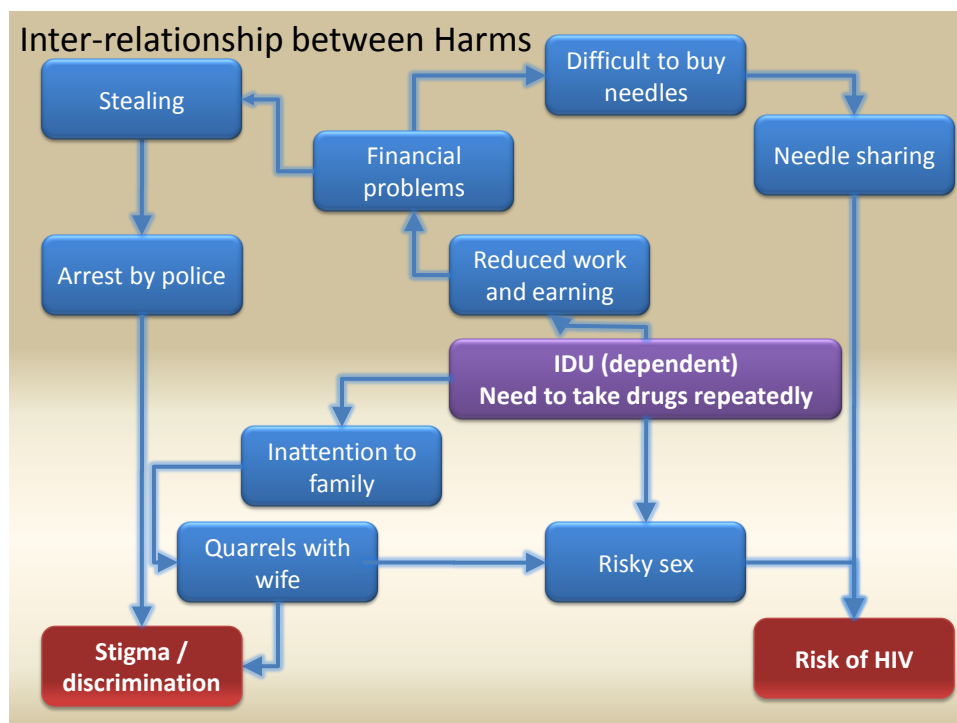
Vulnerability due to Other Factors

Other factors that increase vulnerability are frequency of drug use as well as the social context of drug use. IDUs who injects frequently are at greater risk for developing the HIV infection as it increases the chance of the exposure to the HIV. Frequency of drug use depends on the effect of the drugs. For instance, because of the long-acting nature of buprenorphine, users need to inject less frequently as compare to heroin users.

Problems due to Drug Use

Drug dependence is a chronic relapsing condition, which is often associated with problems such as involvement in crime, family breakdown, social upheaval, poor healthcare, low income, homelessness, use of other drugs, depression, alienation or other personality traits. Drug dependence or drug use affects the individual's physical and mental health, social life, financial status, and family life.

There is a vicious cycle between the various types of harms in a drug user's life. The IDU's intake of the drugs may lead to absenteeism from the work because of which they may lose their job. So, the person starts developing financial problems. As the person does not have enough resources to buy drugs he/she may engage in illegal activities (pick-pocketing, commercial sex etc.). Because of these illegal activities the person may get arrested or imprisoned or may have to face homelessness. Thus, the social standing of the person decreases and the person has to face stigma and discrimination in the society. This may be followed by the guilt, shame or the mental tension which further pushes the person towards drugs. It is difficult for a person with IDU habits to escape this cycle.



Source: NACO Manual on Working with Injecting Drug Users

Counselling IDUs

Before assisting the client the counsellor must be able to assess the stage of the behaviour change the client is in. The stage of behaviour change will determine the techniques and the contents to be used for counselling the client. Some clients may display obvious signs of a drug habit – needle marks on their veins, etc. Other clients may not display obvious signs of using drugs. Clients who attend the ICTC may have a drug habit but may not feel the need to change or modify their behaviours. For clients who attend the ICTC with no sense of how their drug-related behaviours contribute to their risk of HIV infection, the counsellor has to help them recognize the risks. For clients who come to the ICTC with a desire to change, the counsellor could spend less time on the risk identification, and move to understanding the reasons behind the behaviours and developing strategies for moving towards healthier behaviours.

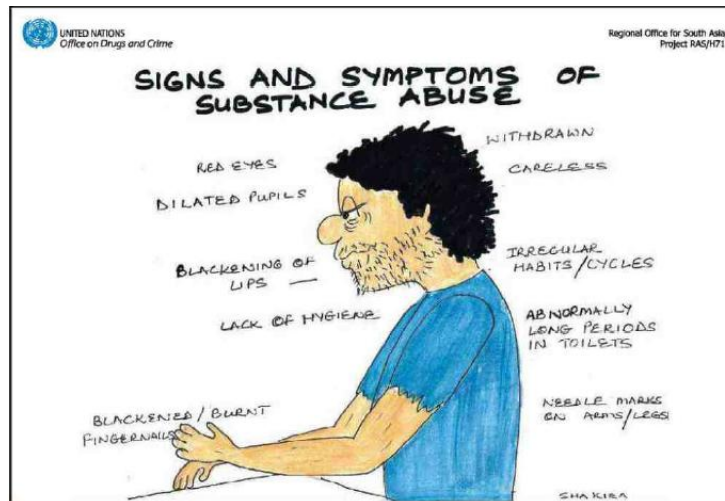
Some younger clients may have begun experimenting with lighter drugs. But because they do not see themselves as fitting the classic profile of a drug addict, they may respond to any probing by the counsellor with a “No.” Here it is important to use a funnelling approach: *“Have you ever smoked? What have you smoked? Have you ever sniffed any substance? What have you sniffed?”* By asking such broad questions, the counsellor may be able to elicit more honest answers than asking a direct question: *“Are you using drugs?”*

Use a funnelling approach:

- *Have you ever smoked?*
- *What have you smoked?*
- *Have you ever sniffed any substance?*
- *What have you sniffed?”*

By asking such broad questions, the counsellor may be able to elicit more honest answers than asking a direct question: *“Are you using drugs?”*

A drug user may seek help because of drug-related health problems due to abscesses/STIs, or because they run out of drugs and are now suffering from withdrawal symptoms, or because they are fed up of their habit and want to stop, or because family or police have told them to seek the help. So, the counsellor must be aware of the reason behind the health seeking behaviour as it will help him/her in planning the care for client.



Source: United Nations Office on Drug and Crimes

Ask all clients about drug use even if they do not fit the classic picture of a drug addict such as the image given above



Risk Assessment for IDUs

It is important to do a comprehensive risk assessment without making assumptions about who is or is not using drugs. Some counsellors restrict their questions to the “likely candidates” – persons who have blood-shot eyes or who have needle marks on their arms such as the person in the picture. But even so-called “decent” people may be using drugs. It is important to use a firm, friendly manner when asking about drugs because unless sufficient rapport is built, a client may not be completely truthful.

Some non-judgmental conversation triggers

- *“We know that one route for spread of HIV is through sharing of needles. Have you ever had any instance where you have had to use a syringe/ needle?” If the client responds “Yes” to this closed question, follow up with an open-ended question: “Could you tell me more about that please?”*
- *“Some people like to smoke, some people like to inhale substances. They may use tobacco or sniff glue or use medical drugs in a combination form. Have you ever done anything like this?”*
- *“As an HIV counsellor, I must make sure that I cover all areas by which a person may be at risk. It is important for you to be truthful with me even if you do not feel like sharing this information. What I hear from you will not go beyond the walls of the counselling room.*



In this context, I must ask you if you have ever used drugs?”

- Display a wall chart with pictures of different substances and ask clients to point to the substances they may have tried out in their life. The accompanying photograph shows peer counsellors from Arunachal Pradesh along with a wall chart where they display the types of pharmaceutical drugs that clients might use/ abuse.

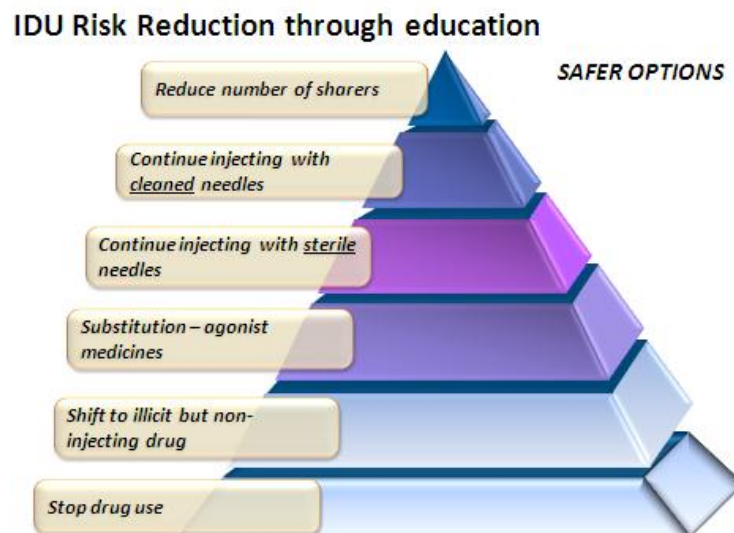
A comprehensive risk assessment will cover the following

- **Basic details:** age, sex, marital status, educational status.
- **Details of drug use:** Do not expect complete details in the first session. But display a nonjudgmental attitude and establish sufficient rapport to elicit three important pieces of information:
 - **Type of drug:** Name of the drug that an IDU would be using (e.g., heroin, buprenorphine, pentazocine, cannabis). If the counsellor is not able to know the exact chemical name, he/she should write the local name which is used in the community and ask other staff for clarification later.
 - **Frequency and amount of drug:** That is the number of times an IDU uses the particular drug. This is important for determining whether the client is dependent on the particular drug.
 - **Mode of use of drugs:** That is how the particular drug is consumed, Certain drugs such as alcohol are only consumed orally. But others such as opioids may be consumed either orally (e.g. opium liquid prepared from the poppy straw), through inhalation (e.g. smoking/chasing heroin), or through injecting (e.g. injecting heroin or pharmaceuticals).
 - **Time of last dose:** It is important to know whether the IDU is currently intoxicated or in withdrawal. Counsellors may note that if a client appears to be intoxicated or under the influence of the drug, they may ask this client to wait for half an hour in the waiting room. This will give time for the drug effect to wear off sufficiently for the person to answer questions in a lucid manner. Asking them to come when they are off the drugs completely is not advisable because then the client may be going through withdrawal. Some counsellors have a tendency to get preachy. It is better to listen to the client carefully and address those behaviours which increase risk rather than launch a frontal attack on all types of substance use. However, it is important to gently alert clients to the danger of progressing from limited use to more frequent use (weekend drinking to daily drinking), and from softer drugs to harder ones (tobacco to heroin).
- **Complications with drug use:** These could be of various types:
 - **Physical:** Health hazards associated with drugs, both local (e.g., redness or swelling at injection site, wounds, sores, blocked veins.) and systemic (e.g., affecting lungs, liver and heart). When there are indications of physical damage, the client should be referred to the doctor.

- **Legal:** Involvement in illegal activities to obtain drugs (e.g. thefts, pick pocketing), arrests/detains by the local police, charged under NDPS Act, driving under intoxication of drugs, physical fights under intoxication of drugs
 - **Occupational-financial:** Inability to work productively, accidents at workplace due to working during intoxication, frequent absenteeism at work, loss of job, frequent change of jobs, loss of income, debts, etc.
 - **Marital / familial / social:** Conflict with family/spouse, neglect of household responsibilities, physical violence towards family members, rejection from family, separation/divorce, homelessness, stigma from society, etc.
 - **Psychological:** Guilt and shame due to drug use, anxiety, depression, etc
- **High risk behaviours:** These include sexual behaviours as well as injection-related risks. They include behaviours which put the client at risk of HIV as well as other health conditions. To get a complete picture of the hazard posed due to his/her practice of drug injection by a particular IDU, the counsellor must ask the IDU to detail out the entire process of injection. With this, the counsellor would be able to pick up the high risk behaviour and practices associated with injecting drugs.
 - **HIV related knowledge and belief:** Instead of asking closed questions, the counsellor should ask open-ended questions (e.g., Instead of asking “whether blood transfusion causes HIV”, the counsellor should ask “what are the common modes of transmission of HIV”).
 - **History of medical and mental illness:** Ask should the presence of any co-occurring medical illness because IDUs are prone to psychiatric illness. Psychiatric illness is more prevalent in those who are dependent on drugs as compared to those who are not.
 - **Current living status:** Details of where the client lives currently.
 - **Motivation level:** The counsellor should assess the client’s motivation to reduce the high risk behaviours including drug use. Though it may be tempting for the counsellor to inform the client that they should stop taking drugs, such a direct approach rarely works. Clients with a drug problem are more likely to be successful with stopping drugs if they are personally motivated to change.

Risk Reduction for IDUs

The ICTC counsellor should enable the client to make decisions regarding reducing their risk. Please see the pyramid diagram which demonstrates Risk Reduction options. The counsellor would frame the message in this manner: *“If you cannot try this, then at least do the next risky action.”* For instance, *“If you cannot stop drugs, then at least to a non-injecting mode.”* Risk reduction recommendations should address condom use and safe injecting and should address how to sustain these practices over time. Practical problems in implementation should be addressed such as where to access condoms and syringes. It is important to inform them about the TI projects and about the Needle Syringe Exchange Programme (NSEP) which makes safe injecting possible.



Source: NACO Manual on Working with Injecting Drug Users

Such an approach which does not seek to drastically change the behaviour of the client but which appears to tolerate the client's "bad" habits may be difficult for counsellors to accept. But it is important for counsellors to recognize that changing or giving up a drug habit is a choice that the client must make from within. Counsellors further need to consider and examine their personal attitudes, values and beliefs, how these may impact their interaction with clients who use drugs. They need to recognize and accept that all people are different and potentially hold attitudes, values and beliefs different from their own. Finally, accepting a client's personal decision does not necessarily mean that a counsellor's own values should embrace this behaviour in her/ his own personal life, rather it means that the counsellor is expressing the value of accepting the client as he/ she is.

Frequently Asked Questions



There are no IDU-TI projects in my district.

So why should I bother with learning about these IDUs?

Even if there are no IDU-TI projects close to your ICTC, this does not automatically mean that there are no drug users. Drug users exist in every society. They may not all be injecting users, however.

All counsellors should be aware of the pathway that most IDUs take: They often start with lower level substances such as cigarettes or *gutkha* and then progress to harder drugs.

So it is important to ask all clients about substance use, including drug use.

Secondly, there is a growing misuse of pharmaceutical drugs which are mixed into a cocktail, crushed and then injected in a liquid form. It is important not to rule out this option.



References

- Des Jarlais DC et al. (2002). HIV risk behaviour among participants of syringe exchange programmes in central/eastern Europe and Russia. *International Journal of Drug Policy*, 13,165–170.
- Government of India (2006). *National Behavioural Surveillance Survey (BSS) 2006*. New Delhi, India: National AIDS Control Organisation.
- Grund, J.P.C., et al, (1991). Drug sharing and HIV transmission risks: The practice of frontloading in the Dutch Injecting Drug User population. *Journal of Psychoactive Drugs*, 23(1), 1-10.
- Kumar, (1998). Community-based outreach HIV intervention for street-recruited drug users in Madras, India. *Public Health Reports*, 113.
- National AIDS Control Organisation (n.d.). *A manual on working with Injecting Drug Users: A trainers manual*. New Delhi: Author.
- UNAIDS (2007). *Injecting drug use: Focused HIV prevention works*. Geneva, Switzerland: Author

Counselling Children at the ICTC

At the end of this unit, participants will be able to

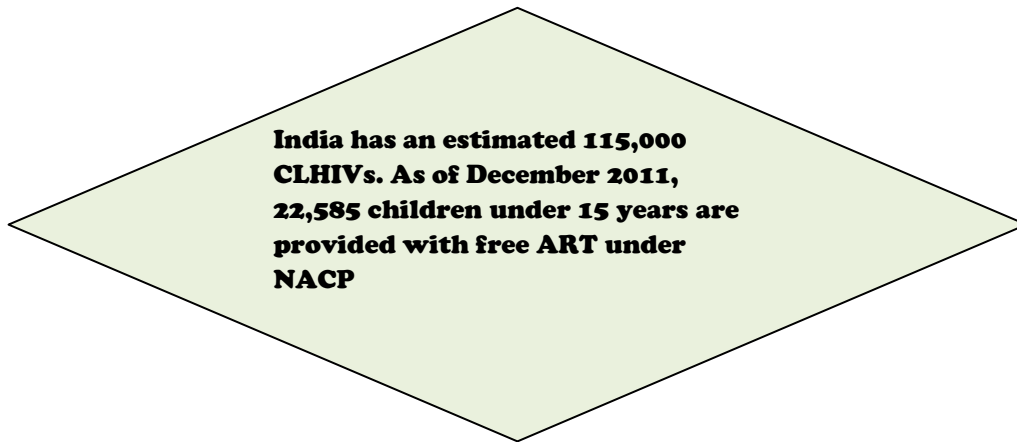
- Describe the development process in children
- Describe how to match counselling according to the development process in children
- Demonstrate strategies for working with child clients
- Explain parental issues in relation to counselling children at the ICTC
- List key issues related to disclosure of HIV status of child clients

The number of children below 15 years who are infected with HIV around the world has increased from 1.6 million in 2001 to 2.0 million in 2007. This is in spite of the fact that improved Prevention of Parent-to-Child Transmission (PPTCT) services means there are smaller numbers of newly-infected children. Of the Children Living with HIV (CLHIVs), 90% have been infected through mother-to-child transmission during pregnancy, during childbirth or through breastfeeding. The other 10% have acquired infection through blood transfusion with HIV-contaminated blood, injections with contaminated needles, sexual contact with other children and sexual abuse.

Counsellors often ask how they can discover how the child got infected. This is a very human need. However, in terms of working with the child client, this question is significant only to the extent that it matters for counselling a child who is sexually active so that measures can be taken to ensure that they are not at risk of sexually transmitted infections, their partner is not at risk of acquiring HIV infection and/or the child is not at risk of sexual abuse. Route of infection issues may also bother the child's parents and guardians. It is not easy to dismiss parental concern because of the emotional overtones of the issue. On the other hand, some parents may actually try to avoid this question because it involves their own concern and guilt at having transmitted infection to their child. Whatever the case, this is an explosive topic in counselling which will be explored in this module.

This module will also focus on how to work effectively with children as this is a competency that is new for the average ICTC counsellor. As pointed out earlier, there are a large number of CLHIVs in India, and so it is likely that as an ICTC counsellor you will encounter such a client in your career. Most counsellors fumble because they are used to dealing with adults and they rely on a verbal style of counselling. Such a style of counselling does not work so well with younger clients. Further, counsellors worry about how much they should tell their child clients.

In this module you will first learn about the process of development in children. Then you will learn how to use this information when working with children. Finally, the module will alert you to some issues when working with parents and caregivers. This module flows into the information provided in the section on Counselling Adolescents.










India has an estimated 115,000 CLHIVs. As of December 2011, 22,585 children under 15 years are provided with free ART under NACP

Understanding Development in Children

Physical Growth

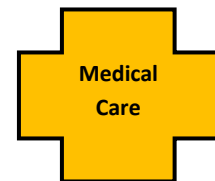
Given below are the developmental milestones of an average, healthy child. These are a set of functional skills or age-specific tasks that most healthy children can accomplish at a certain age.

Developmental Milestones at Different Ages

Birth	6 weeks	10 weeks	14 weeks	6 months	9 months	12 months
						
	Smiling	Controlling the head	Rolling over	Transferring object from one hand to the other	Sitting	Walking with help

Source: National AIDS Control Organization (2010). *Draft guidelines for exposed baby care*. New Delhi, India.

CLHIVs may show delayed growth. Such signs of developmental delay should be brought to the notice of the treating doctor.



Psycho-Sexual Growth

Besides the physical milestones, it is also important for you, as counsellors, to understand how the growing child interacts with other people – his/her growing engagement with the world. There are many theories and models of human development. One well-known theory was proposed by an Austrian physician, Sigmund Freud. He described the growing child's awareness of his/her sexuality and that of other important persons in the child's life. This is a theory of child sexuality as well as a model of life adjustments that the child has to make.



➤ Oral Stage

In the first year of life, according to Freudian theory, the infant is focused on feeding, and the source of comfort and gratification is through the mouth. Thus he called this stage the oral stage. You may have witnessed that children often like to suck their thumbs (even when they are not facing the discomfort of teething or hunger).

➤ Anal Stage

At ages 2 to 3, the child must learn to become accustomed to a routine. One notable sign of this routine is in terms of toilet-training and bowel control. Freud termed this the anal stage. Some children resist this routine and their caregivers have trouble with disciplining them. You may have noticed that children of a particular age are fascinated with bodily functions such as defecation and urination.

➤ Phallic Stage

This stage is the most controversial part of Freudian theory. He stated that at ages 4 to 5, a child discovers his/ her own sexual identity and nature and becomes attracted to the parent of the opposite sex. In this process, he/ she becomes jealous of the parent of the same sex. While it is almost impossible to test this part of Freud's theory, it is apparent that children do become conscious of issues related to being male/ female at this time. They learn what is expected of them as a male/female, and try to copy/ adopt those behaviours.

➤ **Latency Stage**

For the next 6 to 7 years, the growing child becomes focused on same-sex peers. Sexual awareness becomes dormant. This is largely the period of middle school. Children are most focused on their friendships, their talk is often in terms of who are currently their friends. Do you remember your childhood when you were *cutti* and *batti* with different peers?

➤ **Genital Stage**

At around the time of puberty, the child's sexual awareness reawakens and he/she once again begins viewing the world through this lens. However, the sexual awareness is closer to that of adult urges than those displayed by the individual in the phallic stage. Youth are often troubled about how to relate to members of the opposite sex (Please note that Freud's theory focused on heterosexual development though he did give some explanations for homosexual behaviour).

How can an ICTC counsellor use this particular theory?

The first contribution of this theory is to recognize that children go through a child-like process of sexual discovery and awareness in the early years of life and then a more adult process when they are in their teens. Counsellors should not assume that children are completely unaware of sexuality issues. However, it is also important to recognize that the growing child is not mentally prepared for a complete talk on the facts of life with all the issues on the table. Discussions should be tailored to the age and mental understanding of the child.

The second contribution of this theory is that Freud recognized that in stressful situations, people regress to an earlier phase of development – that is people who have successfully moved to the next stage of development will suddenly return to earlier ones. So if a child aged 8 years suddenly begins sucking his/ her thumb or wetting the bed, this is a sign that all is not well with the child.

The third contribution of this theory is also an awareness of how the growing child begins to engage with the world. During the oral stage, the child is only aware of his/ her own needs. During the next two stages, focus is on the parent while in the latency period the child is interested in peers, especially same-sex peers. This may help you while counselling to understand why a CLHIV aged 8 years may feel the rejection of classmates very keenly while an older teenager may grieve the anticipated loss of a relationship with a member of the opposite sex.

Child-Centred Counselling

Child-centred counselling is a therapeutic approach that focuses on the issues, needs and concerns of the growing child. It places importance on his/her experiences. It is a radical approach in India where most often parents and caregivers dictate what should be done from their perspective of what the child needs. By contrast, child-centred counselling focuses on how the world (and the HIV situation) appears from the perspective of the child.

As a small demonstration of what this might mean in a physical sense, sit down on the floor of a room with which you are familiar. Look around you. You probably cannot see the things which are on the top of the table or on a stove-top. From this angle, you cannot perceive dangerous items on these surfaces that might harm you. Adults appear to be so much larger and heavier than you. In a sense, this is a small approximation of how the world appears to the child. They are unaware of many dangerous situations (and so adults feel the need to protect them). There are many “big people” in their life who do not understand what life is like at the lower level. The counsellor must learn to bridge this physical and emotional gap.

Child-centred counselling includes:

- Matching child counselling to the developmental stage
- Understanding perceptions and emotions of children
- Helping children to manage their emotions
- Use of counselling strategies tailored to attract children

Matching Child Counselling to the Developmental Stage

Effective counselling for children matches the developmental stage of the child. Children are expected to attain different skills at each age. So the counsellor must use age-appropriate counselling.

<i>Skills</i>	<i>3–6 years</i>	<i>6–9 years</i>	<i>9–12 years</i>
<i>Communication skills</i>	Begins to recognize written words and can read short sentences.	Understands and is able to follow sequential directions. Child starts reading.	Understands and is able to follow sequential directions. Reading and verbal communications are very well developed.
<i>Cognitive skills</i>	Understands concepts such as size, shape, direction and time. Enjoys rhyme and word play.	Peer recognition starts.	Peer recognition is important.
<i>Physical development</i>	Enjoys doing most things independently.	Develops curiosity about genital organs and starts comparing them with other children.	Growth of armpit and pubic hair, breast development and menarche (beginning of menstruation) in girls

Here are some examples of how to tailor your counselling to the developmental milestones

- **Young children feel reassured with physical touch.**

While counsellors are very aware of barriers to touching adult clients – especially clients of the opposite sex - they must learn when touch is appropriate for children. A comforting rub on the head or the back will reassure children, especially young ones. However, some children who are physically abused may flinch from such contact. So the counsellor should be alert – signs of discomfort should be noted.

- **Children in the age group of 3 to 6 years can follow directions.**

You can take them around the ICTC and explain what happens there. You can create a small ritual for the actual testing process by asking them what a brave soldier would do – not mind a little pain which comes from being pricked. There is no need to trick children. You can also use the child client’s ability to follow directions to encourage a little independence such as gathering the colouring materials and replacing them in the proper slot. Children like being treated as “grown-up” even if they are not.

- **Children in the age group of 6 to 9 years enjoy time spent with friends.**

So you can ask them about their friends. This will help you to build the interest of the child in the counselling process as well as identify issues they face like difficulty with friends, avoidance from friends as a result of stigma, etc. A good counsellor will recall the names of the child’s friends because this is one way of entering their world. She/he will patiently listen to the stories of what “Adi said” and what “Kriti did.” This is important for child-centred counselling because it gives importance to those things which are important for the child.

- **Remember to ask adolescent clients about their physical milestones related to puberty.**

Be prepared to handle misconceptions and concerns. These are discussed in greater detail in the module on counselling adolescents as well as in the section on male and female anatomy.

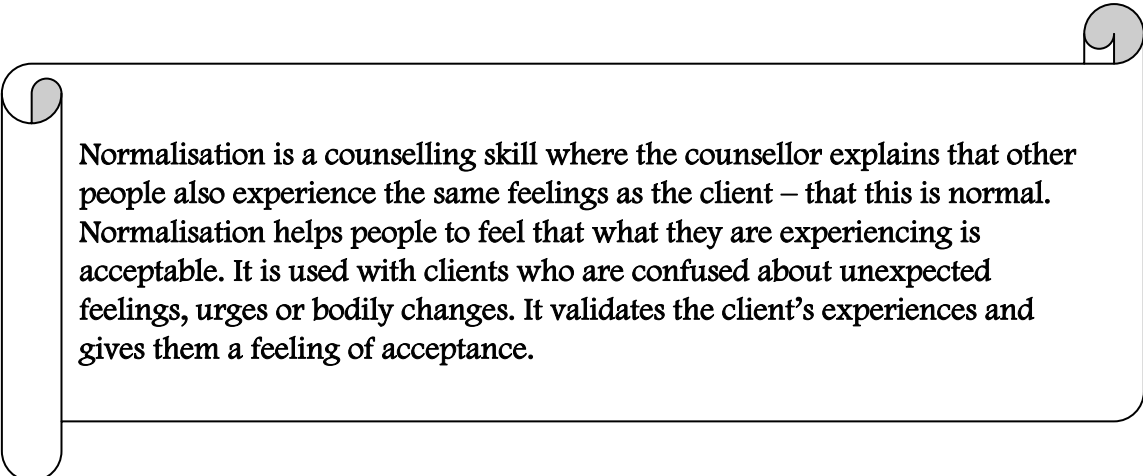
Understanding perceptions and emotions of children

While children experience emotions, they may not be able to recognize or label them in the same way as adults. A simple phrase that captures this is '*kuch kuch hota hai*' (Hindi phrase meaning something is happening). Also the reasons behind their emotions may be different from that of adults. For instance,

- Children may express anger rather than sorrow when a parent dies. They may also fear that the other parent will also die.
- Some children may feel guilty about their parent's death.

Listed below are different emotions a child may express and ways you could assist the child to cope with or manage these emotions. The most important thing that a counsellor can do for a child client in each of these situations is:

1. **Help the child to express their emotions.** Often children are told not to express emotions, especially negative ones such as anger and sadness. Enabling the child to express emotions in a safe environment is an important task for the counsellor.
2. **Normalise the feeling.** Normalisation is a counselling skill where the counsellor explains that other people also experience the same feelings as the client – that this is normal. Normalisation helps people to feel that what they are experiencing is acceptable. In the case of a child client, it removes the "*kuch kuch hota hai*" feeling. In the case of an adolescent client, normalisation makes them feel less guilty about their new-found sexual desires.



Normalisation is a counselling skill where the counsellor explains that other people also experience the same feelings as the client – that this is normal. Normalisation helps people to feel that what they are experiencing is acceptable. It is used with clients who are confused about unexpected feelings, urges or bodily changes. It validates the client's experiences and gives them a feeling of acceptance.

3. **Explore the reason for the feeling.** Emotions may have a reason such as a change in the child's life. It is easier for a child to answer a question such as, "Since when are you feeling this way?" as opposed to "Why are you feeling this way?" The first question can help the counsellor to understand the coinciding events that may be responsible for the changed behaviour or feelings of the child.
4. **Lastly, assist the child to manage the feelings.** It is important not to tell children that feelings will go away on their own. Rather, children should be helped to know who their supports are, and what they can do to lessen the intensity of the feelings.

When reading the list of emotions mentioned below, it is important to understand that the child may demonstrate only one or two of the signs mentioned in the list.

Helping children to manage their emotions

Dejection

Dejection is a state of being in low spirits or in depression.

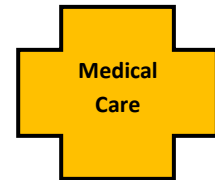
Dejection may be expressed as any of the following:

- ❖ Feeling miserable or sad
- ❖ Lacking energy
- ❖ Finding it difficult to perform small tasks
- ❖ Not wanting to socialize
- ❖ Difficulty in thinking clearly
- ❖ Seeing little hope for the future
- ❖ Being irritable, angry and anxious at times
- ❖ Difficulty in sleeping

Management of dejection

- ❖ Allow the child to express their feelings.
- ❖ Ask the child what would make them feel better; Help them to adopt these changes.
- ❖ Normalize the situation for the child (explain it is normal to feel like this and often others also feel the same).
- ❖ Explain that dejection is temporary.
- ❖ Ensure that the child has support and friends. Discuss the support provided by the caregiver.
- ❖ Explore the reason for the child's dejection.

- ❖ In serious cases, or if the dejection persists for three months or more, refer the child to a psychologist or psychiatrist.



Anger

Anger may be expressed as any of the following:

- ❖ Verbal or physical abuse/violence
- ❖ Feeling hot and flustered
- ❖ Throwing a temper tantrum
- ❖ Having frequent disagreements or arguments with the caregiver
- ❖ Trembling or shaking of the limbs
- ❖ Headaches
- ❖ A tight feeling in the chest

Management of anger

- ❖ Normalize the situation and the emotion for the child.
- ❖ Help them to identify appropriate ways to work off their anger such as taking a deep breath, running 5 times around the garden/ compound, hitting a 'punch-me' doll or a pillow, counting back from 20, throwing a cricket ball against a wall repeatedly, etc.
- ❖ Ask them to draw or enact their anger.
- ❖ Explore the reason for the child's anger.

Helping children to manage their emotions

Anxiety

Anxiety may be expressed as any of the following:

- ❖ Abdominal discomfort
- ❖ Diarrhoea
- ❖ Dry mouth
- ❖ Rapid heartbeat
- ❖ Tightness in the chest
- ❖ Shortness of breath
- ❖ Difficulty in sleeping
- ❖ Difficulty in concentrating
- ❖ Hyperactivity
- ❖ Restlessness

Management of anxiety

- ❖ Ask the child to express their feelings.
- ❖ Discuss their responses.
- ❖ Try to find solutions to the causative problems.
- ❖ Normalize the feeling.
- ❖ Try using relaxation techniques (such as deep breathing, lying down, going for a gentle walk, stretching, having a warm bath). Enlist the help of caregivers for this.
- ❖ Discuss who could help the child.

Fear

Fear is a very natural response to a chronic illness, and will regress/progress through numerous stages as the child's health improves or worsens.

Some fears are normal in children. e.g., fear of strangers, being away from parents, ghosts.

Fear may be expressed as any of the following:

- ❖ Tightness in the chest/throat
- ❖ Lack of appetite
- ❖ Restlessness/overactivity
- ❖ Tightness in the chest
- ❖ Shortness of breath
- ❖ Difficulty in sleeping
- ❖ Difficulty in concentrating
- ❖ Hyperactivity
- ❖ Restlessness

Management of fear

Fear is a very natural response to a chronic illness, and will regress/progress through numerous stages as the child's health improves or worsens.

- ❖ Normalize the feeling.
- ❖ Explore the source of the child's fear.
- ❖ Make sure they receive support to overcome fear from friends and family.
- ❖ Religious guidance can also be of benefit where relevant (This should be the child's choice).

Use of counselling strategies tailored to attract children

From a child-centred perspective, it is easy to recognize that the regular strategies of counselling do not work with children. The counsellor must develop new skills. In this module, we describe three strategies: drawing, story-telling and puppetry. These are easily incorporated into the routine of the ICTC and do not require too many resources. However, the counsellor who is innovative may use these simple techniques and develop a deep rapport with their child clients.

➤ **Drawing**

Drawing is an expressive medium which can be implemented from using simple blackboard chalk or charcoal to most expensive oil paints and canvas. Ancient human beings felt the urge to describe their lives through drawings on the walls of their cave dwellings. Young children also, at early ages, may scribble on the walls of their home.

As a therapeutic technique, this is an easy-to-implement strategy. Children usually enjoy drawing unless they are put off by the regimented discipline that is imposed by unimaginative school teachers. Psychologists have long understood that through the medium of drawing they can even gauge a child's level of intelligence. For instance, one intelligence test requires the child to draw a man, a house and a tree. You can try this with children of different ages and see the differences for yourself.

Through drawing as therapy, the counsellor can facilitate communication with child clients on their emotional state. For instance, the counsellor may ask the child to draw a picture of their family or their school. The placement of the human figures can tell you a lot about whether the child feels accepted or rejected by family and peers. The choice of colours (bright versus dark) can tell you of the child's sense of optimism or sense of hopelessness. The pressure they apply on the pencil or the crayon may indicate strong feeling.

Drawing may be used with children of all ages. The task can also help children to feel successful in completing the task and take pride in explaining the drawing from their perspective. Further, if the counsellor displays the drawing on the board, it can help them to feel a sense of acceptance at the ICTC.

How an ICTC counsellor can use drawing in counselling

- Provide the child with drawing material: Paper, crayons, pens, etc.
- Ask the child to draw a theme that you, the counsellor want to pursue, such as the illness in their body.
- Follow the drawing session by asking the child to describe and explain the drawing.
- Use open-ended questions to probe deeper.
- Let the child “narrate” the sequence of events in their environment.

Some themes you could give the child to draw

- A normal day in the child’s life
- A routine day for the caregiver
- What makes the child sad/ angry/ unhappy
- How and when medicines are taken
- The child’s family
- A day at school



➤ Story-telling

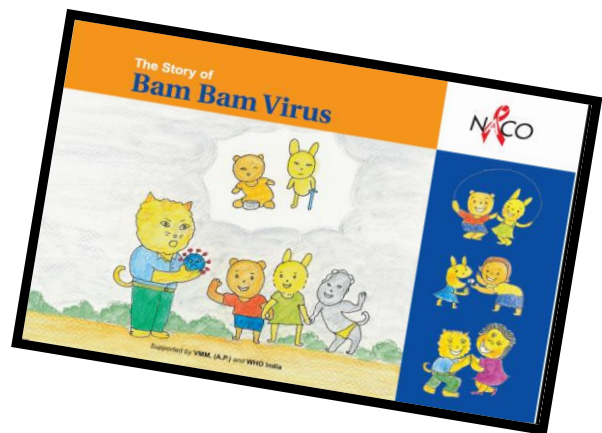
Story-telling is another expressive therapy. Children generally like to hear stories as well as make up their own. Story-telling can be used with children individually or in groups.

Advantages of story-telling during counselling:

- ✓ Children easily identify and emotionally relate with characters in the story.
- ✓ Listening to a story about someone in a similar position can be very comforting for the child, when it is difficult to talk about painful issues.
- ✓ Stories can help the child recognize that they are not alone in the given situation. The story can give the child a sense of being understood.
- ✓ Through stories you can help the child to solve problems or cope with the situation. For example, if a child hesitates to have their blood drawn through a syringe, a story with an interesting character who faced the same situation may help motivate the child.
- ✓ Story-telling does not require you to stock any material at the ICTC.
- ✓ You can find many culturally relevant stories that are helpful to people in the ICTC.

Different methods for story-telling:

- ✓ Tell the full story and ask questions later.
- ✓ Give a story outline and ask the child to build up the story
- ✓ Present the first half of the story and ask the child to complete it
- ✓ Provide a topic and ask the child to develop their own story
- ✓ Ask older children to write the story as a poem

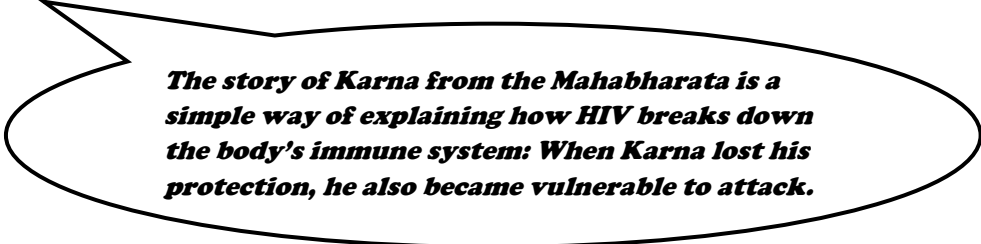


However, you need to consider the age and maturity level of the child while choosing the method. For instance, you may tell the full story to children below five years while children above ten years may be encouraged to create their own story. Teenagers may enjoy the challenge of telling a story in rhyme (poetry form).

While telling a story, take care of the following:

- Avoid using real names or events.
- A familiar story or folk tale can be used to convey to the child a specific message which is related to their problems.
- Use animals to make it interesting and impersonal, such as in the Bam Bam virus story.
- At the end of the story, encourage the child to talk about the characters and explain their behaviour.
- At the end of the story, encourage the child to talk about what happened. For example, ask about the message of the story to confirm that the child has understood the story's relevance.

When you ask the child to develop stories based on a topic, these stories should be used for problem-solving. For example, if the topic is 'a sick child', you can ask the child about what happened to the child in the story and why. This would help the child to understand what they have to do.



The story of Karna from the Mahabharata is a simple way of explaining how HIV breaks down the body's immune system: When Karna lost his protection, he also became vulnerable to attack.

Some story triggers for story- telling and puppetry:

- There is a family of a mother, a father and two children. The mother and father are constantly ill. (Ask the child to complete the story)
- A five-year-old boy lives with his grandmother in the village. The grandmother is very old and finds it difficult to take care of the house and the boy. (Ask the child to complete the story).
- A little girl had to take medicine every day. (Ask the child to create a story)

➤ **Puppetry**

Puppetry is a popular folk art which can be integrated easily to counselling. A counsellor can use string-puppets, finger-puppets, hand-puppets made from paper bags or old socks and puppets created using gloves.

One method of making puppets is highlighted at the end of this module. The act of creating puppets is in itself a therapeutic activity and can help the child to express himself or herself. Asking the child to use a puppet can also be a powerful way for the child client to express his/ her needs and feelings directly by using the voice of the puppet.



How to use puppetry

- ✓ Give the child a puppet and “interview” the puppet about what is happening in the child’s life: *“Mr. Puppet, could you tell me how Shanti is feeling today?”* or *“Mr. Puppet, could you tell me why Sharad feels so sad?”* Start with a few easy questions on how the child felt on the first day at school, and then graduate to more intense questions.
- ✓ Provide the child with an outline for a story, or ask the child to develop and perform their own story. You may also combine story-telling and puppetry.
- ✓ Ask the child to use the puppets to develop the story.
- ✓ Ask the child to explain the story using puppets. You may help the child in moving the puppets. Sometimes you may need to ask questions to help the child to move the story forward.
- ✓ After the performance, discuss the role of the puppets and their thoughts, emotions and behaviours.
- ✓ Relate the discussion to the child’s situation through simple questions like *“Do you sometimes feel like this puppet?”*

How to use these techniques therapeutically

The three methods described are expressive techniques: They permit a child to explain and express their thoughts and feelings. Children often feel very uncomfortable and disturbed with some of these negative feelings. When the child expresses them (through the voice of the puppet, for instance), the counsellor may soothe the child and say, *“It appears that you are upset about the illness. It is normal to feel this way. Many children in your situation feel like you do.”* The counsellor here has used the skill of normalization. This tells the child that it is okay to react to a difficult event with sorrow or even anger. The counsellor can then move to the next step – to resolve and settle the situation.

When to find time for these activities at the ICTC

As an ICTC counsellor, you may wonder where to find time for these activities. Afternoons with a lighter load may be an appropriate time. You may also ask the caregiver to come later in the morning so that child clients do not get bored with waiting in OPD. Alternatively, you can set the child a task to do, seat them in a quiet spot in your centre, meet other patients and then speak to the child about the task after half an hour.

*Remember! It is okay if the child laughs during your counselling session.
Everything should not be about the illness!*



Guiding Child & Parent through the Testing Process

One way in which counsellors engage with child clients is when they are brought in for the HIV test – in older children this is through the rapid test process while in infants the ICTC will follow the procedures for Exposed Baby Care. For instance, because of Provider-Initiated Counselling, children who are diagnosed with tuberculosis may be referred to the ICTC.

The counsellor must realize that the process of testing is scary for children as well as adults. Here are some important points while guiding the child and parent through the testing process:

- ✓ Explaining the test procedure to the child
- ✓ Explaining the meaning of the test to the child
- ✓ Explaining the reasons for the test to the parent
- ✓ Explaining a negative diagnosis to the parent
- ✓ Breaking the news of a positive diagnosis to the parent

Explaining the Test Procedure to the Child

The ICTC is located in a health facility. Often children associate the hospital with death and pain. Entering the hospital is a scary experience where they may see people in bandages. The counsellor may appear like a doctor as many wear an apron. The lab technician also wears an apron. Even if the counsellor does not go into details about the implications of the test result, the child needs reassurance about the procedure of being pricked.



Some ways to do this are:

- **Talk to the child in a reassuring voice.** Often doctors and other health personnel ignore children and focus on parents. Paying them attention makes them feel important.
- **Show them a dummy syringe without the needle** (a fresh one of course) and point out how much blood will be taken. Reassure them that you will not be draining all their blood. Children's ideas of the body system are not fully formed.
- **Younger children enjoy imaginative games.** So if you have a spare syringe tube (clean one without the needle), you can give them one with which they can pretend-play: You can allow them to "draw your blood."
- Since the counselling room is separate from the testing procedure room, **the counsellor should spare the time to walk with the child client and parent to this room.** It may be worthwhile to interrupt the queue to get the child's blood drawn first. Keeping them waiting only prolongs their anxiety.
- Sometimes finding a vein for a very small child is difficult. Parents and child tend to get tense through the procedure. **It is important to maintain a quiet, calm voice** that will percolate through to the persons concerned.

Explaining the Meaning of the Test to the Child

This is a tricky issue. As counsellors you are aware that informed consent means that the client must understand the implications of the test procedures. This is not an easy decision with children. Caregivers and parents may choose not to tell children the reason for the test. So a counsellor may have to use general terms to explain this reason for drawing blood: *“Sometimes doctors are not able to make out if a person is sick unless they can see the germs in the blood of that person. So we are going to run a test on a small amount of your blood. Once we know if that germ is present in your blood, we can give you medicines to remain healthy and strong.”*

At this point, there is no need to go into a detailed description of ART and its life-long nature. This will only confuse the child. If the child is HIV-positive, then the actual medicine details can be explained. The principle, therefore, of explaining the meaning of the test is to help the child understand, in age-appropriate language, what is happening to them, and the reason for this.

Parents and caregivers must be given the details of the implications of the test result:

- **In case of a positive result** - the need for a CD4 count followed by life-long treatment
- **In case of a negative test result** - possible need to retest a few months later.

Explaining the Reasons for the Test to the Parent

This is another tricky issue. The reasons for testing the child are often because of parental infection, particularly maternal infection. Parents may be reluctant to test the child for various reasons. These reasons should not come in the way of the child's right to receive the best possible treatment. So the counsellor must explore and debunk all of them.

- **Parents may wish to avoid their own personal guilt because they feel responsible for the child's infection:**

The counsellor should focus the attention on the needs of the child – “While you may be really upset personally about the fact that the child may have got infected through you, it is important not to delay the test. Let us focus on your child right now and what we can do to keep him/her healthy. If we find a positive result, there are treatment options. But we can only decide whether your child is eligible if we know his/her status.” Later, the counsellor may choose an appropriate time and venue to work therapeutically on parental guilt.

- **Parents may be reluctant because they think there is no hope:**

The counsellor should emphasize that early detection means the possibility of early treatment.

- **Parents may not want to burden the children with knowledge of a terminal illness/ a chronic illness:**

The counsellor should tell them that getting the test done does not mean that the parent has to immediately share the news of the test result with the child. This news can be gradually broken down to the child in an age-appropriate manner.

- **Parents may worry that the news of the child's status will cause them to be stigmatized:**

Reassure them about confidentiality.

- **Parents of PITC referrals may ask why the child needs to be tested again:**

Explain that the TB test will not explain HIV status, and that HIV and TB often go hand in hand: The current test is just to rule out HIV infection in the child. Make sure they continue TB treatment.

Breaking the News of a Positive Diagnosis to the Parent

As ICTC counsellors you are likely to have gone through the process of sharing the test result with a client. We will not repeat many of the issues that are associated with post-test counselling. We urge you to read your induction training materials. However, here we will discuss what a positive test result means for the parent.

It is a common human need for parents to want the best for their children in the present and in the future. When a baby is born, the reactions of parents with a healthy baby are different from those whose baby is born with a deformity or handicap. The latter must first adjust to the fact that their child has a condition that they may carry through their life which will affect their future prospects. The parents, in effect, go through a process where they grieve the image of the perfect child that they carried through the process of pregnancy – that vision of an ideal child. When they have given up this idealized vision, they will be better able to take decisions for the benefit of the child.

Parents learning about the positive-HIV status of their child also go through a similar process of grieving. No doubt you would have prepared them in pre-test for the possibility of a positive result. But human nature is such that it hopes for a positive outcome. HIV counsellors must be prepared for the grief reaction of the parents but also focus them on making a speedy decision for the next step (that is going to the ART centre).

How to break bad news

Counsellors often ask how they can manage the burdensome task of giving bad news. One technique is the Sandwich technique: It follows the physical layout of a sandwich – two slices of bread with a filling.

- **Upper slice of bread:**

“I have some bad news to give you. You may or may not be expecting this.” Announcing that the news is bad gives the parent a few seconds to prepare themselves to actually hear the words which are going to dash their hopes.

- **Sandwich filling:**

“The child’s test result is positive.” This is the actual news of the test result.

- **Lower slice of bread:**

“This is still a shock for you and I am here to help you absorb this.” This is the offer of support from the counsellor. Just as the bread supports the filling, so the counsellor offers support for digesting the bad news.



Explaining a Negative Diagnosis to the Parent

A negative test result may not mean the child is HIV-free. The counsellor needs to follow operational and technical guidelines to interpret the meaning of a negative test result for the child. This has to be clearly communicated to the parent. Sometimes a repeat test may be required. The counsellor must inform this to the parent or guardian and ensure that they understand when they have to come again.

Disclosure of HIV Status to Children

Child clients may or may not know that they are HIV-positive. A study by Population Council (2007) on Indian children less than 12 years of age showed that less than one in five are aware of their HIV status. Similar findings have also been reported by clinicians at a Regional Paediatric Centre in Mumbai (Bhosale et al, 2010). Reasons that caregivers report for not sharing their own/ as well as the child's HIV status with the child include fear of people's reaction, the child being too young to understand, and a fear that the child would tell others in the community. The last reason displays the caregiver's internalized stigma – namely that caregivers fear discrimination from family, community, school, and hospitals (Population Council, 2007). One caution should be mentioned here – some of these results rely on caregiver reports which international research has shown may not be very reliable (Unfortunately, there is not much evidence on this topic from India).

Children who are taking ART are aware that they have to take medicines every day, while their friends or siblings do not. But they are often not aware of the reason for this. Sometimes, they have questions or they may be reluctant to consume medicines. Caregivers often resort to various half-truths (e.g., *"You have pneumonia."*), incentives or threats to elicit co-operation from their charges (Bhosale et al., 2010; Population Council, 2007).

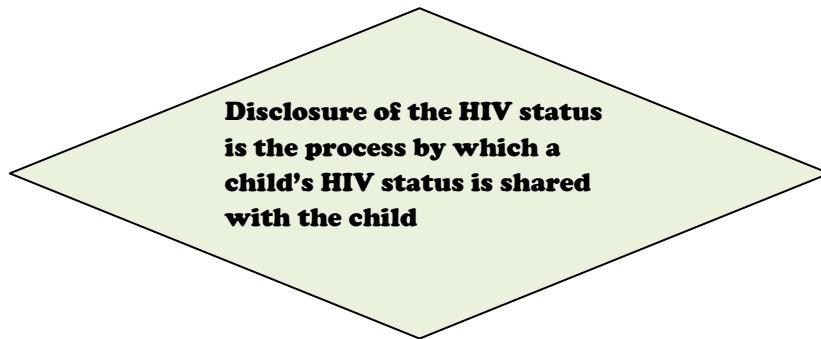
It is well known that adherence to ART is better when the person is aware of their status. It may be assumed that the same also holds true for the child. A child client has a right to know about her/ his status not just for ensuring adherence, but also in terms of recognizing them as individuals. As a counsellor, you may have to facilitate appropriate disclosure of the HIV status to him or her during the counselling sessions.

Facilitating disclosure does not mean that you have to talk to the child yourself. You may also encourage guardians/ parents to do so – in your presence or on their own. Sometimes, the counsellor at the ART centre may have initiated the process and you may need to follow up. In other cases, you may need to start the process depending on the age and maturity level of the child. Disclosure is not something that should be done in one sitting alone. You may have an opportunity through follow-up sessions to undertake the process of disclosure. You should also understand that even if you believe that you have finally explained about HIV and the fact that the child's body has this virus, you may find yourself having to repeat the explanation to the child more than once. The reason for this is because the child may take time to absorb this information.

Understanding Disclosure

Disclosure of the HIV status is the process by which a child's HIV status is shared with the child. Disclosure is important for promoting adherence to treatment. Disclosure should be carried out in a sensitive, caring manner. When disclosing the HIV status to the child, you and the caregiver should consider the following:

- Why should the HIV status be disclosed?
- When should the HIV status be disclosed?
- How much information should be disclosed?
- How should the status be disclosed?
- Who else should know the child's status - school principal, extended family?



The First Step

As a first step in the process of building rapport with the child and caregiver, it is imperative for the counsellor to identify whether the child is aware of his/ her HIV status. If the child is unaware of his/her HIV status it is important that the counsellor encourages disclosure by the caregiver to the child during follow-up sessions. For the caregiver to disclose the HIV status to the child, the counsellor can "practise" disclosure with the caregiver through role-plays. In case the caregiver does not want to disclose the status, the counsellor can disclose it to the child with the caregiver's consent and in the presence of the caregiver.

Why should the HIV status be disclosed?

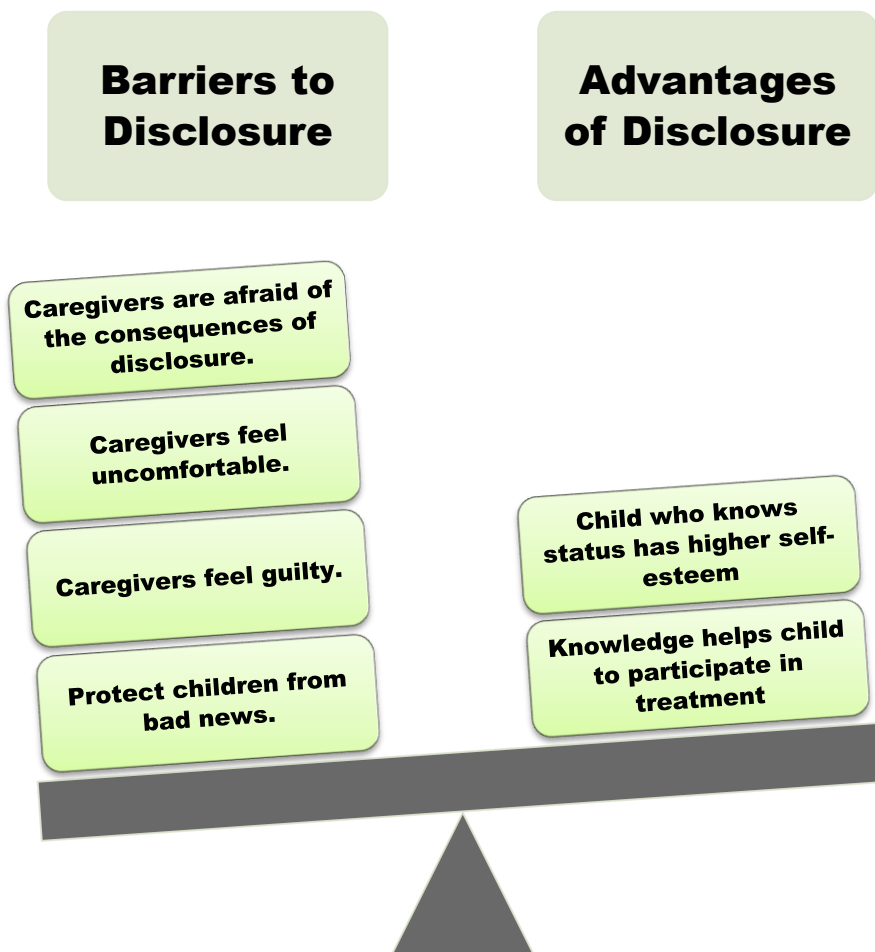
With psychosocial support, children are usually able to deal with disclosure of their HIV status. In cases where children learn their HIV status from others such as neighbours/friends, they tend to suppress their emotions and have difficulty in accepting the situation and adapting to it.

We can reduce the psychological trauma of disclosure (e.g., fantasies, nightmares) by:

- ✓ providing children simple, concrete and direct information
- ✓ through a person they trust
- ✓ in a supportive environment.

➤ **Barriers to disclosure of the HIV status to children**

- Caregivers want to protect children from bad news.
- Caregivers feel guilty.
- Caregivers feel uncomfortable about the subject and do not know what to say to the child nor how to answer their questions.
- Caregivers are afraid of the consequences of disclosure.
- Caregivers are afraid of becoming emotional when disclosing the status.
- Caregivers fear that the child may talk about their HIV status to others, thus revealing the HIV status of the caregiver.
- Cultural taboos may prevent the caregiver from talking openly and honestly to the child.
- There may be no caregiver available for disclosure (as in the case of orphans).



➤ **Advantages of disclosing the HIV status to the child**

- As children grow up and mature, they have the right to information about their illness. This knowledge encourages active participation of the child in their own medical care. Studies suggest that children who know their “HIV-positive” status have higher self-esteem and are better able to cope with their illness than children who have not been told about their positive status. Children who find out about their HIV-positive status from a person other than the caregiver may lose trust in the caregiver. In addition, caregivers who have disclosed the HIV status to their children experience less depression than those who have not told their children.

When should the HIV status be disclosed?

There is never a perfect time to disclose HIV-positive status to a child. The time for disclosure should be determined by the child's developmental level and emotional maturity. Children as young as six years may be able to understand the implications of HIV-positive status on their lives. The time to disclose also depends on the preparedness of the caregiver to disclose or his/ her willingness to let others disclose the status to the child.

Age-specific advice on disclosure

<p><i>Upto 2 years</i></p>	<ul style="list-style-type: none"> ✓ Talk to the child simply and naturally about his/ her health. ✓ Avoid transmitting anxiety to the child through body language or voice tone.
<p><i>2–3 years</i></p>	<ul style="list-style-type: none"> ✓ Be aware of children's sensitivity to adult's feelings through body language. ✓ Talk openly and naturally about the child's health without transmitting anxiety. ✓ If the child is sick, talk gently about his/her illness, and provide constant loving care.
<p><i>3–5 years</i></p>	<ul style="list-style-type: none"> ✓ Stimulate questions by asking the child what s/he understands about having to go to the clinic, taking medicine, being sick often, and what s/he fears. ✓ Listen carefully, answer truthfully and naturally, give as much information as the child seems ready to take in. ✓ Use simple language, such as "A virus (or germ) inside you that can make you sick," "Medicine will make the body stronger to fight against the virus," "The same virus your mother has sometimes makes you sick."

Source: WHO (2004). *IMAI chronic care management*,

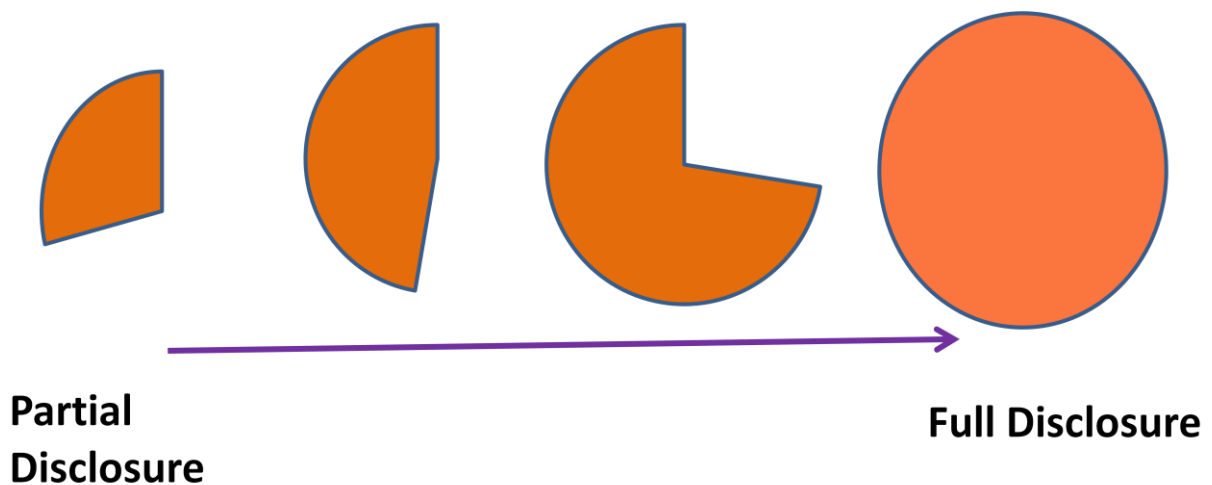
How much information should be disclosed?

There are two types of disclosures that can be undertaken based on the age of the child, developmental level, emotional maturity, and the level of understanding and communication skills.

- Partial disclosure provides partial information to the child about their health and HIV status (e.g. *"You have an infection in your blood."*).
- Full disclosure provides the child with complete information about their HIV status and its implications for their health. Full disclosure involves naming the virus and the likely mode of transmission.

Disclosure is usually a process and not a one-time event, and involves both caregiver and the child. This process may start with partial disclosure and eventually proceed to full disclosure.

By starting with partial disclosure, children become comfortable with the concepts presented. In general, partial disclosure should be recommended as a way for caregivers to begin the disclosure process. This process will help all parties feel more comfortable.



How should the HIV status be disclosed?

- ✓ Break down information to a level that children can understand. The information should be appropriate to the child's developmental level. For example, what is initially understood as *"soldiers that help your body fight off sickness"* can later be termed *"white blood cells"* and eventually the more specific *"CD4 cells."*
- ✓ Use interactive communication strategies for disclosure (story-telling, role-play, etc.).
- ✓ Repeat concepts over time, as children are unlikely to immediately grasp the meaning of abstract concepts such as illness or infection.
- ✓ Repeatedly initiate health-related conversations to ensure that children truly accept the information.
- ✓ Be prepared for the child's reactions and further questions.

Suggestions for encouraging caregivers to disclose the HIV status to the child

➤ **Matters to be discussed with caregivers**

- There is never a perfect time for disclosure. Do not wait until you think your child is old enough to discuss health and illness.
- You do not have to fully disclose the status and you can initiate this dialogue at a basic level without mentioning the word HIV.
- It is better that your child learns about his/her HIV status from you than from others
- You can begin the conversation with the child in simple steps: *"Why do you think you have to go to the doctor?"* or *"How do you feel about taking medicines regularly?"*

➤ **Other steps**

- Identify sources of support for both the caregiver and the child. This may include other family members, close friends of the child, counselling assistance, child support groups, etc. Once the caregiver decides to disclose, encourage partial disclosure at the beginning. Assure them of your support in the process of disclosure

Who else should know the child's status?

The principles of Why, When, How should be considered before disclosing the child's HIV status to significant others in the child's life such as the school and the extended family.

➤ **Why should the status be disclosed?**

Disclosing the HIV status to others can be beneficial. However, this should be done very carefully.

Advantages of disclosure

- ✓ Creation of multiple caregivers, support and assistance from the extended family for the care of the child which helps to reduce burn-out of the caregiver.
- ✓ School principal or teachers might be able to extend support to the child when the child is unable to attend school and adequate care in case the child is unwell or injured.

Disadvantage

- ✓ Disclosure of HIV status could result in loss of privacy and discrimination. At school, the child may not be allowed to participate in physical activities or may be asked to leave the school. This is a common situation in India.

➤ **When should the status be disclosed?**

Disclosure to others should be in the best interest of the child and should be discussed with the child if possible.

➤ **How should it be disclosed?**

The caregiver should be well prepared when disclosing to others. Role-plays can help the caregiver prepare for possible reactions (best-case and worst-case scenarios), questions and responses. The caregiver can also seek support from other caregivers.

Common expressions among children following disclosure

You should be prepared to handle the responses of the child to the news of HIV status. The common expressions among children and how to counsel in such situations are given below.

Common expressions among children	Possible explanation for the expression	Counselling content and skills
<p>The child's perception and understanding of the causes of the disease.</p> <p>E.g. Verbal expressions such as</p> <ul style="list-style-type: none"> ✓ "I am a bad boy and so I am suffering." ✓ "My friends are fine, why do I remain sick?" 	<ul style="list-style-type: none"> ✓ What is told to the child about his/her infection ✓ The child's level of understanding ✓ Family structure, functioning and communication within the family 	<ul style="list-style-type: none"> ✓ Provide the child with basics of HIV/ AIDS ✓ Ask the child: "What makes you feel you are a bad boy?" "You seem very upset as you often fall sick." ✓ Provide the child with information on OIs and side-effects of ART. ✓ Counsel the caregiver on home management.
<p>Guilt and distress associated with the disease</p> <p>Feeling agitated or angry</p> <p>Showing behavioural, cognitive and social difficulties. E.g. bedwetting, constant crying, etc.</p> <p>Verbal expressions such as "I have made my family unhappy."</p>	<ul style="list-style-type: none"> ✓ A child may blame himself/herself, i.e., feel guilty. ✓ Negative emotions expressed by the caregiver may be seen as a source of guilt for the child 	<ul style="list-style-type: none"> ✓ Encourage the caregiver to motivate the child and provide positive reinforcement for good actions. ✓ Ask the child: "What makes you unhappy?"

<p>The child's perception of health affects self-esteem, confidence or self-image.</p> <p>E.g. Refuses to go out and play with other children</p>	<ul style="list-style-type: none"> ✓ The onset of OIs ✓ The association of the child with his sick or deceased caregivers ✓ The difference between the child and healthy children, which often make them feel inferior 	<ul style="list-style-type: none"> ✓ Provide the child with information on OIs and side-effects of ART. ✓ Encourage the child to participate in CLHIV groups. ✓ Develop the social skills of the child. ✓ Guide the child to participate in a role-play where the counsellor can take on the role of the child and the child of others in his/her environment.
<p>Anticipated grief and anxiety</p> <p>E.g. Feeling a loss of security, fear of changes in family or caregiver structure, crying without reason, searching for people and ensuring they always remain around, etc.</p> <p>✓ <i>"I will also die soon."</i></p>	<ul style="list-style-type: none"> ✓ The perception of death evolves with age. The fear of his/her own death and that of the caregivers haunts the child. This fear can be agonizing at times, particularly in cases where children have already lost one parent. 	<ul style="list-style-type: none"> ✓ Encourage the child to express rather than suppress feelings. ✓ Assist the child in strengthening support systems and developing new friendships/relationships ✓ Ask the child: <i>"You seem worried about your physical well-being."</i>

<p>Inability or unwillingness to cope and adhere to treatment</p> <p>E.g. repeatedly reports that he has not taken his medicines: "I forgot to take my medicines."</p>	<ul style="list-style-type: none"> ✓ Coping with the disease and the additional burden of the treatment schedule ✓ Social, cultural, economic and personal beliefs of the caregiver and child regarding treatment 	<ul style="list-style-type: none"> ✓ Involve the child and caregiver in CLHIV and peer group activities. ✓ Use interactive communication strategies to identify barriers to treatment and assist the child to overcome these barriers. ✓ Help the child identify and use reminder systems. ✓ <i>"Some children do forget to take their medication. Can you describe why this may happen?"</i>
---	---	---

Summing Up

Working with children requires a counsellor to develop new skills and strategies for counselling. She/ he has to be willing to move away from a verbal style of counselling. But the reward inherent in working with child clients makes this effort worthwhile.

Frequently Asked Questions



How many Children Living with HIV does India have?

It is estimated that India has about 115,000 CLHIVs. As of December 2011, NACO's ART CMIS reported that 22,585 children under 15 years were provided with ART by the national programme at 295 ART centres and 550 LACs.

How is an ICTC counsellor likely to encounter a child client?

There are two ways for this to happen: You might see a child who has been infected through the maternal route – sometimes as a newborn infant (requiring Exposed Baby Care and Early Infant Diagnosis) and sometimes as an older child who is diagnosed later. The second way in which you might encounter a child client is a slightly older child who has not been infected through the maternal route. For instance, a child may be affected through sexual transmission. One common source of child clients is the referral process from the TB programme.

When can I find time to do activities like story-telling at the ICTC?

Afternoons with a lighter load may be an appropriate time. You may also ask the caregiver to come later in the morning so that child clients do not get bored with waiting in OPD. Alternatively, you can set the child a task to do, seat them in a quiet spot in your centre, meet other patients and then speak to the child about the task after half an hour.

Why is there a need to tell children their HIV status?

Children who are aware of their HIV status are better adjusted and have higher self-esteem than children who are not informed that they are HIV-positive. When children are aware of their status, they are also more likely to be adherent to treatment.

Frequently Asked Questions



Why cannot SACS make a CD with the puppets for me to use at the ICTC?

The expressive methods described in this module are meant to be used in a manner tailored to suit individual children. Children may have a short attention span and may not pay attention to a film. Further, the personal manner of the counsellor which demonstrates attention for the child client is an important aspect of rapport-building with child clients. This cannot be duplicated through an IEC film.



References

- Bhosale, V., et al. (2010). Disclosure of HIV status of children: The parents perspective. Poster session presented at the *National Conference on Paediatric HIV*. New Delhi, India.
- Bawden, J. (1991). *Puppet box*. Britain: Knight Books.
- National AIDS Control Organization (2006). *HIV counselling training modules for VCT, PPTCT and ART counsellors*. New Delhi, India: Author
- National AIDS Control Organization (2007). *Paediatric ART counselling training modules*. New Delhi, India: Author
- National AIDS Control Organization (2010). *Draft guidelines for exposed baby care*. New Delhi, India: Author.
- Sarna A., et al. (2007). *Exploring the barriers to accessing care and treatment for HIV-infected children: A diagnostic study*. New Delhi, India: Population Council

Counselling Adolescents at the ICTC

At the end of this unit, participants will be able to

- List the characteristics of adolescence
- Analyse the ethical issues related to HIV testing of adolescents
- Demonstrate skills in counselling adolescents

Adolescents constitute about 22% of the population in India. As an ICTC counsellor, you may have interacted with some of them as your clients.

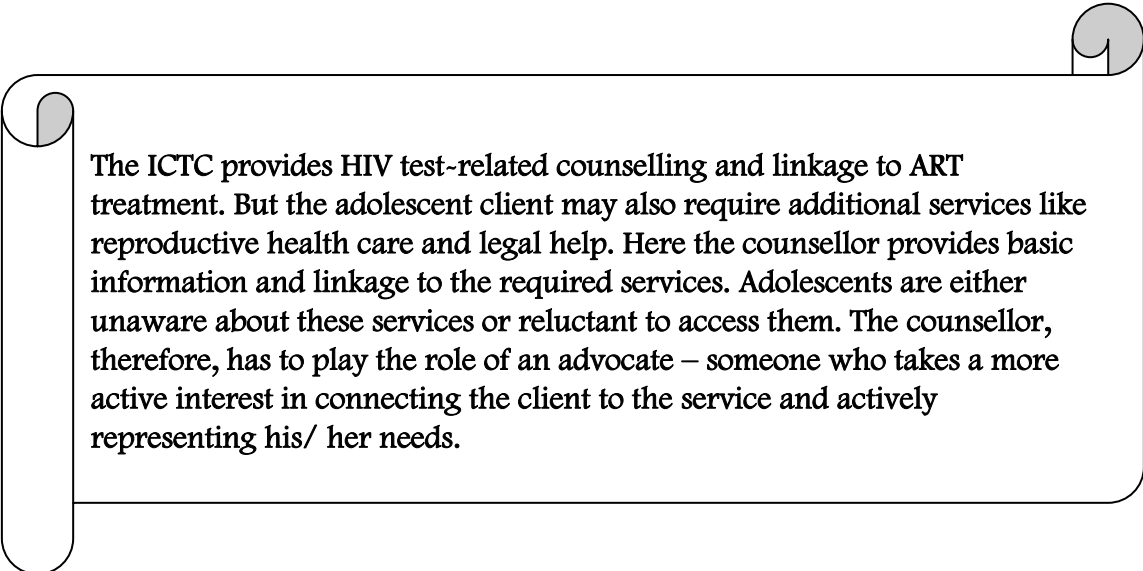
- Adolescents may be brought to ICTCs by their parents, guardians and teachers, or they may visit on their own.
- They may be referred by health care providers after presenting with conditions suggestive of HIV infection, such as fever, weight loss or TB.
- Sometimes counsellors receive adolescents who visit the ICTC after attending adolescent health education classes in schools.
- Occasionally, there are adolescents who are referred to the ICTC after being identified as victims of sexual abuse.

In all these cases, counsellors are approached either because the adolescent is in a difficult situation, or the parent/guardian finds it difficult to address some critical situation in the adolescent's life. Some issues may be directly related with HIV, while others are not. In all cases, adolescents as well as their parents/guardians expect proper guidance and help from the counsellor. You can help by

- Providing accurate information regarding their situation
- Supporting them to make critical decisions
- Linking with required services
- Extending psychosocial support

The ICTC provides HIV test-related counselling and linkage to ART treatment. But the adolescent client may also require additional services like reproductive health care and legal help. In such cases the counsellor should provide basic information and linkage to the required services. Adolescents are either unaware about these services or reluctant to access them. The counsellor, therefore, has to play the role of an advocate – someone who takes a more active interest in connecting the client to the service and actively representing his/ her needs.

Often, counsellors report difficulties in working with adolescents: Even though they look like children, they may ask questions or have doubts which counsellors generally expect from adults. Conversely, there may be adolescents who have a more mature, adult appearance but still ask questions that reflect their naivete and lack of worldly experience.



The ICTC provides HIV test-related counselling and linkage to ART treatment. But the adolescent client may also require additional services like reproductive health care and legal help. Here the counsellor provides basic information and linkage to the required services. Adolescents are either unaware about these services or reluctant to access them. The counsellor, therefore, has to play the role of an advocate – someone who takes a more active interest in connecting the client to the service and actively representing his/ her needs.

In order to effectively help adolescent clients at the ICTC, a counsellor should have

- ✓ A sound understanding about adolescent development and related issues
- ✓ An understanding about their vulnerability to HIV and their sexual and reproductive health concerns
- ✓ An ability to relate with the adolescent
- ✓ Unconditional positive regard and congruence
- ✓ Skill in tailoring counselling to meet the needs of adolescent clients and their families

This module covers these issues.

Basic Information on Adolescence

Adolescence is the period of human development between childhood and adulthood. It is a period of exceptionally rapid growth and development. It is during this time that the individual's personality really takes shape.

In infancy, developmental milestones occur at a similar time for most infants. However, among adolescents, there is much greater individual variation in the achievement of developmental milestones as well as the rate of growth and development. These changes are influenced by the individual's age, health and nutrition status, by family and social situations, cultural beliefs.

This module operationally focuses on male and females between 10 and 19 years.

Physical changes during adolescence

BOYS

- ✓ Fast bodily growth (height, weight, width)
- ✓ Growth of sweat and oil-producing glands of the skin
- ✓ Growth of hair in the pubic region, armpit, chest and face
- ✓ Development of muscles
- ✓ Change in tone/voice (Masculine voice).
- ✓ Enlargement of penis
- ✓ Production of sperms (within one year of the onset of adolescence)

GIRLS

- ✓ Fast bodily growth (height, weight, width)
- ✓ Growth of sweat and oil-producing glands of the skin
- ✓ Growth of hair in armpit and pubic regions
- ✓ Development of breasts
- ✓ Widening of hips
- ✓ First menstruation (10-16 years)

Sexual development during adolescence

The secondary sexual characteristics such as breasts and body hair appear during adolescence. By the end of adolescence, the individual is physically mature and the reproductive organs and systems are fully functional. In addition, the individual starts experiencing sexual desire and sexual attraction. Some adolescents initiate sexual behaviours like masturbation during adolescence.

Girls and boys display different rates of change. The growth rate for a girl is faster at the age of 10-11 years and she attains 98% of her adult height by the age of 16. Menstruation usually begins between 10 and 16 years of age. Some girls experience mild emotional upset during this period.

Adolescent changes in boys begin approximately two years later than in girls. Their sexual growth is characterized by the growth of penis and testes. Boys may experience an involuntary erection during sleep (that is, a physiological reaction that is not within their conscious control). Another prominent change is the change in voice due to enlargement of the voice box.

Cognitive development during adolescence

Brain development continues in the prefrontal cortex - the area of the brain which contributes to development of social and problem-solving skills, regulating emotions and moderating moods. Hence, the capacity for abstract thinking increases gradually. However, it is important to note that, there are individual variations and making choices vis-à-vis HIV is still a heavy decision.

Emotional and social changes during adolescence

Adolescence is characterized by the following emotional and social changes

- ✓ Preoccupation with body image
- ✓ Desire to establish own identity
- ✓ Desire for freedom and distancing from parents
- ✓ Fantasy / daydreaming
- ✓ Rapid mood changes
- ✓ Attention-seeking behaviour
- ✓ Attraction towards the opposite sex
- ✓ Restlessness
- ✓ Self-exploration and evaluation

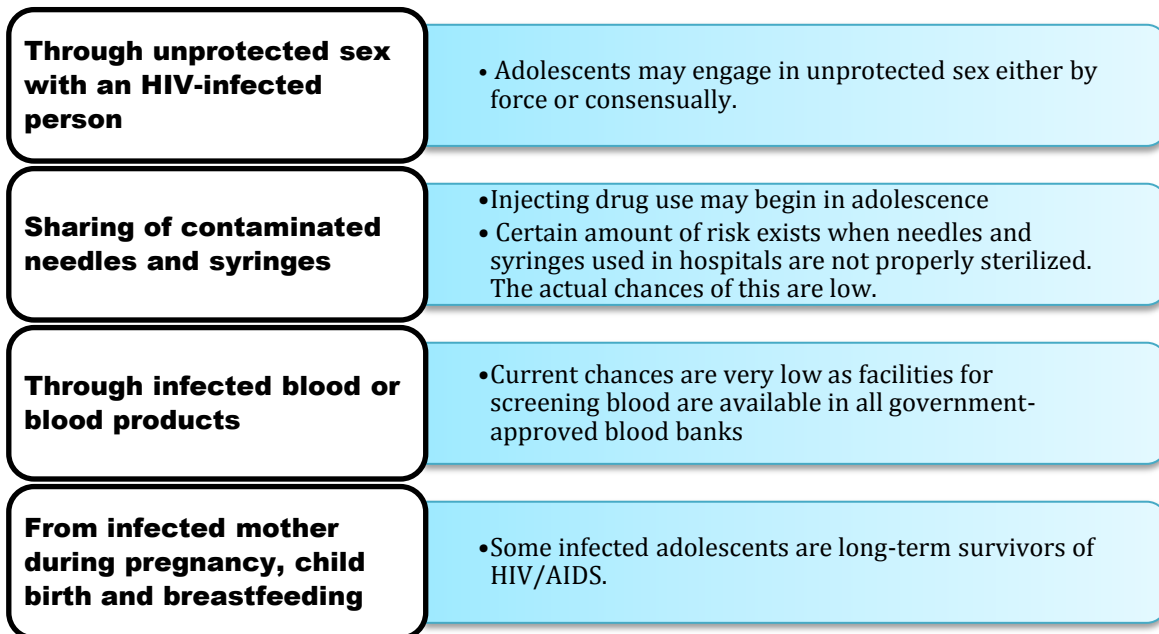
- ✓ Search for affiliation
- ✓ Influence of peer group on behaviour
- ✓ Formation of new relationships

As a counsellor, you should note that all these changes have implications for health also. For instance,

- The normal physical signs of growing-up such as growth of pubic hair, enlargement of penis, breast development and menstruation may cause undue anxiety and tension in adolescents.
- The desire to have sex may lead to experiments and unsafe sexual encounters risking pregnancy or STIs like HIV.

Adolescents and HIV

HIV spreads from one person to another through exchange of, or contact with, infective body fluids through four routes. Adolescents are at risk of transmission through all these routes:



As indicated above, the chances of survival of children infected at birth through maternal infection do exist. However, ICTC counsellors also face the possibility of encountering children who acquire the virus through their engagement in high-risk behaviours. We mention this here because sometimes ICTC counsellors appear to think that an adolescent has only one way of being infected – through the parental route. This could be due to failure to acknowledge adolescent sexual activity.)

Adolescents and HIV risk

Early sexual engagement

In India, adolescent sexual relations occur within and outside marriage. The sexual relations of many sexually active adolescent girls occur within the context of marriage. But there is also a measureable degree of premarital sex among adolescent boys and girls. This may not always be consensual (based on their willingness). Evidence indicates that a number of adolescents experience coercive sex, that is, they are forced to enter into sex. This is true for both adolescent girls and boys - even in the context of the marital relationship. Studies suggest that sexual behaviour falls along a continuum from non-penetrative activities (such as holding hands, kissing and touching) to sexual intercourse. You may have received adolescent clients who are upset or worried about such activities in their life. This presents you an opportunity to counsel the adolescents on safe sex - in particular asking them to delay their sexual initiation where possible, or to use safer sex options where not possible.

Sex with multiple and/or non-regular partners

The nature of sexual partnerships differs significantly between boys and girls. The majority of sexually experienced adolescent girls in India report having premarital sex with a steady partner with marriage in mind. However, boys have multiple partners which include casual partners and male or female sex workers. Some studies report that between 20 and 40 percent of adolescent boys engage in sex with casual partners.

Absence or lack of condom use

The vast majority of sexual encounters among adolescents does not involve condom use. This is true for sexual relations within and outside marriage. NFHS-2 reports that, only 8% of married adolescent girls reported using any method of contraception. Further, those who use condoms may not do so regularly and consistently. Leading reasons for non-use of condoms include unplanned or

spontaneous sex, lack of awareness of the condom as a means of protection, lack of negotiation skills in how to buy a condom and the perception that condom use reduces sexual pleasure.

Presence of STIs and lack of care-seeking behaviour

RTIs and STIs are identified as factors which increase the possibility of HIV infection. According to NACO's behavioural surveillance survey (2006) between 3 and 5 percent of youth report symptoms such as discharge, ulcers or sores in the genital areas. Lack of awareness about the symptoms and treatment as well as reluctance to seek care prevent adolescents from consulting a doctor for these symptoms. Also, the asymptomatic nature of STIs among females makes adolescent girls unlikely to seek care.

Substance abuse

Substance abuse reduces the capacity to make decisions on safer sexual relations and often leads to lack of condom use. Drug use is often initiated during adolescence.



Reducing Sexual Risk

One quick memory aid for counsellors for risk reduction suggestions for adolescents' sexual risk behaviour taking is the ABC approach.

➤ **A stands for Abstinence.**

For young people who have not yet started sexual behaviour, encourage them to delay sexual initiation.

➤ **B is for Be faithful.**

For young people who have begun having sex, encourage them to reduce their sexual partners, preferably to one.

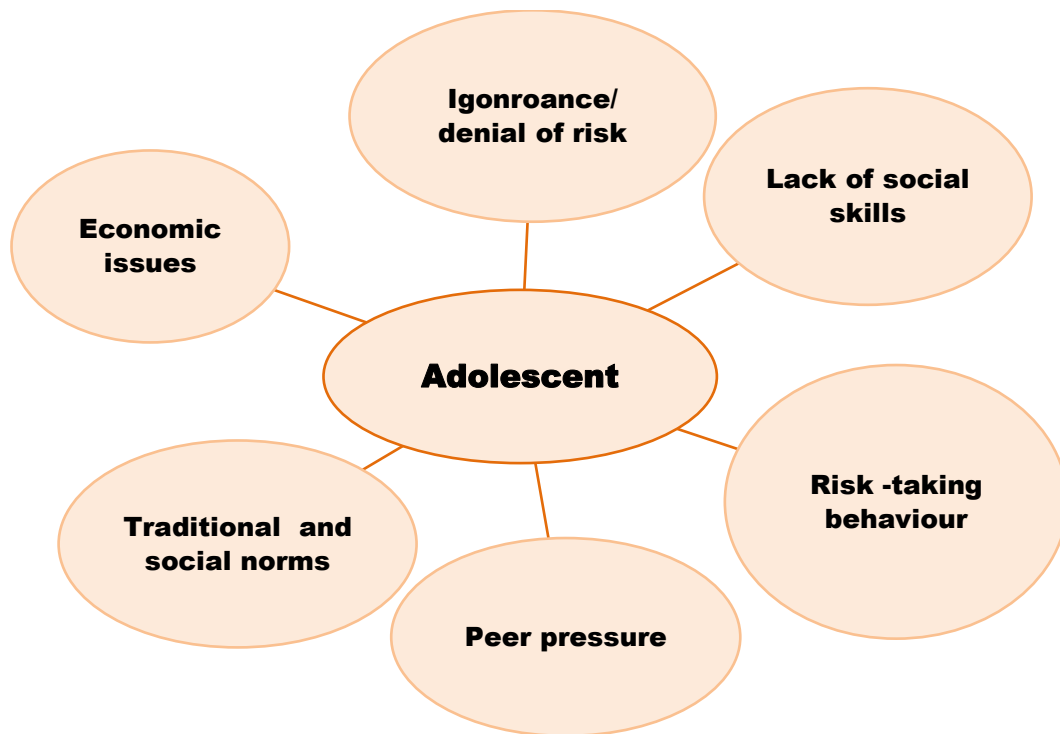
➤ **C stands for Condom.**

Young people who are sexually active, especially those who have more than one partner or who are not sure if their partner is faithful to them, should be encouraged to use a condom.



Adolescents and vulnerability to HIV

No single factor makes adolescents susceptible to HIV. Rather there are many factors that mutually influence each other and cause adolescents to become vulnerable to HIV.

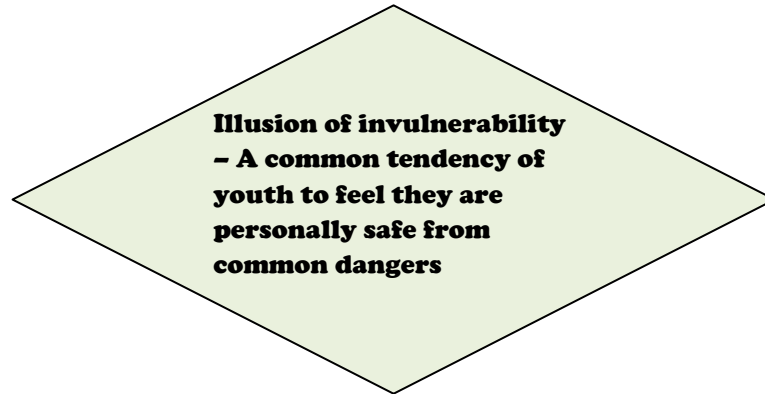


Lack of awareness and denial of risk

One major factor which makes adolescents vulnerable to HIV is their lack of awareness about HIV and the risks associated with different behaviours. As reported by the NACO Behavioural Surveillance Survey (2006), only one-third among the age group of 15-19 years demonstrated comprehensive knowledge about HIV. Others could not state even two modes of transmission and ways of prevention. Rather their thinking was characterized by misconceptions. Neither parents nor teachers provide them adequate information on HIV and how to protect themselves from the infection. The implication is that the adolescent client is in sore need of information that is accurate.

Adolescents tend to ignore their risk of HIV infection even when they are informed. This ignorance is very much associated with their “illusion of invulnerability” – this is a common tendency of youth to

feel they are personally safe from common dangers. Also, the long incubation period of HIV leads to low understanding about the risks and consequences of HIV infection among adolescents as they do not see people in their age group suffering from HIV or AIDS. This makes them deny the risk of HIV infection to themselves.



Risk-taking behaviour

Due to their desire for independence, adolescents resort to activities, which they view as signs of adulthood such as smoking and consuming alcohol. They are also influenced by the images of adulthood portrayed in the media. Sexual activity is one such experimentation.

Lack of social skills

During adolescence, individuals move from the close and secure atmosphere of family supervision to more open and wide social networks. They lack social experience and this limits their ability to identify the potential risks and consequences of early sexual engagement, sex with non-regular partners, consuming alcohol and injecting drugs.

Peer pressure

Adolescents strongly identify with their peer group - friends in the same age group. Often peer opinion is valued more than that of the family. Peers influence the individual's behaviours, including risky practices. For instance, adolescent boys may engage in sex with a sex worker or girlfriend to prove their masculinity among their peers.

Economic issues

Poverty, while not a factor specific to adolescence, is another factor which increases vulnerability to HIV. Due to poverty some adolescents stop schooling and start working at early ages. Lack of proper education has long-term effects on the adolescent's future career options. Limited career options lead to migration and life on the streets, which increase the likelihood of high-risk activities such as injecting drug use and early sexual engagement. Poverty in the household may also push girls into sexual abuse or sex trade through trafficking. This increases their vulnerability to HIV.

Traditional and social norms

Social and traditional norms increase the vulnerability of adolescents in two ways

- By limiting their options for receiving adequate information regarding HIV and risk: For example, taboos related to sex prevent adolescents from seeking information regarding safe sex or from being able to purchase a condom.
- By influencing the different high-risk behaviours: For instance, the traditional norm about virginity till marriage makes some sexually active adolescent girls opt for anal sex which is the riskiest sexual activity.

➤ **Please note that adolescent girls are more vulnerable than adolescent boys**

Compared to boys, adolescent girls have additional factors which place them at greater risk

- Coercion into sexual relationships which limits the girl from protecting herself and negotiating for safe sex.
- Sexual abuse and trafficking.
- Traditional norms which limit the girls from accessing information or negotiating for safe sex.
- Biological vulnerability: Women are biologically more vulnerable to HIV due to the large surface area of the vagina. Early sexual involvement adds to this vulnerability. During adolescence, female sexual organs, especially the vagina, are developing and there is a greater possibility for rupture in the vaginal lining and easier penetration of HIV during intercourse.



Consequences of high-risk behaviours

The high-risk behaviours of adolescents lead to different physical, emotional and social consequences for the adolescent.

- Early pregnancy and parenthood (within and outside marriage)
- Unsafe abortions and related complications
- STIs, including HIV
- Infections passed on through unsafe needles like Hepatitis B
- Complications related to drug abuse like addiction and issues of overdose.

You can receive more information about adolescence from

- WHO 's Adolescent Job Aid
- NACO's Adolescent Health Education manual
- Training module on Orientation Programme for ANM/LHVs to provide adolescent-friendly reproductive and sexual health services

The Adolescent Health Clinic functioning at Community Health Centers is one facility to refer adolescent clients for sexual and reproductive health care. Some of these clinics function one day per week.

Counselling adolescents

The focus of counselling is on the primary client, in this case, the adolescent. To tailor counselling for the primary client, there are some basic issues to consider

- ✓ Whether to involve the adolescent in the counselling
- ✓ How to counsel them
- ✓ How to communicate with them

Involving adolescents in counselling

Counselling should engage the adolescent directly and actively. This requires you to use strategies which are acceptable to them. Even though you may recognize that the guardian is important as the final authority, the adolescent is still the primary client and focus should be on his/her needs. As children enter adolescence, their parents are still largely responsible for them, and the main communication is often between the health worker and the parent/ guardian. But the growing adolescent is also responsible for his/her health.

In the Indian context, the parent/guardian tends to remain involved with key decisions in the adolescent's life even after he/she attains legal maturity at the age of 18.

Therefore, the challenge for the counsellor is to maintain an effective clinical relationship that addresses this delicate balance. It is important to meet adolescents alone, as well as with their parents/guardian.

It has been observed that some counsellors are reluctant to talk to the adolescent and completely focus on the parent/guardian. It is strongly recommended that adolescents should be involved in the counselling process as much as possible. However, permission from the parent/ guardian is essential before discussing issues with the adolescent.

How to Counsel Adolescents

It is essential to build a strong rapport with the adolescent client. Here are some tips:

Understand their interests

- Adolescents are interested in building new relations, but at the same time they look for credibility. You must be open and sincere to them. Also you should communicate your trustworthiness *“I would like to talk to you about some personal matters in your life. This is to help you solve some issues you are facing. You can be truthful with me. I would like to know what you feel about the things we discuss. I am not going to blame or scold you.”*
- The peer group is very important for them. Therefore, include questions about their friends. This will make them feel interested in talking with you as well as help you to gauge how influential their friends are in their lives.
- Acknowledge their identity, as they do not want to be treated as children. However, you should be careful not to assume they are adults even if they appear very mature - they are still growing.

Address their concerns

- One common concern is “Nobody understands me.” Another common concern is about their physical appearance. The counsellor should explicitly acknowledge their concerns: *“It is common for young people to feel like nobody understands them. Is there something in your life which you feel nobody understands?”*

Constructively respond to their feelings

Feelings may act as barriers to communication. The adolescent may feel

- **Shy** about discussing personal matters.

Normalise the feeling: *"It is common/ normal to feel this way. I understand that it is not easy to talk to someone you just met."*

- **Helpless** in describing what he/she is feeling.

Normalise this feeling.

- **Anxious** that he/she is in a serious condition with bad consequences.

Reassure them that the test process will give information on whether they are infected, and that there is treatment to keep the condition under control.

- **Scared** by the hospital environment.

Normalise this feeling.

- **Defensive** about being the subject of discussion or because he/she is referred against his/her will.

Ask them why they think their parent/ guardian referred them to you, and if there is possibly a helpful motive behind the action of bringing them to the ICTC.

- **Resistant** to receiving help.

This is something that must be overcome in a gentle manner. The counsellor may not always succeed at first visit.

- **Embarrassed** that he/she is seeking ICTC services.

Acknowledge that embarrassment is a common reaction but also point out that they are here to learn something important about their health. Besides explaining that the visit has a valid purpose, also inform them about the fact that their visit to the ICTC will not be known to anyone other than their guardian.

- **Worried** that someone will see and inform parents or teachers.

Normalise feelings of shyness, anxiety and embarrassment. Explain that it is common or normal to feel this way.

Differences in Counselling Adolescents

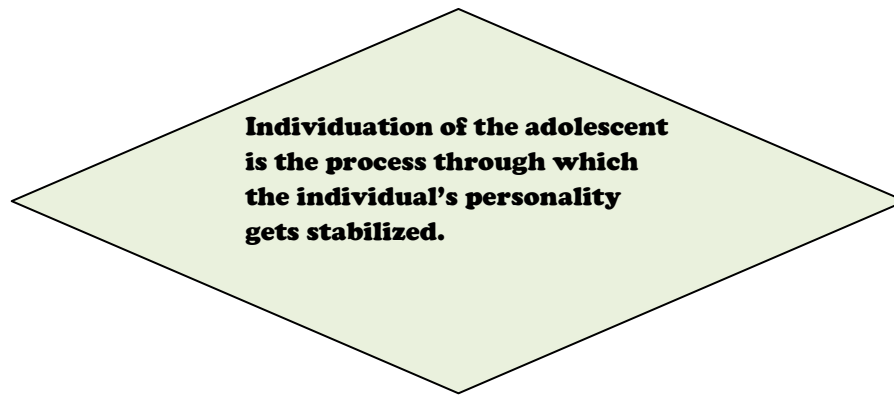
Your counselling must accommodate the following differences between adolescents and children, and between adolescents and adults.

Adolescents and children

<i>Children</i>	<i>Adolescents</i>	<i>Implications</i>
Dependent on parent/guardian	Less dependent on parent/guardian or family Social interactions with non-family members are significant	Adolescents may not want their family to be involved in counselling, especially when sensitive matters are discussed. But the family may insist on being part of counselling
Cognitive skills are limited (i.e., the mental skills used in acquiring knowledge such as reasoning, concentration, and perception)	With more developed cognitive skills, adolescents are able to understand complex matters and apply the knowledge at advanced levels.	Communication strategies can be tailored accordingly. For instance, you can share real-life stories (without putting real names) rather than stories with imaginary characters.
Identifies self in relation to parents/family (X's son/daughter)	More interested in building identity as an individual	Counsellor needs to respect the individual as a growing adult

Adolescents and adults

<i>Adolescents</i>	<i>Adults</i>	<i>Implications</i>
Moving to cognitive independence, but in a dilemma whether they have the personal ability to choose and be responsible for their actions	Relatively free to make decisions and choices without excessive influence from family and others	The decision opted by the adolescent may not always be right and beneficial for him/her. The counsellor must help the adolescent understand the risks and benefits of each solution. He/she may also need to facilitate adolescent's consultation with parents/family on critical matters and actions.
Look for Personal identity Individuation New relationships	Look for Stability Continuity Raising family	The counsellor must respect the identity of the adolescent and also help them to analyze their desires and needs.



How to Communicate with Adolescents

Communicating with adolescents focuses on two things:

Style of communication

- Ensure that you are not communicating in a way that reminds the client about a dominating parent.
- Ask direct questions such as *“Do you smoke?”* rather than indirect ones like *“Your father says that he has seen cigarettes in your pocket and has doubts that you smoke. Is he right?”*
- Avoid judgmental and evaluative statements such as *“Your friends are bad because they smoke cigarettes. You have to avoid them.”* Adolescents do not like having values imposed on them. Rather you can say, *“Your friends smoke cigarettes. You have heard that this is not good for health. How do you feel about friendship with them?”*

Content of communication

- Provide information using simple language which the adolescent understands. Technical words can be replaced with explanations such as mentioning CD4 cells as the cells in the body which fight against illnesses.
- Provide information in amounts that the adolescent can manage. You can check by asking, *“I am giving you a lot of information. Are you able to take all this in right now? Or do you require a break?”*
- Involve adolescents in discussions rather than provide them with suggestions. This will make them feel important and keen to participate in counselling.

Another major challenge is communicating with accompanying adults in a manner that is respectful both to the rights of the adolescent and to their parent. Do not exclude parents/guardians. Instead, make it clear that the adolescent is the centre of the consultation. Do this routinely as a way of respecting the adolescent’s rights and maintaining their trust.

HIV Counselling and Adolescents

Involvement of Parents

Counselling for HIV testing for adolescents follows the same process as for adults. You need to include the different steps in each session as described in the NACO HIV counselling training modules (NACO, 2006). However, as the client is an adolescent, one specific issue you should keep in mind is to maintain a balance between the rights of the child and that of parents/guardians. Indian law recognizes the rights of the parent to decide for their child – unless the parent’s decisions endanger the child. The adolescent under 18 is considered a child.

Under such circumstances, how can a counsellor honour the spirit of involving the adolescent as a person capable of stating his/ her own needs and rights? The counsellor must respect the rights and needs of both parents and adolescents. She/he may speak privately with adolescents and explain to them that it is important to be honest and truthful for proper assistance related to their health. However, she/he must also make clear to the adolescent client the limits of confidentiality -that is if the counsellor learns during the session that the adolescent’s safety is at risk through suicide or abuse of any sort, she/ he is duty-bound to inform the guardian.

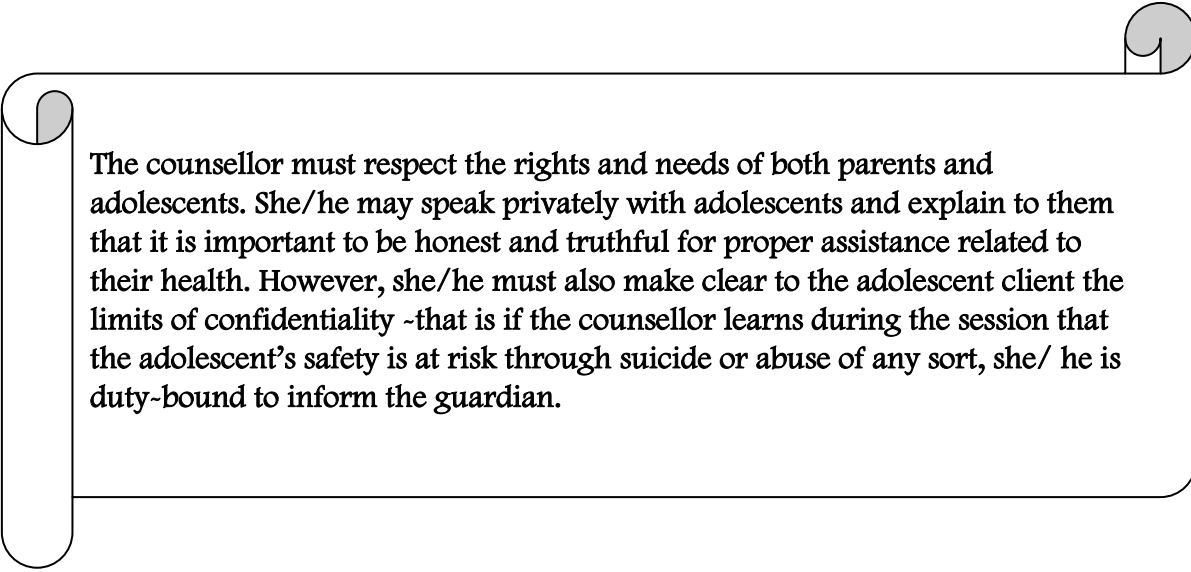
The counsellor could say in one-on-one interactions with adolescent clients, *“You must recognize that part of being a grown-up person is to take responsibility for your health and your life. For this reason, I request you to be as honest as possible. As a counsellor, I must keep the things you tell me confidential – that is I cannot tell other people unless there is a need. Young clients of your age often worry that what they tell a doctor or a counsellor or a nurse will be conveyed to their father/ mother, and this will get them into trouble. It is true that there are some things that I must inform your parents, for instance, if something in your life is a danger to you, to your health, to your safety. I must do this because as the adults responsible for you, we want to keep you safe and healthy. In case there are such issues, I will inform you about them and the two of us can discuss how to break the news. Understand that you are not alone any more. I will try to help you.”*

In the previous statement the counsellor has done many things – She/ he has invited the adolescent to share personal concerns in an honest way. She/he has indicated the willingness to

maintain confidentiality. But she/he has also clarified the limits of confidentiality. In case she/he needs to break confidentiality, she/he has indicated that she/he will be present and support the adolescent – that is she/he will take the role of an advocate.

In case the counsellor does have to report some issue to the parent or guardian, the adolescent should be first prepared for this disclosure and the actual disclosure should be handled as soon as possible with the adolescent in the room. The recommendation for early disclosure is to minimize the time spent by adolescents worrying. It is also important because the reasons for breaking confidentiality are often life-saving or life-altering.

The counsellor while discussing how to disclose to the parent can encourage the adolescent to understand that anger from parents often covers up worry and anxiety. Further, when speaking with the parent or guardian, the counsellor has to play the role of advocate.



The counsellor must respect the rights and needs of both parents and adolescents. She/he may speak privately with adolescents and explain to them that it is important to be honest and truthful for proper assistance related to their health. However, she/he must also make clear to the adolescent client the limits of confidentiality -that is if the counsellor learns during the session that the adolescent's safety is at risk through suicide or abuse of any sort, she/ he is duty-bound to inform the guardian.

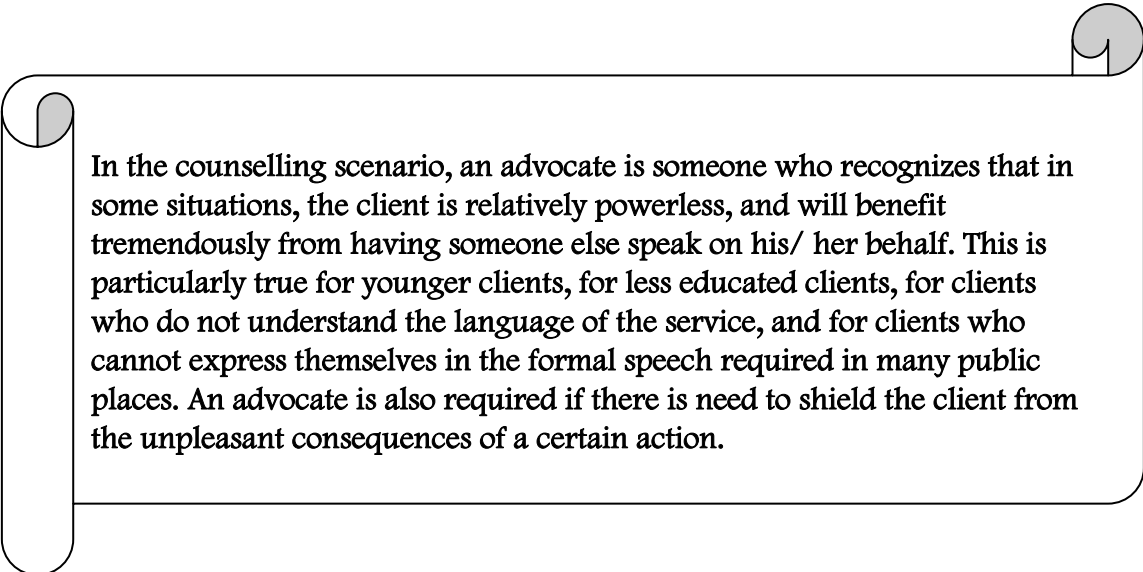
Who is an advocate?

In the counselling scenario, behaving as an advocate has very little to do with legal advice. An advocate here is someone who recognizes that in some situations, the client is relatively powerless, and will benefit tremendously from having someone else speak on his/ her behalf, voice his/ her needs. This is particularly true for younger clients, for less educated clients, for clients who do not understand the language of the service, and for clients who cannot express themselves in the formal speech required in many public places. An advocate is also required if there is need to shield the client from the unpleasant consequences of a certain action. In this case, the counsellor may have to act as an advocate for the adolescent to prevent them from parental harshness and over-reaction.

As an advocate, the counsellor will make sure the client feels supported. But the counsellor will also try to facilitate the client to take steps forward to speak for themselves in other, similar situations.

A good example of being an advocate is the lovely scene in that iconic film Lage Raho Munnabhai: Munna in his first attempt as a radio counsellor advises a young man to confess to his father that he has squandered his life savings. When the young man does so, Munna halts the father's instinctive disappointment and anger by pointing out the courage of the young man and redirects the focus to solutions.

Of course, the situation does not end with the disclosure. The adolescent, the guardian and the whole family will require support even after the session.



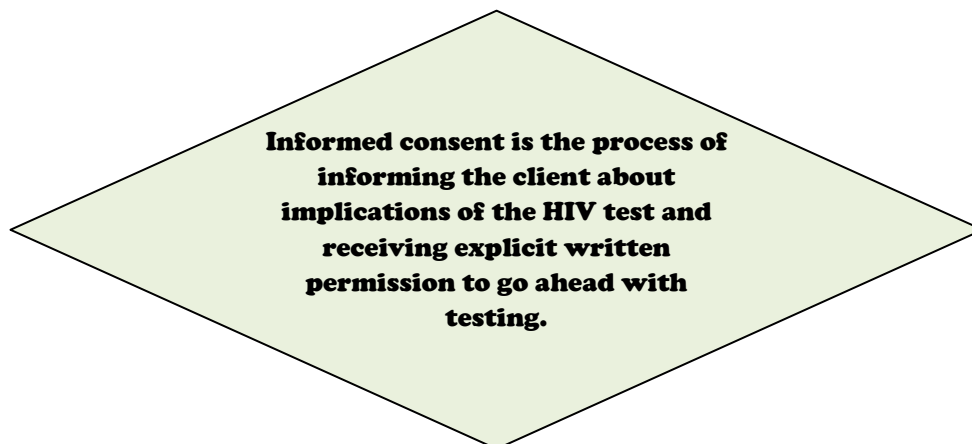
In the counselling scenario, an advocate is someone who recognizes that in some situations, the client is relatively powerless, and will benefit tremendously from having someone else speak on his/ her behalf. This is particularly true for younger clients, for less educated clients, for clients who do not understand the language of the service, and for clients who cannot express themselves in the formal speech required in many public places. An advocate is also required if there is need to shield the client from the unpleasant consequences of a certain action.

Eliciting Informed Consent for HIV Testing

Counselling the adolescent is a delicate and difficult balance between the needs of the adolescent and the responsibilities of the parent.

You are familiar with the concept of Informed consent. It refers to the process of informing the client about the implications of having the HIV test (or any medical procedure); assessing existing knowledge, attitudes and beliefs about HIV/AIDS (or any other relevant health condition); exploring the advantages and risks involved; and receiving explicit written permission to go ahead with testing (or the relevant procedure). In case of provider-referred clients, informed consent is implied in nature. The client is clearly informed about the right to opt out of HIV testing. If he/ she does not opt-out, then the counsellor can consider that he/she has agreed to get tested.

The difference with adolescent clients is that, under Indian law, parents/ guardians must give informed consent. If there is no parent/ guardian, then the district magistrate is empowered to give informed consent. In addition to this the counsellor must also get the adolescent's permission for the procedure. The adolescent who fails to give permission cannot *legally* refuse the test. But this is a situation which indicates the need for sensitive management by the counsellor. In case there is a difference of opinion between the parent/guardian and the adolescent, the ICTC may consider delaying the test and doing more counselling to probe the reasons for the difference of opinions.



Asking consent from parent/guardian

- You should ask the parent or guardian for consent: *“I have explained about this test for your son/daughter. Are you okay with testing him/her for HIV?”*

Asking permission from the adolescent

- You should also ask the permission from the adolescent using age-appropriate questions:
 - *“Your parents think, and I agree, that it would be better for your health, if we do a blood (an HIV) test for you. For the same, a small amount of blood would be taken using a needle. Is it okay?”*
 - *“The doctor suspects that you have an infection in your body, which can ruin your health. If the infection is present, you may need to take medicines to make your body healthy. A blood test will help to know that whether the infection is present or not. Your parent/guardian has said that they wish you to do it. Do you agree with it?”*
 - For adolescents who understand about HIV, more details should be given.
- If adolescents do not agree to have their blood drawn, then you need to counsel them more keeping the guardian well-informed. As mentioned earlier, consider delaying the testing process to a subsequent session.

Ensuring Privacy and Confidentiality

Adolescents are generally reluctant to talk to adults about personal matters. Sometimes they are shy and embarrassed. Some do not express their secrets for several reasons including the fear of being blamed or disbelieved. One such secret is early sexual engagement, especially consensual sex. Here they may also be trying to protect the person involved. Even in case of nonconsensual sex, young people keep silent because they are worried about the impact on their family. They may believe the threats of the person who has abused them.

Make the adolescent comfortable by

- Ensuring and conveying to the adolescent that the room offers audio-visual privacy (*"You can talk to me freely. People outside this room will not see you or hear what you say"*).
- Ensuring that other staff members do not intervene during the counselling session (To adolescent: *"Nobody will come here while we talk"*; to others who interrupt: *"I am with a client. We can talk later."* or *"Can you please wait till I have finished talking to my client?"*)
- Making parents/guardian wait outside the room while you engage the privately for a brief while.

You should remember that parents have a right to know what is happening in their child's life and have the responsibility to take care of him/her. This is specifically required in case of HIV positive test results. You should prepare the adolescent to share the information with parents. (*"Your parents do care for you. I agree that they may react harshly to this news. However, I think they would care about your future and support you."*). Where required, you may offer help to the adolescent to talk with the parent/guardian in the role of an advocate.

Please note that, there would be some cases, where disclosure to parents may not be appropriate for the well-being of the adolescent like drunken parents or parents abusing children. Here the parent is the one who is presenting the risk to the adolescent. Here your advocacy role is slightly different - that is to mediate between the parent and adolescent, and advocate for the rights and well-being of the adolescent client. You may even ask the adolescent if there is another adult in their family or social circle who they do trust and who can speak up for them, such as a trusted aunt.

Exploring the reason for the ICTC visit

Adolescents may visit the ICTC on their own or may be brought by parents, guardians or teachers. Their need for HIV testing may not always be explicit, as often they may come for other reasons like counselling or STI services. As the counsellor, you must provide attention to their felt needs as well as explore the risk for HIV exposure.

The specific reasons for the HIV test can be

- One/both parents have HIV infection
- The adolescent
 - shows symptoms suggestive of AIDS-related illness
 - is pregnant
 - has been sexually abused and penetrative sex has occurred (anally, vaginally and orally)
 - had sexual exposure unrelated to sexual abuse
 - shares infected syringes and needles
 - is at risk due to exposure to unsafe blood (through untested blood transfusion) or unsterilized needles.

The above reasons may not be explicitly stated. You may need to explore them through sensitive questions. Try to ensure that the adolescent is also allowed to participate in the session.

- ✓ *“I appreciate that you brought your son/daughter here. May I know what brought you to the ICTC?”*
- ✓ *“May I know what help you require from me?”*
- ✓ *“Is your son/daughter suffering from any health issues?”*
- ✓ *What has made you visit the centre today without your parents?”*

Risk Assessment

You must do a risk assessment of the adolescent – directly addressing questions to the adolescent. Frame questions such that they are clear to the young client. You may do a general assessment with the adolescent in the pre-test counselling, which can be followed up with a proper risk assessment during the post-test counselling. The HEADS Assessment will be of help in doing the general assessment with the adolescent. This has been adapted with minor changes from WHO's Adolescent Job Aid, a handy desk reference tool for primary level health workers.

Home	Where they live With whom they live Whether there have been recent changes in their home situation How they perceive their home situation
Education/ Employment	Whether they study/work How they view their performance in studies/work How they perceive their relations with their teachers and fellow students, or employers and colleagues Whether there have been any recent changes in their situation What they do during their free time
Activity	What activities they are involved in outside study/work What they do in their free time – during week days and on holidays Whether they spend time with family members and friends
Drugs	Whether they use tobacco, alcohol, or other substances Whether they inject any substances If they use any substances, how much they use, when, where and with whom
Sexuality	Their knowledge about sexual and reproductive health

	<p>Their doubts and concerns about sexual and reproductive health</p> <p>Their thoughts and feelings about sexuality</p> <p>Whether they are sexually active; if so, the nature and context of their sexual activity*</p> <p>Whether they are taking steps to avoid sexual and reproductive health consequences such as pregnancy and STIs*</p> <p>Whether they have in fact encountered such problems (unwanted pregnancy, infection, sexual coercion)*</p> <p>If so, whether they have received any treatment for this*</p> <p>Their sexual orientation*</p>
Safety	<p>Whether they feel safe at home, in the community, in their place of study or work, etc.</p> <p>If they feel unsafe, what makes them feel so</p>
Suicide/depression	<p>Whether their sleep is adequate</p> <p>Whether they feel unduly tired</p> <p>Whether they eat well</p> <p>How they feel emotionally</p> <p>Whether they have had suicidal thoughts</p> <p>Whether they have attempted suicide</p>

*These questions may be embarrassing for some of the adolescents, and if required, you may keep them for the post-test counselling. The reason for the suggested delay is to ensure the counsellor has time to develop rapport. However, this is not a recommendation to avoid asking these questions.

HEADS assessment will give you a clear picture about the adolescent's situation. You need to frame appropriate and relevant questions to do a proper assessment of the adolescent, including his/her risk for contracting HIV.

Knowing the route of transmission is important to help the adolescent to reduce the risk. It is not for blaming the adolescent or their parents.



Ensuring the Best Interest of the Adolescent

The UN Convention on Child Rights (CRC) recommends that the best interests of the child shall be a primary consideration in all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies.

In the ICTC setting, the counsellor has the responsibility to ensure that HIV testing is in the best interest of the adolescent. Hence, you should try to understand what will be gained by testing the adolescent and how will it help him/her or how will improve his/her life. Testing should be carried out, only if, it is in the best interest of the adolescent.

The following questions will help in this decision

- Is the adolescent presently showing any symptoms of HIV-related illness?
- Will the test results enable the adolescent to obtain medical treatment that is not available otherwise? (e.g., ART, CPT)
- Will the test results reduce the adolescent's anxiety about health?

*General HIV testing for all adolescents is NOT recommended as a way
the ICTC to increase its numbers.*



for

Post-test Counselling for HIV-negative Results

Post test counselling for adolescents follows the same process as for adults. However, the result is shared with the adolescent depending on his/ her age, maturity and ability to cope, and as agreed by the parent/guardian. Parents/guardians may have to be informed first.

Adolescents with identified risk behaviors such as drug use and early sexual engagement require special attention during the post-test counselling, even if their test result is HIV negative. The focus of the session should be on eliminating or reducing the risk behaviours. The strategies can be

- Avoiding involvement in groups/networks which encourage risky behaviours
- Avoiding risky partners
- Delaying sexual involvement
- Opting for low-risk patterns of behaviour
- Using condoms
- Increasing family bonding
- Life-skills training
- Treatment for drug-addiction
- Building the self-esteem of the adolescent

Some of these strategies require the guardian or other family members to be involved in the helping process. Some may require additional time from the counsellor. The services of adolescent health clinics can be utilized in such situations.

Normalisation is a counselling skill that is used to reassure clients that feelings such as guilt, anger and anxiety are common or normal reactions. After this the counsellor works with the client on ways to resolve the problem situation.

Sharing the Results with the Parent/Guardian

The adolescent may have acquired the infection either from the parent or through other modes. Even when the parent is not infected with HIV personally, the HIV diagnosis of an adolescent can be devastating to the parent/guardian. Helping them to cope with the diagnosis is also important.

➤ **Guilt, if adolescent has been infected through the perinatal route.**

They may express it through blaming themselves or the partner, cursing self, etc. In such cases, you may allow them to express their feelings in a non-harmful way. Normalization is one way to handle these emotions:

“I understand your feeling, it is quite natural. You feel that you are responsible for this situation.”

“I can understand your feeling that you are responsible for your son/daughter getting infected with HIV. But, I would like to remind you that he/she can live a healthy life with HIV, and does require your support. I think you would be able to support him/her at this stage also, to take positive steps to reduce the harm caused by HIV.”

➤ **Guilt for not guiding/looking after the adolescent properly.**

This is again a common response and you can use the normalization technique used above. The focus can be on making the parent/guardian understand the role they have to play in ensuring the healthy living for the adolescent:

“We have to accept the truth that your child is HIV-positive. But at the same time, we have to do many things to ensure that he/she lives comfortably and healthy.”

➤ **Anger towards the adolescent for the high-risk behaviours.**

Anger expressed in a harmful way can have destructive consequences over the individual. Some parents may not express anger towards the adolescent in the presence of a counsellor, but may express it outside the counselling room. You should be able to handle the expressed anger in a non-harmful way in the centre and also should try to rule out dormant anger in the parent/guardian.

If parent/guardian expresses anger towards the adolescent in your presence, you should calm down him/her first and acknowledge their emotions. Then they can be helped to understand what they are undergoing.

"Is it your only reaction? Is there anything else worrying you?"

You may help the parent/guardian in expressing the anger in a constructive way:

"It is normal to be angry when you learn this news. Other parents also felt angry like you initially. Later they started thinking about what they can do"

"How do you think that your child is feeling now? What is the most important thing right now – to express your anger or to try to support your child?"

"I can see you are upset and angry. Is this the only emotion you are feeling right now?"

➤ **Anxiety about the adolescent's health and future life.**

Parents and guardians will be worried about the health of the adolescent and also of his/her future. The messages about ART can help here.

➤ **Anxiety about own HIV status.**

Some parents who have not been tested for HIV, may be worried about their own HIV status. Recognise their fear and offer them testing services. *"I understand that you are worried that you may be HIV-infected. Let us see, whether you had any exposure before,"* or *"If you have any doubt, let us clear it. You can get tested for HIV here itself."*

➤ **Feelings of shame.**

"How will we look at each other's face? This is such a shameful infection", "He/she has ruined the image of the family," and, *"People will blame me"* may be heard from the parents/guardians. Acknowledge the feelings and help them to look past the blame and shame.

➤ **Fear of stigma.**

It is quite natural that parents/guardians fear stigma. Here you may need to help the parents/guardian to keep the HIV status of the adolescent confidential and in addressing the issues related with stigma. For instance, you may offer follow-up counselling sessions and counselling for other members of the family.

Disclosing the HIV Result to the Adolescent

'Disclosure' originally means sharing the status of one with somebody else. However, in the context of children and adolescents, whose results we may discuss first with parent/guardian, disclosure to adolescent refers to the act of informing the adolescent about his/her HIV status.

The decision to disclose HIV test result rests with the parent/guardian. This decision should depend on the awareness and involvement of the adolescent in the process and his/her maturity level. The disclosure to the adolescent should be treated as a process, rather than a one-time event. It starts from the pre-test session and goes beyond the act of informing the adolescent that he/she is 'HIV positive' or 'HIV Negative'

If the adolescent was fully aware of the purpose for the blood test, a good practice would be to break the news together to both.

Disclosure counselling during post-test counselling

If the adolescent was fully aware of the purpose for the blood test, he/ she will need to know the result. Not knowing will make the adolescent feel tremendously anxious, fearful and confused. Hence, you may need to prepare the parent to tell the result to the adolescent in an appropriate way: *"He/she (the adolescent) was very anxious about the test. He/she may want to know what the outcome is. How do you think we can address this?"*

Help the parent to decide what and how they are going to convey to the adolescent. You may also analyse possible reactions from the adolescent and prepare the parent/guardian to handle them.

Disclosure counselling during follow-up sessions

When an adolescent has not been informed fully, encourage the family to come for follow-up sessions. This does not mean that follow-up sessions should not include other issues. But, in this case, it is the counsellor's responsibility to follow the process through to a reasonable conclusion.

The general contents of disclosure counselling can be

- ✓ Exploration of the advantages and disadvantages of disclosure
- ✓ Deciding on what, how, who for disclosure. Ideally, parents or guardian should reveal the HIV status to the adolescent. However, this may not be appropriate in case of family abuse, family issues and violence. The counsellor can reveal the status to the adolescent with permission from parent/guardian. Parents/ guardians should be present for this.
- ✓ Assessment of possible reactions from the adolescent and tailoring information to reduce the impact of the news.
- ✓ Managing the responses of the adolescent to the news
- ✓ Helping the adolescent to keep HIV status confidential
- ✓ Planning for ongoing counselling sessions to support the adolescent and family

Linking with Required Services

ICTCs cannot address all the needs of adolescent clients. Hence there is a need to connect them with respective service facilities or providers.

Facilities under NACP

- ✓ ART centre for pre-ART registration and/or treatment
- ✓ STI clinic or STI care providers in case of STI/RTI symptoms
- ✓ TI projects if the adolescent is an IDU or does sex work
- ✓ Community Care Centres
- ✓ Drop-in-centres for PLHIVs

Other facilities/providers

- ✓ Adolescent health clinic
- ✓ Designated Microscopy Centre for TB diagnosis
- ✓ De-addiction centres
- ✓ Legal help cells/advocates
- ✓ Other agencies providing care and support services

You may provide basic information about the service available at the facility before sending the adolescent there. As already mentioned, the adolescent may be reluctant to access the service with adults. Therefore prepare the adolescent and his/her parent/guardian for this. Explain that sending them to another facility is not an abandonment of them as clients. Rather it is to help them receive the help they need.

Ensuring Follow-up

Even if you are able to make the adolescent client diagnosed with HIV believe in living a healthy life with proper treatment, adequate diet and exercise, there can be many other concerns. Follow-up counseling sessions offer an opportunity for the adolescent and parent/guardian to express and share these concerns in a supportive environment. Follow-up after the test-related counselling also includes your efforts to

- ✓ Ensure the adolescent's registration at the ART centre
- ✓ Facilitate disclosure of HIV status to the adolescent
- ✓ Facilitate reduction in identified risk behaviours of the adolescent
- ✓ Help the adolescent to deal with identified particular situations in his/her life such as sickness in the family, stigma and trafficking

Apart from offering follow-up counselling services, the adolescent or parent/guardian may seek professional assistance to deal with particular problems related to HIV in their life. This can again relate with stigma, problems with peers, issues related with knowing one's own HIV status and anxiety about life. Some of these issues are discussed earlier in the chapter. This section discusses how to handle other issues.

➤ **Stigma**

If the adolescent does not know his/her HIV status, he/she may be embarrassed with the experiences of stigma. At the same time, some may get to know about their HIV status from others through such experiences. (For instance, neighbours making their children stay apart from the HIV-positive adolescent). During follow-up sessions, the adolescent should be asked about such events in their life and assisted to overcome their effects. Parents/caregivers must be supported to handle such situations and disclose the status to the child, when required.

➤ **Difficulty in identifying with HIV-negative peers**

Peers are important for adolescents. Due to HIV infection, they may themselves stay apart from HIV-negative peers or experience rejection from them. If they themselves stay apart, they should be helped to continue healthy relationships. Tell them that HIV does not spread through casual contacts. They may require help to boost their self-esteem also. You may also choose to work with peers during outreach sessions (that is if the client's status is

already well-known in the community): Help them to identify and appreciate the positive things in the individual rather than cursing him/her for HIV infection.

➤ **Anxiety about sexual relationships and future planning**

Sexual relationships or marriage may be a cause of anxiety. Talk to them about delaying sex or reducing risky sex behaviors. Help them to learn ways of practicing safe sex. Also convey messages on being honest to their intended partner. Explain that apart from the legal situation which makes it compulsory to disclose to a potential spouse, honesty and trust are important in a relationship, even if they sometimes have painful consequences.

➤ **Concerns about the care of sick family members**

Some of the adolescents may be required to take care of sick family members, including parents. They may need to spend time at hospitals, take care of other ill people at home, undergo stressful moments such as chronic illness in a family member, death and need for money for treatment or related costs. Adolescents may need somebody to hear and console them, guide them during critical steps (such as accessing IP services, consulting doctors), and social and financial support. You can link them with social support systems, such as Drop-In-Centres.

➤ **Concerns about with heading the family**

In case of death of both parents, some adolescents are pushed to undertake the responsibility of looking after the family. They may need to stop their education and take up jobs to support the family. In such cases, even though, you will not be in a position to continuously support the adolescent, you can offer the support through follow-up sessions. They also may be linked with Drop-In Centres run by PLHIV networks for support.

Summing Up

Counselling adolescents is neither like counselling children nor like counselling adults. While similar counselling skills are used in all three situations, it is the style of communication that makes the difference as well as the type of issues that the counsellor must handle. Further, the counsellor must also negotiate between the rights of the adolescent and those of the parent.

Frequently Asked Questions



Who is an adolescent?

Various agencies define adolescence differently. The World Health Organization (WHO) has defined adolescence as the stage between age 10 and 19. So does the Government of India's Reproductive and Child Health (RCH) programme. However, the National Youth Policy of the Government of India considers that adolescents are individuals in the age group of 13 to 19. This module operationally focuses on male and females between 10 and 19 years.

In terms of the ICTC, you need to be aware that the legal age of consent for an HIV test is 18 years. Prior to that a person is a minor.

How can an adolescent get infected with HIV?

HIV spreads from one person to another through exchange of, or contact with, infective body fluids through four routes. Adolescents are at risk of transmission through all these routes:

- Through unprotected sex with an HIV-infected person
 - Adolescents may engage in unprotected sex either by force or consensually.
- Sharing of contaminated needles and syringes
 - Injecting drug use may begin in adolescence
 - Certain amount of risk exists when needles and syringes used in hospitals are not properly sterilized. The actual chances of this are low.
- Through infected blood or blood products
 - Current chances are very low as facilities for screening blood are available in all government-approved blood banks
- From infected mother during pregnancy, child birth and breastfeeding
 - Some infected adolescents are long-term survivors of HIV/AIDS.



References

- Geldard, K. & Geldard, D. (2004). *Counselling adolescents: The proactive approach*. London, UK: Sage Publications.
- IEC Division, Ministry of Health and Family Welfare (n.d.). *Orientation programme for ANMs/LHVs to provide adolescent-friendly reproductive and sexual health services: Handouts*. New Delhi, India: Author.
- IEC Division, Ministry of Health and Family Welfare (n.d.). *Orientation programme for Medical Officers to provide adolescent-friendly reproductive and sexual health services: Facilitator's Guide*. New Delhi, India: Author.
- International HIV/AIDS Alliance in India (n.d.). *Breaking barriers: Facilitating HIV testing and disclosure for children and adolescents*. New Delhi, India: Author.
- International HIV/AIDS Alliance in India (2009). *Facilitating HIV testing and disclosure with children and adolescents*. New Delhi, India: Author.
- Jejeebhoy, S.J., & Sebastian, M.P. (2003). *Actions that protect: Promoting sexual and reproductive health and choice among young people in India*. New Delhi, India: Population Council.
- Nath, A. (2009). HIV/AIDS and Indian youth: A review of the literature (1980 - 2008). *Journal of Social Aspects of HIV/AIDS Research Alliance*, 6 (1), 2-8.
- National AIDS Control Organisation & National Institute of Medical Statistics (2006). *National behavioural surveillance survey (2006): Youth*. New Delhi, India: Author.
- National AIDS Control Organisation (2007). *HIV counselling training modules for VCT, PPTCT and ART counsellors*. New Delhi, India: Author
- World Health Organization. (2009). *Adolescent job aid: A handy desk reference tool for primary level health workers*. Switzerland: Author.
- World Health Organization. (2009). *IMAI one-day orientation on adolescents living with HIV*. Switzerland: Author.

Counselling Discordant Couples

At the end of this unit, participants will be able to

- Describe the issues and concerns specific to sero-discordant couples
- Demonstrate couple counselling skills in relation to sero-discordant couples
- Explain options related to family planning and pregnancy open to sero-discordant couples

Till date the focus of the National AIDS Control Programme (NACP) in India has been on persons with high-risk behaviours such as sex workers. Couples have not been given much attention. However, sero-discordant couples also present a high risk of HIV transmission to the non-infected partner. One estimate indicates that there could be a 10 to 20% annual rate of transmission in this particular group (Nadol, 2009)

NACP has prioritized people with high risk behaviours and this approach has shown some success in bringing down the rate of new infections in the Most-at-Risk Populations (MARPs). One research study in India has demonstrated that, over a ten-year period, the rate at which FSWs get infected with HIV is slowly declining – especially in the Southern states (Mehendale, Gupte, Paranjape, Brahme, Kohli, Joglekar, et al., 2007). But the same study found that the rate of infection of non-sex-worker women (sic.) has remained more or less the same. This is the group that would include married women whose only risk is sexual relations with their spouse. Counsellors in the National AIDS Control Programme also report seeing more and more discordant couples. This population is clearly growing and ICTC services must respond to their needs.

This module will deal with the issues of sero-discordant couples and appropriate counselling approaches. Counsellors in India may mostly see married male-female couples. But they should take note that similar definitions and issues also apply to unmarried couples who are in a committed, sexual relationship, and to MSM couples (Men who have Sex with Men).

Who are Discordant Couples?

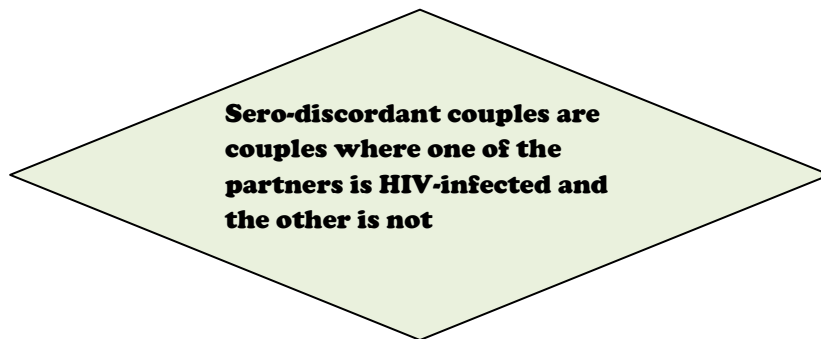
Sero-discordant

Sero-discordant couples are couples where one of the partners is HIV-infected and the other is not. They are also called discordant couples. They could be heterosexual or homosexual.

Sero-concordant

Some experts also describe concordant couples – these are couples whose sero-status is the same. So we may speak of concordant negative couples where both have tested negative to the virus and concordant positive couples where both have tested sero-positive.

Some experts further try to distinguish between the issues of sero-discordant couples where the infected partner is male and those couples where the infected partner is female. They designate these sero-discordant couples as M+F- and M-F+ respectively. You can create similar designations for MSM couples.



Where do We See Discordant Couples?

Sero-discordant couples are common in those communities with a generalised HIV epidemic. Therefore ICTC personnel in Category A and B districts are more likely to encounter them.

In general, this trend will increase. One reason is that improvements in the effectiveness and availability of ART make it possible for HIV-infected individuals to lead longer, healthier lives. Some of them may feel healthy enough to opt to get married, or enter into a relationship.

Counsellors at ART centres and at Link ART Centres are also more likely to interact with discordant couples and should prepare to work with their issues. At ICTCs, counselling personnel may see one half of the couple. Their task involves motivating the other partner to get tested. They also face the challenge of disclosure of sero-discordant status to the couple.

There is a positive aspect to this situation. When it is known that one partner or spouse is HIV-positive while the other is negative, the counsellor has an opportunity to prevent transmission in that situation – the intervention at this level provides a quicker “pay-off” than any other programme for the general public (Ateka, 2006). This simply means that we know a lot of HIV transmission takes place within these relationships and we can relatively easily reduce the numbers of people thus infected through suitable counselling.

Factors that Affect Discordance?

Biological Factors

Gender:

Transmission is more likely from a male to a female than from a female to a male. Women have an in-built biological vulnerability because their genital tract has a larger mucosal surface which makes entry of HIV easy.

Age and Early Sexual Debut:

There is some evidence that adolescent females are more physiologically vulnerable to sexually transmitted infections such as chlamydia than adults (Centers for Disease Control, 2004). In India there is a sizeable amount of young women who marry in their teens. They are at greater risk if their husbands have HIV. Also, some young people begin sexual relations (heterosexual and same-sex) before marriage and while still in their teens. This is supported by NACO surveillance data as well.

Viral Load and Stage of Disease:

Transmission increases when HIV viral load is high. This is more likely during the window period and the advanced HIV disease stage.

Presence of Sexually Transmitted Infections:

Sexually transmitted infections (STIs) increase the risk of transmission. For instance, the virus which causes genital herpes (Herpes Simplex Virus 2) upsets the mucosal barrier and increases the chances of getting HIV through increased shedding. Also it is important to understand that HIV itself may increase the vulnerability of a PLHIV to HSV-2 or that it may make an existing infection more

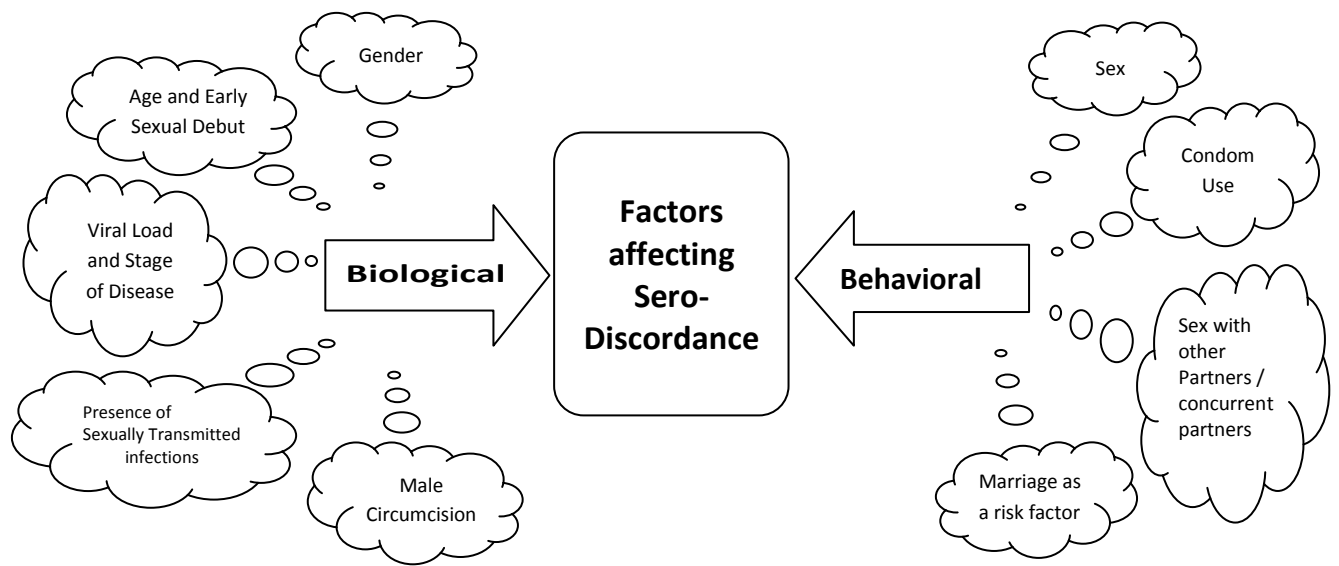
severe. Both these scenarios result in increased length and frequency of ulcerative episodes. During such episodes, it is easy for HIV to be transferred to the non-infected partner.

There are two mechanisms which operate here. When the PLHIV has such an ulcerative condition, he/she has a greater mucosal surface through which to pass on HIV. Even if the non-HIV-infected partner is the one with the STI, this partner becomes more vulnerable to HIV because of the increased surface through which HIV may enter the body.

Male Circumcision:

Male circumcision is the removal of the foreskin of the penis. Observational studies show that circumcised men have a lesser risk of HIV infection compared to uncircumcised men once they are past the stage of healing from the circumcision: Removal of the foreskin reduces the surface area for contact with HIV.

In case clients ask about this, the counsellor may explain that male circumcision has shown a significant protective effect against the conversion from discordance to positive concordance by reducing HIV transmission by HIV-infected males as well as by infected females (Freeman & Glynn, 2004). However, care should be taken here because circumcision is associated with the religious practices of some communities like Jews and Muslims. At no point should counselling on this point take the form of a recommendation or suggestion. However, clients who ask a question have the right to expect an honest answer that is technically accurate. You may word your response thus: *“Scientific studies show that HIV transmission is lower when males are circumcised once the healing process is over. But this is an individual choice. Also, you should understand this will only reduce (not eliminate) transmission.”*



Behavioural Factors

Sex:

HIV transmission within the relationship depends on the probability of transmission per sex act, and the total number of sex acts in that relationship. The number of sex acts can be measured by frequency of sex acts and life-span of that relationship. Simply put, the more often a discordant couple has sex, the greater the chances of HIV passing on to the non-infected partner. However, it is also important to explain to clients that each and every sex act carries the risk of transmission of HIV and STIs.

The type of sexual practices also influences the possibility of transmission. As HIV counsellors, you are aware, there is a hierarchy of sexual behaviours that are more risky. Anal sex is more risky than vaginal sex which in turn is more risky than oral sex. Using a condom will reduce the risk. Sex during menstrual periods also carries a higher risk of transmission. The same can be said about sex which involves more friction or where the natural vaginal lubrication has been removed by wiping or drying. Some women habitually use cotton or rags or other materials to dry the vagina. It is important to ask about such habits.

Condom Use:

Some counsellors complain that even though couples know that condoms can reduce HIV transmission, they still “avoid” or “refuse” to use them. It appears counter-intuitive or irrational that any “sane” person would want to reject condom use. Here counselling personnel should recognize and be prepared to counter different reasons:

➤ **Denial of HIV:**

One common reason why sero-discordant couples may fail to adopt condom use is because one or both partners are in denial about the presence of HIV. Also some may try to rationalize the non-use of condoms saying that they have not been infected so far.

➤ **AIDS fatigue:**

With the improved treatment options, a PLHIV may lose concern about re-infection. The negative partner may also become less concerned about infection. This move away from safer sex practices is a common observation in couples who have been dealing with HIV in the relationship for a long time. Such AIDS fatigue is also more likely when people are on ART, and when the viral load and symptoms are brought under control. PLHIVs and their partners may become complacent about using a condom or may just become bored or tired. In contrast are those PLHIVs who stop using condoms when their sickness increases because, at this point, the risk of re-infection does not personally matter to them any more.

➤ **Lack of pleasure:**

Some men report that condom use decreases stimulation (though in most cases this is likely to be a minor loss of sensation) and leads to loss of erection.

➤ **Inability to maintain an erection:**

Older men are more likely to experience this problem. Similarly, a small number of men living with HIV who are on ART might experience lowered sexual function.

➤ **Desire to get pregnant:**

This is discussed in detail later.

➤ **Relationship factors:**

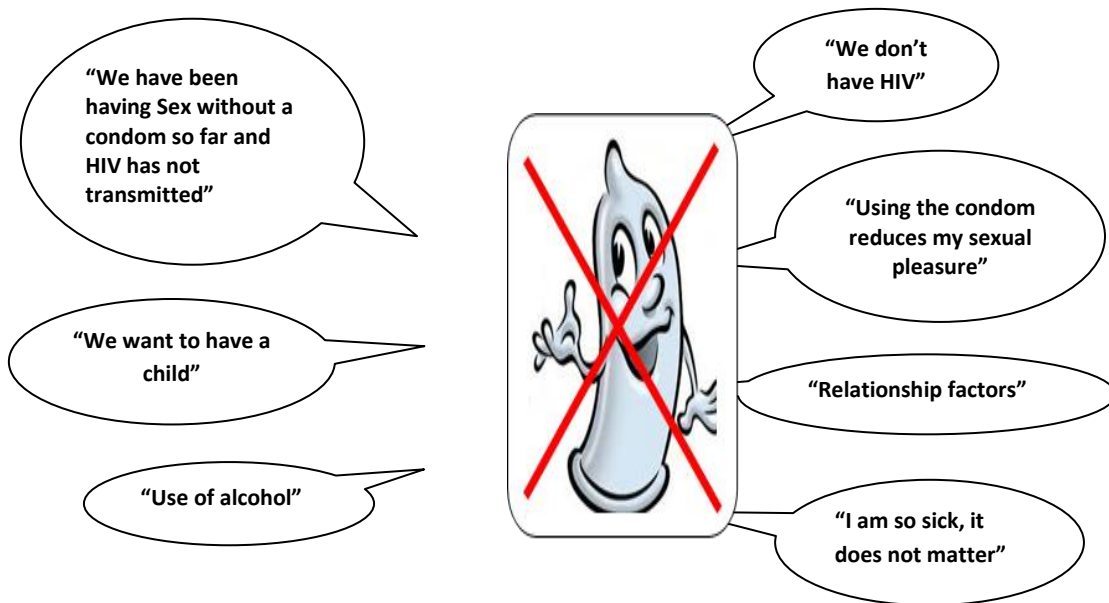
This covers many aspects of women’s vulnerability. The reality of relationships between men and women shapes women’s behaviours. Women who are financially dependent may find it difficult to discuss and insist on using a condom. The same is the

case for women in relationships which follow traditional gender roles. Also among some women there is a belief that unprotected sex is a sign of trust in their partner. They may justify the resistance to using a condom as an expression of love, or God's will.

➤ **Use of alcohol:**

This has been linked to sexual disinhibition and failure to practise safer sex. It might reduce motivation to use a condom as well as the person's ability to wear one properly. In some instances, alcohol consumption accompanies domestic violence.

Sex with or without a condom may occur with regular partners as well as non-regular partners.



Sex with other partners / concurrent partners:

Research in India shows that, despite traditional norms emphasizing faithfulness and monogamy, sex outside marriage and sex with more than one partner is very frequent. Both men and women may have more than one partner, and reasons cited include "fun, curiosity, and under the influence of alcohol."

Women may have sexual partners outside their primary relationship – consensually (for social, sexual, financial or emotional support) or non-consensually. In India, women may have sex with a colleague or an employer. Sometimes, women may be coerced (forced) to have sex with a family member. Women's status in the family also makes it less likely that they can negotiate ways to protect themselves.

In terms of national priorities under NACP III, two bridge populations become important:

- ✓ Migrant workers – who are away from their families for long periods of time
- ✓ MSM population - research shows that MSM are often forced to marry and have sex with their wives as fear of stigma prevents them from disclosing their status to their family and wife. They may actually engage in more high-risk behaviour than their unmarried counterparts because of their need to avoid being labelled. They may be more likely to take part in anonymous sex

It is important to recognize that the very knowledge of discordant status may affect such multi-partner sex practices: As intimacy between the primary sero-discordant couple gets affected, one or both partners may seek sexual fulfillment outside the primary relationship. Here they may or may not use a condom. They may practise behaviours that they feel unable to ask from their primary partner – e.g., anal sex. They may or may not inform their primary partner.

The implications of such behaviours are that they may transmit HIV to these other partners, they may get reinfected with HIV (namely super-infection), or infected with other STIs. There is always a strong possibility of further damage to the relationship with their primary partner. It is also possible that a non-infected person may feel both relief and guilt when they learn about the partner's activities with other partners. The partner who seeks sex outside the relationship may still value the emotional attachment within the primary relationship and may want to preserve it.

The challenge for the counsellor is twofold:

- ✓ Managing protection for the steady partner
- ✓ Managing protection for the casual partner.

It is important not to judge the couple's choices and lifestyle.

Marriage as a risk factor

In the case of married discordant couples, marriage itself could be viewed as a risk factor. What this simply means is that the recognition of risk within marriage is low. For instance, married, Indian women hold a strong perception that indiscriminate sex outside of marriage is responsible for HIV spread, and only a very small number of women perceive themselves as being at risk. They are unlikely to adopt protective behaviours with their spouses. The NFHS also documents the low usage of contraception. This is a major counselling challenge because the counsellor has to battle this misconception and break through their illusion of safety and security.

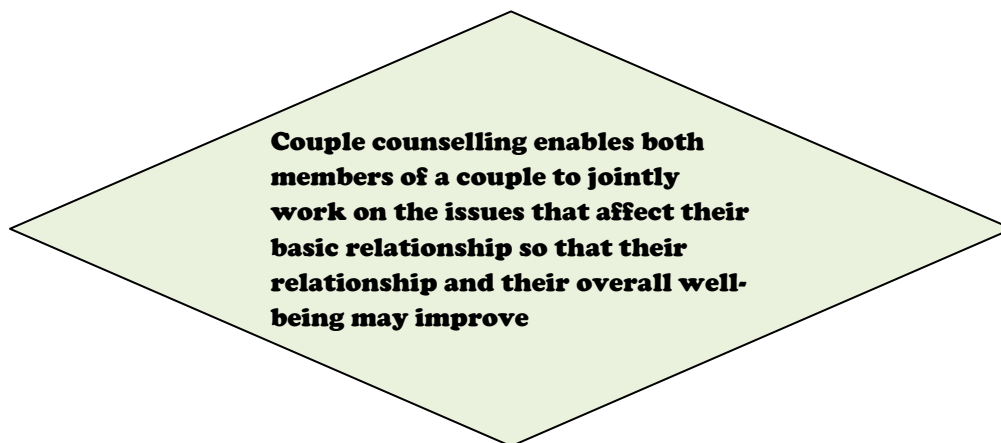
Using Couple Counselling at the ICTC

Thus far as ICTC counsellors, you have most likely focused on individual behaviour change. This is also the perception of various NACO and SACS officials from their monitoring of the programme. Few, if any, counsellors use couple counselling skills.

When working on issues related to the impact of HIV on the couple's relationship and the reciprocal impact of the relationship on the PLHIV's adjustment to HIV, couple counselling may be more effective than interventions targetting individuals. Couple counselling interventions recognize that people who are embedded in a relationship can make suitable behaviour changes only to the extent that their relationship permits. These interventions focus on communication, problem-solving and negotiation skills because the couple must learn how to discuss sex and condom use, build intimacy and support. Good communication skills are required in order to consistently practise safe sex.

The NACO Counselling Module (2006) defines family and marital counselling as "a systematic effort to produce beneficial changes in a marital or family unit by introducing changes in the patterns of interaction between members of the family or partners. Its aim is the establishment of more satisfying ways of living for the entire family and for individual members." The focus is on changing the pattern of interaction.

Couple counselling has similar objectives. It seeks to enable both members of a couple to jointly work on the issues that affect their basic relationship in the hope that their relationship as well as their overall well-being may improve. The idea is to view the two members as a unit.



ICTC or ART or CCC counsellors, who choose to use couple counselling, have to move away from their normal habits of dealing with one client at a time. They have to be willing to go beyond the biomedical management of HIV and be ready to accept and embrace the “messiness” that is part of the private and personal lives of client couples. Further, while individual counselling may look at past behaviours and possible sources of infection, couple counselling with sero-discordant partners is more related to the here-and-now. The advantage to the programme is that counselling partners together may reduce absolute time spent by counsellors on counselling them separately. But the counsellor needs to set the stage carefully because there are many explosive issues which require sensitive handling. One of the primary functions is to help the couple to develop problem-solving skills which they can use to work through these potentially stressful situations.

Working with discordant couples is an area where there is not much written material. This section draws heavily from the CDC (2007) Manual on Couples HIV Counseling and Testing but also examines how to adapt some of the recommendations in the context of India. After describing some of the basic principles and skills, the section will discuss some ways to use them with sero-discordant couples.

Building and Maintaining Rapport with the Couple

In couple counselling, counselling personnel have three arenas of focus: the needs of each member in the couple and the couple as a unit. Counselling with a couple, therefore, must devote adequate time to each of these three areas. The client couple must be able to recognize that each of these areas merits concern, and that the counsellor is devoting a suitable amount of session time to each aspect. One way for the counsellor to spend equal importance to all three areas is for the counsellor to spend time individually with each client as well as with both partners together. This is important because many Indian women are not accustomed to articulating their needs. They may require more personal contact to open up and discuss them. Let us not assume that Indian women are not accustomed to articulating their needs. While care should be taken to uphold individual's concern, counselors need to reinforce stereotypes either.

A key theme underlying all the skills is that the counsellor should remain neutral and convey respect for each individual as well as for their relationship. Only by demonstrating a balanced and equal concern, can the counsellor earn the trust and confidence of both partners. This is easily put in action:

- by permitting each member in the couple equal amount of "air time" – time to talk

- by discussing the issues of each partner

- by establishing boundaries and expectations at the beginning of counselling sessions

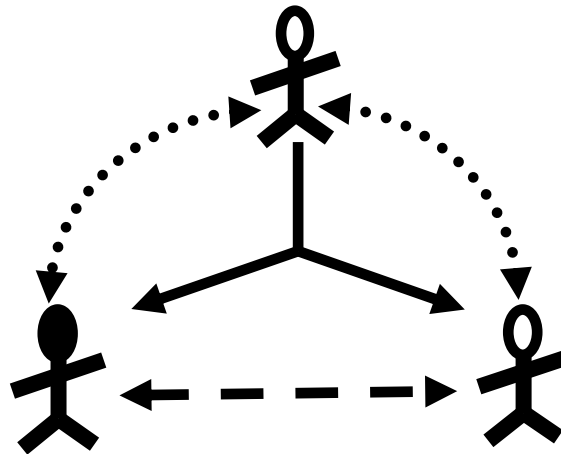
While interacting with sero-discordant couples, the counsellor must work on issues of both the infected partner and the non-infected partner.

The counsellor must also facilitate dialogue between the partners, raise difficult issues that they must address, ease tension between them and diffuse blame. It is necessary to support the couple to address their issues and concerns as partners - in terms of "we" rather than as two, separate "I's." This kind of focus may strengthen their capacity to cope with the realities of HIV in their shared life.

Four Primary Conversations in Couple Counselling

There are four primary conversations that occur in any couple counselling session.

1. Communication between the counsellor and the couple
2. Communication between the partners
3. & 4. Communication between the counsellor and each partner



➤ **Communication between the counsellor and the couple**

The solid arrow in the centre refers to the communication between the counsellor and the couple as a unit. It focuses on the shared past of the couple, the common current reality and their common dreams for the future. The counsellor draws from the couple their joint view on issues and causes them to think about their life together.

Some examples of such communication are *“What hopes did you have for your child?”* and *“What plans do you have for your family’s future?”*

➤ **Communication between the partners**

The dashed arrow between the partners refers to their interpersonal communication. During the counselling session, the way they speak to each other will give the counsellor clues about areas where they need to work. Also, the counsellor may give some homework to the couple to encourage such conversations outside the therapy room. The idea is to encourage the couple to work as a team and to use their different strengths and resources to improve their functioning.

An example of such homework would be: *"When you go home I would like you to discuss with each other your plans for the future. We can talk about this in our next meeting"* or *"What have the two of you decided about making a will/ a nomination on the life insurance policy?"*

Observations from the field show that counsellors frequently turn to one or another partner for information about specific matters. For instance, when discussing children, counsellors may focus only on mothers. When discussing finances, they may turn to males. In the example above the key phrase is *"both of you."* It is important for the counsellor to use the words as well as to internalize the attitude. This will make both partners feel involved. Further, the counsellor can push the couple to plan together for their future.

When couples are not used to talking to each other, the counsellor may have to jump-start the conversation. One technique to do this is to ask each partner, *"Could you tell me about your partner's wishes about pregnancy?"* After hearing the answer, the counsellor can turn to the partner and ask them if the answer was accurate.

➤ **Communication between the counsellor and each partner**

The dotted arrows cover the communication between the counsellor and the individual partners. These are the last two primary conversations. Here the counsellor provides each person a space to ventilate (express) his/her feelings on issues. The counsellor encourages the silent partner to vocalize his/ her wishes.

The counsellor may focus on asking each partner to discuss their unique past – that is the non-shared part of their lives: *"I want each of you to talk about how your respective families have handled crisis situations in the past."*

It can also serve to sensitize the partners to the emotions of the other person: *"I want you to tell me how you felt when you learned about your partner's diagnosis and realized that it might be due to an affair."*

Finally, these conversations can also serve to bring awareness about the other person's needs. So the counsellor may turn to the female client and say, *"Could you tell me how you feel, as a mother, about this situation?"* Then the counsellor could turn to the male and ask, *"Having heard your wife's feelings on this topic, I would like to ask you if you were aware of them, and whether this changes your mind in any way?"*

Who can be an Effective Couple Counsellor?

A counsellor who has the following qualities can strive to be an effective couple counsellor.

Counsellor self-awareness

It is important for each counsellor to examine her/his own beliefs, biases, feelings, and reactions because these do affect her/his counselling. For instance, the counsellor's gender may predispose her/him to favour or be alert to the feelings of the partner of their gender. A counsellor who has suffered through the infidelity of her/his own partner may experience hostility towards the sero-positive partner.

The counsellor will be consciously able to provide unbiased empathy, understanding, and support to the couple only after getting in touch with her/his own personal attitudes, and emotions. In order to avoid tilting in favour of one partner or the other, or on one side of an issue/life-decision, it is important to begin examining one's own attitude towards hot-button topics like marriage, being faithful, whether PLHIVs have a right to enjoy sexual pleasure or to have children. It is important to identify one's limitations and strengths only allows counselors to be more effective and efficient.

Capacity to tolerate intensity

All experienced counsellors are aware that counselling involves dealing with strong emotions and feelings. Counsellors who are used to working with individuals may be surprised at the depth of feeling evoked in couple counselling. In general, the relationship of any couple is complex and ever-changing. For sero-discordant couples, presence of HIV status and its complications raises the level of emotional intensity. Counsellors must learn to tolerate this intensity while simultaneously maintaining a consistent and supportive stance of both partners and their relationship. This will involve tackling challenging subjects like infidelity and sexual desires where the counsellor must facilitate an open and frank conversation. This will reinforce the couple's confidence in the ability of the counsellor to deal with their problems.

If you are a first-timer at these techniques, it is important not to get discouraged and feel personally inadequate. The ability to manage intensity is a skill that develops over time and with experience and maturity.

Ability both to validate and to challenge

Couples (and individuals) sometimes make life choices that are surprising and may appear irrational. A successful couple counsellor is able to validate the couple's feelings and perceptions while at the same time questioning the decision. For instance, couples may cite many reasons for why condom use is difficult. While the counsellor may accept their reactions, she/ he has to also point out how not using a condom places the uninfected partner at risk. A dialogue to this effect might be: *"Yes, I can see that using a condom tends to reduce the sexual pleasure. But have you thought about how not using a condom puts your partner at risk,"* or *"You have mentioned that you two have stopped using a condom because you want to express your love without a barrier. But is this the only way to show your love for each other."* Note the non-judgmental tone used by the counsellor in this statement.

An HIV counsellor must always encourage the couple to consider how they may act to reduce the transmission of HIV. But she/ he must also recognize and acknowledge through words the reasons why they fail to do so, or their negative feelings about behaviour changes.

Couple counsellors try hard to understand the strengths and weaknesses of the couple. They are also aware that those behaviors that increase the risk of HIV transmission may be pleasurable, while behaviours that reduce risk are desirable but also carry disadvantages.

Couple relationships, like all social structures, are shaped by culture, gender dynamics, religion and economic status. These may be responsible also for producing some of the apparently, contradictory decisions. For instance, counselling personnel may find themselves asking, "Why is this couple trying to have a baby when they cannot afford the travel to the CCC, or when they are barely able to take physical care of themselves?" In such circumstances, some judicious, but respectful, questions may throw up answers such as, "In our community, it is a great shame to be seen as sterile or infertile," or "According to our religious practice, a son is needed to light the funeral pyre." These situations also call for the skill of validating and respectfully challenging at the same time. But counselling personnel must learn to gracefully accept that clients ultimately have the right to choose their own actions.

Patience

It is important to state how necessary it is for the counsellor to be skilled and patient. Counselling is a new field and is often misunderstood, sometimes even by counsellors. Learning to accept the client's choices, even when they appear to be unreasonable or harmful, calls for patience from counsellors. In couple counselling, the kind of "taking turns" between the partners (as described in the section on Communication between the counsellor and each individual client) may be difficult for Indian clients to practise and for counsellors to elicit. The counsellor needs a great deal of patience. She/ He must also reassure clients and give them permission to state their needs.

Some Couple Counselling Techniques

Normalize feelings, reactions, and experiences

The effort here is to help the couple to recognize that their feelings such as guilt and betrayal are common and that other couples also feel similar emotions. Learning that their emotional reaction is common or natural gives the clients a sense of reassurance and validation that their emotions are justified – *even if they cannot act on their deepest hurt or anger*. The counsellor here, demonstrates acceptance of the emotion, and *not* of any harmful or negative behaviour.

- ✓ *“Many couples in this situation feel like you do right now.”*
- ✓ *“You are not the only one who feels this way. Other husbands (or wives) also feel betrayed (or guilty or angry) like you do right now. I can reassure you that many of them also manage to work through their problems.”*

Effectively use silence while conveying a supportive and calm face

We have already seen that couple counselling involves a high level of intense feeling. Sometimes creating a deliberate moment of silence may bring the emotion to a manageable level. The counsellor may also use this technique when she/ he judges that the couple would benefit from a period of silence so they can collect their thoughts and respond accordingly. Sometimes, the counsellor’s silence may prompt the couple to open up. Many counsellors are uncomfortable with silence or pauses in the conversation. But if used effectively, this is a very effective technique.

- ✓ *“It seems like the atmosphere in the room is very hot. I’d like us all to be silent for just a little while so that we can regain our composure.”*
- ✓ *“Let us pause a bit while I let you think about what I have just explained.”*

Focus on the present and future

It is common for a couple to recall past deeds and hurts. These may surface during the session. It is, therefore, helpful for the counsellor to gently bring back the focus of the session to the here and now, and to emphasize that the past cannot be altered. But it is also important not to use this technique to avoid an issue or to brush it under the carpet.

- ✓ *“It is easy to recall past incidents that have been painful in the relationship. But these cannot be rewritten or undone. All that we really have control over is our current and future direction.”*

Here there are some gender dimensions of which a counsellor should be aware. In India, married women are often expected to suppress their anger and betrayal when their spouse is unfaithful. Counselling personnel should be careful to avoid conveying to female clients that infidelity is acceptable, and thus negate or fail to validate their deepest anguish and hurt. Rather this technique should be used when clients appear to be narrating woeful stories that they have told several times before.

Couple Counselling Techniques

- **Normalize feelings, reactions, and experiences**
- **Effectively use silence while conveying a supportive and calm face**
- **Focus on the present and future**
- **Redirect questions about identifying the potential source of infection**
- **Express confidence in the couple’s ability to deal with HIV-related issues**
- **Work with intense emotions**
- **Redirect and reframe questions that are blaming or potentially hostile**

Redirect questions about identifying the potential source of infection

Related to the point above is the almost inevitable desire of the partners to identify when exactly HIV was transmitted. This is bound up in the possible infidelity of the infected partner and it also moves the focus of counselling to the past which cannot be undone. So the counsellor should point out that any discussion about the source of the infection is neither helpful nor relevant to the couple's current situation and life decisions.

- ✓ *“While the question of how and when HIV got in is something that everyone asks, you should also realize that HIV is present and we have to deal with it. Knowing where it came from does not really help our decision-making for the immediate present and the future.”*
- ✓ *“Let me answer your question about when HIV entered with a short story. If a house is burning down and there are two people still stuck in the building, what is the immediate need? Would you stop to guess how the fire started or would you try to rescue those people and put out the fire? In a similar manner, worrying about where HIV came from, and trying to pin-point the source will distract you from the more urgent concerns before you.”*

Once again it is important to emphasize that this technique should not be used to cover up really important issues such as wife-beating, emotional abuse or spouse's alcohol misuse. This technique is recommended to help client couples progress to concrete decision-making on key issues such as registering at the ART centre, getting their child or spouse testing. The counsellor should address underlying conflicts during follow-up counselling sessions.

Express confidence in the couple's ability to deal with HIV-related issues

The counsellor must project a sense of optimism that the couple will be able to deal with their life decisions. She/ he can accomplish this by jointly reflecting with them on their strengths and shared history. By examining how they, as a couple, have effectively addressed challenges in their lives, the counsellor can highlight their strengths. The counsellor should not only acknowledge these strengths but should show appreciation that the couple is willing to deal with HIV.

- ✓ *“It appears to me that together you have survived some difficult times. I am sure that once you have a chance to catch your breath, the same strength will help you in this current situation also.”*

- ✓ *“Together, I believe, the two of you have the strength needed to deal with these difficult events. It might be helpful to make a list of all the difficult times you have faced successfully in the past.”*

Work with intense emotions

In couple counselling, it is important to acknowledge the feelings expressed by the couple verbally and nonverbally. As these emotions may be overwhelming, it is important to also reassure them that as time passes the intense emotions and reactions will change or shift. This is a common and known pattern.

- ✓ *“Many couples show the same initial reactions as you, but I have seen that over time this gradually changes, and they adjust.”*
- ✓ *“It is normal to feel so upset (or sad or angry). But slowly you will find yourself adjusting and coping.”*

Redirect and reframe questions that are blaming or potentially hostile

The emotional intensity between couples is sometimes due to blaming and angry reactions. The counsellor can defuse this situation by identifying underlying softer feelings and helping the couple to recognize that. For instance, fear, anxiety, and uncertainty are sometimes expressed as anger.

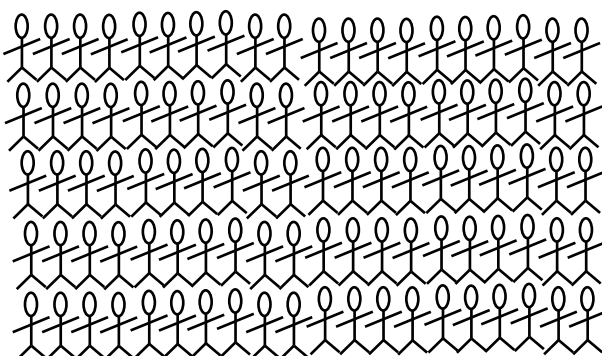
One way to understand this concept is to recall an instance when you saw a child run towards some danger like a burning stove or a busy road. Your reaction might have been to rush and pull the child away, to express relief (“Thank God, I got you in time.”) or to shout at the child for not being more careful. What is underlying all of this is deep fear at the possibility of hurt to the child. But this is expressed differently.

- ✓ *“It is common to feel many mixed-up emotions at the same time. Could you list what is going on in your mind right now?”*
- ✓ *“Sometimes people express frustration and anger but they are also experiencing many other things at the same time.”*

Couple Counselling and Programme Realities

One often-heard comment from counsellors is, “Where is the time to use these techniques?” Counselling practitioners in the NACP services may have a strong view that their supervising officers from SACS and NACO are only interested in targets. So applying the counselling techniques described is an unachievable ideal. Here, we may point out to you that safer sex between discordant partners is a programme goal. The techniques of couple counselling offer you a way to reach this goal. We would advise you to try out at least one technique. Then when you are familiar, try out another. If you do not appear to make progress with client couples, remember that behaviour change is a long-term process. Persevere in your task.

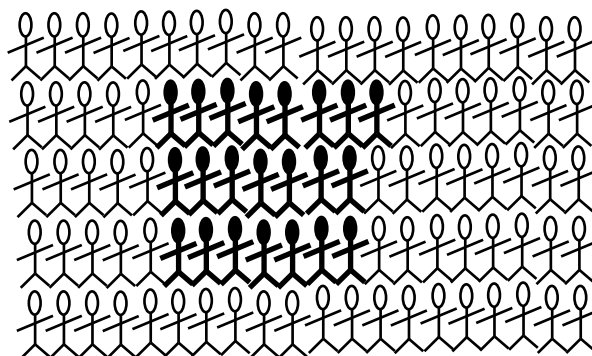
These skills and techniques can be used to build up the communication skills of the partners where HIV is not the only topic of conversation. They can be used to focus the couple on active problem-solving and overcoming the barriers to condom use.

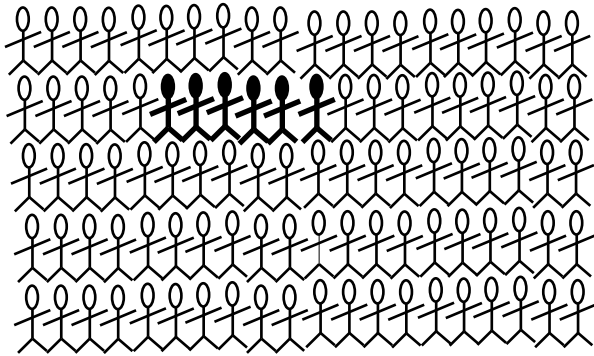


The other issue to recognize is the efficacy of counselling. There is some evidence that a good couple intervention may reduce the risk of HIV transmission within a sero-discordant couple from 22% to 6%.

Imagine that these figures are 100 HIV-negative partners in discordant couples.

If they are sexually active with one another regularly, within 1 year, an average of 22 of these 100 HIV-negative partners will become infected unless they change their risk behaviors. This rate of transmission is higher than the rates of tuberculosis or malaria transmission. In subsequent years without intervention, we can expect more and more negative partners to become HIV-infected.





However, in one study of couple counselling, the majority of discordant couples changed their behavior and only 6 of 100 became infected within 1 year, suggesting that 16 infections were prevented.

This demonstrates the importance of couple counselling and its impact on HIV transmission.

Important Issues of Discordant Couples

Testing the Partner

Knowing if one is HIV-infected is the first step to taking action. Most people are unaware of their status. Therefore, the first challenge would be to get the partner in for testing. As pregnant women are encouraged to undergo the rapid HIV test, they may be the first partner whose status is detected. But it is important to note that the male partner should also be encouraged to come for testing. Where possible, both should be encouraged to go for testing together. Doing so may reduce questions such as “Who got HIV first?” Counsellors can especially encourage pregnant women to bring their partners for testing when they come for their next ante-natal check-up. This will provide them scope to practise some of their couple counselling skills. They should motivate the partner to get tested and note the results in Columns 19, 20 and 21 of the ICTC Register for Pregnant Women.

Consequences of Disclosure

The disclosure of HIV status is not random - PLHIVs disclose to people who they view as supportive. Disclosure may also be high when PLHIVs know that treatment options and services are available. The counsellor can, therefore create a supportive environment for sharing the news of the discordant status by presenting the current status of services available. They can explain about the treatment options available (ART, DOTS, CPT) to reassure the couple that there is hope of a healthy life for the infected person. They can explain to couples expecting a baby that PPTCT services include nevirapine for mother and child, as well as Early Infant Diagnosis (EID) options.

It is important not to underestimate the impact of the presence of a counsellor. A counsellor who discusses the HIV status, the facts of sero-discordance and future protective actions in a calm, matter-of-fact manner provides a powerful cue to the couple of how they may themselves react.

How to break the news has been covered in other sessions in induction training. So it will not be repeated here. However, it is important to identify some of the consequences of this act for the couple's relationship.

➤ **When partners fail to show a visible reaction**

Sometimes, partners may fail to show a visible reaction. The counsellor should not accept at face value the immediate reaction as it could be due to denial or an inability to cope with the stress. Two techniques mentioned in the previous section may be useful in breaking through the silence.

- ✓ *"It is common to feel many mixed-up emotions at the same time. Could you list what is going on in your mind right now?"*
- ✓ *"Many couples in this situation feel like you do right now – like they don't know how to react."*

➤ **When couples report fear of infecting the negative partner**

Some discordant couples report tension related to their fear of infecting the negative partner. Some relationships are strained by the loss of trust because of the positive partner may have been unfaithful. There may also be tension from the fear of stigma and discrimination from outside the family

➤ **When couples play the blame game**

Some couples may play the blame game. Here the counsellor could use the redirecting and reframing response. The other scenario is also possible where the sero-negative partner feels unable to protest their partner's lack of faithfulness. The counsellor may use silence to elicit the feelings of the silent partner or acknowledge the possibility of mixed-up emotions.

➤ **When interpersonal violence erupts**

Sometimes interpersonal violence erupts within the family. This is a situation where couple counselling is likely to be ineffective. Words cannot deflect physical blows. The counsellor needs to use community support networks to support the victimized partner and to deal with the physical violence. Here the counsellor will play the role of an advocate.

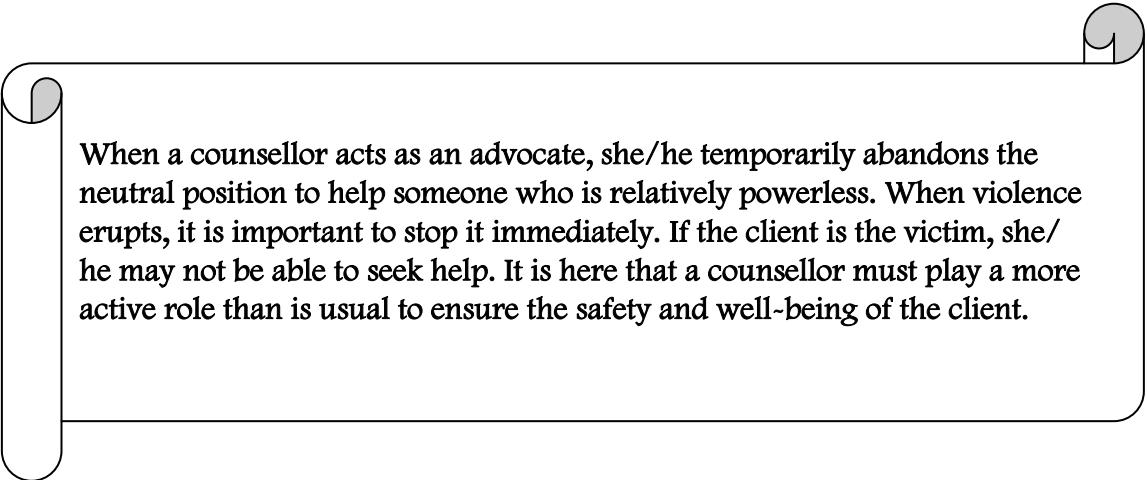
➤ **When couples break up over the diagnosis**

One question that might arise is whether couples break up over this diagnosis. Here, the research is mixed. It appears that many partners decide to remain together while a few do break up. But, one thing is certain – there are bound to be many issues which may trip up the couple, especially at stress

points in their lives. Break-ups are also, perhaps, influenced by the perception of stigma in the community.

Some positive trends reported by some couples are that the negative partner displays support by encouraging the positive one to take their medicine on time, to monitor their health and to eat well. Here, as might be expected, gender plays a role – if the female is the uninfected partner she is more likely to be supportive.

To sum up here, the counsellor may be in a Catch-22 situation: To emphasize confidentiality may safeguard the PLHIV's social support structure, but this carries the high risk of transmission to the discordant partner. On the other hand, disclosure to the uninfected partner may prevent infection but at the cost of that partner's social support.



When a counsellor acts as an advocate, she/he temporarily abandons the neutral position to help someone who is relatively powerless. When violence erupts, it is important to stop it immediately. If the client is the victim, she/he may not be able to seek help. It is here that a counsellor must play a more active role than is usual to ensure the safety and well-being of the client.

Disclosure to Other Persons

This may also create tension in the couple's relationship. For instance, family members of the negative partner may put pressure on the negative partner to leave the positive partner for their safety and continued health.

Sexual Intimacy

Intimacy between the partners in a discordant couple is usually affected. The uninfected partner may fear having sex because it carries the possibility of transmission. When couples are sexually active, they may complain of a loss of spontaneity because they have to plan for sex and plan to use a condom at every encounter. Partners may also complain of less frequent sexual intercourse, or an avoidance of certain coital acts such as anal sex or taking semen in the mouth during oral sex. Condom use all the time may also diminish sexual pleasure and expectancy.

The counsellor should check in frequently about what couples are doing and their reasons for the same. Some couples rely on questionable assumptions of what is safe and unsafe in the area of sexual intimacy. For instance, couples may point out that having sex till date without a condom has not caused the sero-negative partner to sero-convert. It is important to emphasize to a couple that the risk of one act of transmission could add up over many acts of sex. Just because the negative partner has not sero-converted till date is no guarantee that they will continue to remain negative. Also, explain that it is possible to get infected through even one act of sex.

Though Indian culture discourages communication between men and women regarding sexual behaviour, the counsellor can through couple counselling encourage the partners to communicate with each other and to make conscious decisions about the sexual life. It is important for the counsellor to support women as social norms permit them little scope for negotiating sex with their partners. For instance, in one study in India, Women Living with HIV/AIDS have reported that when they refuse sex their spouses react violently (Thomas, Chandra, Selvi, Suriyanarayanan, & Swaminathan, 2009).

Exploring the Sex Life of Discordant Couples

Some simple questions to do this are:

- ✓ *How often do you have sex?*
- ✓ *How often do you have sex with a condom?*
- ✓ *When you say sex, can you tell me what you and your partner do? Probe for oral sex, anal sex, emission.*
- ✓ *Do you or your partner take alcohol before sex?*

Abstinence

One consistent finding in HIV research is that, over time, couples shift from having safe sex or no sex. Many Indian sero-discordant married couples tend to report that they are sexually abstinent. However, when trained to negotiate safer sex practices, a sizeable number also report resuming their sex life (McGrath et al., 2007). Research from non-Indian couples describes a noticeable decline in sexual activity reported immediately after learning of the sero-discordant couples. However, six months later, the number of couples still abstaining from sex reduces. Further, the number of those who are practising sex without a condom also increases.

The implications of these findings for couple counsellors are clear: It is important to ask about sex at various follow-up visits. The initial report of sexual abstinence may not be valid a year later. Secondly, education about safer sex is important because it provides safer options for the couple.

Sex without a Condom

In one of the few documented studies on sero-discordant, Indian couples, 457 such couples were followed in Pune city (Mehendale et al., 2007). The researchers compared the transmission rates in this study to those found in studies with African countries. In comparison, Indian sero-discordant couples show a lower rate of transmission to the uninfected partner. The researchers explained this lower rate to a higher rate of condom usage by Indian couples for the purpose of contraception. The key point to note here is not that the rate of sero-conversion was lower. The key point to note is why it was lower – because of condom usage. This is something counsellors should inform clients about in their counselling while encouraging them to use condoms consistently.

It is common for clients to over-report or exaggerate how regularly they use condoms. One simple way to check this is to ask each partner separately how often they had sex without a condom, and to note the discrepancies.

Also, giving a couple a condom and having them handle it will give you a good idea of how comfortable they are with this method. This activity will also give you a chance to correct any improper use. Sometimes, couples might mention feeling squeamish at having to touch a lubricated condom. Seeing the counsellor use it will help to reduce this sense of awkwardness and strangeness.

The reasons for non-use of a condom have been discussed earlier. The counsellor should ascertain each individual partner's wishes in the matter.

➤ **When both members wish to pursue sex without a condom**

When both members in the pair wish to pursue sex without a condom, the counsellor should encourage an open discussion between partners on the topic of safer sex. She/ he should help them to see that their previous assumption may have been that it is okay to have sex without any barrier protection, and that this assumption is no longer true with HIV in the equation. She/ he should then encourage them to express their concerns and discuss various family planning options with them. For these individuals who knowingly expose themselves to HIV, the minimum the counsellor can do is to insist that the negative partner get tested every six months.

➤ **When couples appear to get tired of having safe sex**

When couples appear to be getting tired of having to constantly be vigilant, it is important to be supportive: Point out their success in using condoms till date. Encourage them to express their affection using non-penetrative sex.

➤ **When couples point out they have not been infected so far**

Some discordant couples may point out that they have not been infected thus far. Others point out to God's protection. The current negative status of the partner may thus contribute to a false feeling of safety. Here the counsellor's task is to point out that the cumulative effects of risk: The transmission risk of one sexual act could add up over many acts of sex. Just because the negative partner has not sero-converted till date is no guarantee that they will continue to remain negative.

➤ **When couples want to avoid using condoms as a sign of love**

However, there are other situations which are difficult for the counsellor to handle, for instance dealing with partners who avoid using condoms as a sign of love. It is hard to argue against such an appeal that involves love. The counsellor may have to frame the action of using a condom as a sign of love. This might be expressed as, *"It is common for couples to feel that nothing should come in between them during love-making. A condom, however, is a sign of caring from the Positive Partner towards the Negative Partner. Also, the two of you should consider whether it is selfish or an act of love for a Negative Partner to try and remain uninfected so that they can show their love by caring for the Positive Partner when they fall sick."*

➤ **When only one partner wants to use a condom**

Another extremely difficult situation is when only one partner wants to use a condom. Arguments about condom use usually follow a similar direction where verbal exchanges become heated and may even proceed to become physically or emotionally violent. When alcohol is consumed, the violence is closer to the surface and accusations of infidelity may fly between the partners.

A study on Positive Women described it well: “Their... narratives revealed a vicious cycle that was set into motion when sexual intimacy was initiated. The woman’s request for condom use was rebuffed. She pleaded. He got angry. She was silenced. He persisted. She capitulated. And they had unprotected sexual intercourse. Then she lived with the worry and guilt (Stevens & Galvoa, 2007).”

While we know that condoms are important for protection of the negative partner in the relationship, taking an absolutist stand or a mechanical approach to condom use is unlikely to be very effective. Instead, it may cause the negative partner to live in fear and guilt about their sexual activity and their positive partners to react against efforts to control their personal behaviours.

Sex with other partners

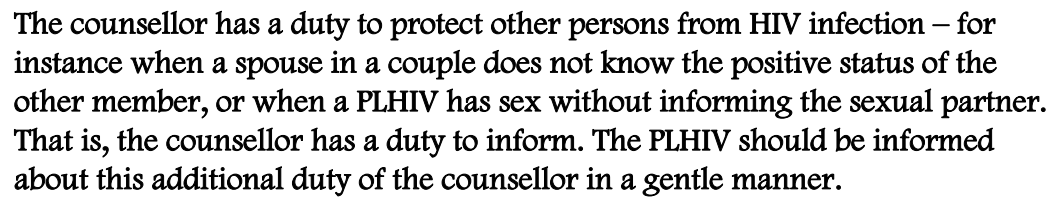
Sometimes, one or both partners may have other sexual partnerships where they may choose not to use a condom. Here they may practise behaviours that they feel unable to ask from their primary partner – e.g., anal sex – and such partnerships may increase when intimacy between the primary couple is affected.

Through such partnerships PLHIVs may transmit HIV to the other partners, they may get re-infected, and there is always a strong possibility of further damage to the relationship with their primary partner. It is also possible that the non-infected, primary partner may be aware of these relationships and may feel both relief and guilt. It is also possible that the partner who seeks sex outside the relationship may still value the emotional attachment within the primary relationship and may want to preserve it.

The challenge for the counsellor is twofold:

- Managing protection for the steady partner and
- Managing protection for the casual partner.

The counsellor may have to question each partner separately about their risk behaviour. However, it should be noted here that the counsellor cannot take sides by keeping such disclosure a secret. In couple counselling, the counsellor has to deal with the couple as a unit. At the legal level, the counsellor still has a duty to protect the other person from HIV infection in the outside relationships, namely the counsellor has a duty to inform. The PLHIV should be informed about this additional duty of the counsellor in a gentle manner without applying blame to the PLHIV.



The counsellor has a duty to protect other persons from HIV infection – for instance when a spouse in a couple does not know the positive status of the other member, or when a PLHIV has sex without informing the sexual partner. That is, the counsellor has a duty to inform. The PLHIV should be informed about this additional duty of the counsellor in a gentle manner.

Reducing Risk

There are some simple ways to reduce the risk of HIV transmission to the non-infected person in the relationship

Treat sexually transmitted infections

Research shows that discordant couples who receive intensive couple counselling, along with active treatment of STIs fare better in terms of prevention of HIV transmission to the uninfected partner.

Alternative non-penetrative sexual practices

Counsellors may educate the sero-discordant couples about using dildos (sex toys), using other body parts such as rubbing the penis in the palm of the hand, the navel, between the thighs or underneath the partner's breast. Partners should be advised to be more gentle towards each other and to avoid forced sex which involves friction.

ART Adherence

Encouraging the positive partner to register for ART and to follow up by way of adherence is useful for protecting the negative partner also. ART reduces the viral load which in turn reduces transmission. This provides reason for the non-positive partner also to support the efforts of positive partner and to come in for testing every 6 months. However, the counsellor should also underline the fact that ART does not completely remove HIV

Termination of the Relationship

Some positive partners in a discordant couple may opt to end the relationship in order to protect the negative partner, or the negative partner may abandon the positive partner in order to protect themselves. While the former option seems to resemble a Hindi film, it is important to treat these choices as genuine. One study in Uganda noted a trend where sero-discordant couples broke up in order to try new concordant relationships where they may try for children. Break-ups, however, are not that common. For every story of a broken relationship there is a story of a couple who stick together. As noted before, there is a gender influence here as M+F- are more visible than M-F+.

Dealing with broken relationships is difficult. The counsellor's role in these situations is to provide hope as well as accurate information. As the ICTC is a health facility, the counsellor is usually in contact with the partner who is positive. The counsellor should encourage them to remain adherent to ART and not lose hope. If possible, the negative partner should be motivated to remain within the relationship and accurate information should be provided about ways to avoid being infected. When breakdown is inevitable, the positive partner should be assisted to make the adjustments required. This is a time when they may be very vulnerable and both their adherence and mental health might suffer.

Pregnancy

Many sero-discordant couples may want to have a child. This may be a strongly felt need even among couples who already have one or more children. One or both members of the couple may experience a desire for parenthood even knowing that this carries the possibility of HIV transmission. The desire to be a parent is also often mixed with the fear of transmitting infection to the child. Some experts have even suggested that the wish for parenthood may explain, to some extent, why there is a high transmission rate between sero-discordant partners.

Factors that Influence the Desire to Have Children

There are many factors which influence a couple's desire to have children as well as the actual decision to conceive or to continue with a pregnancy.

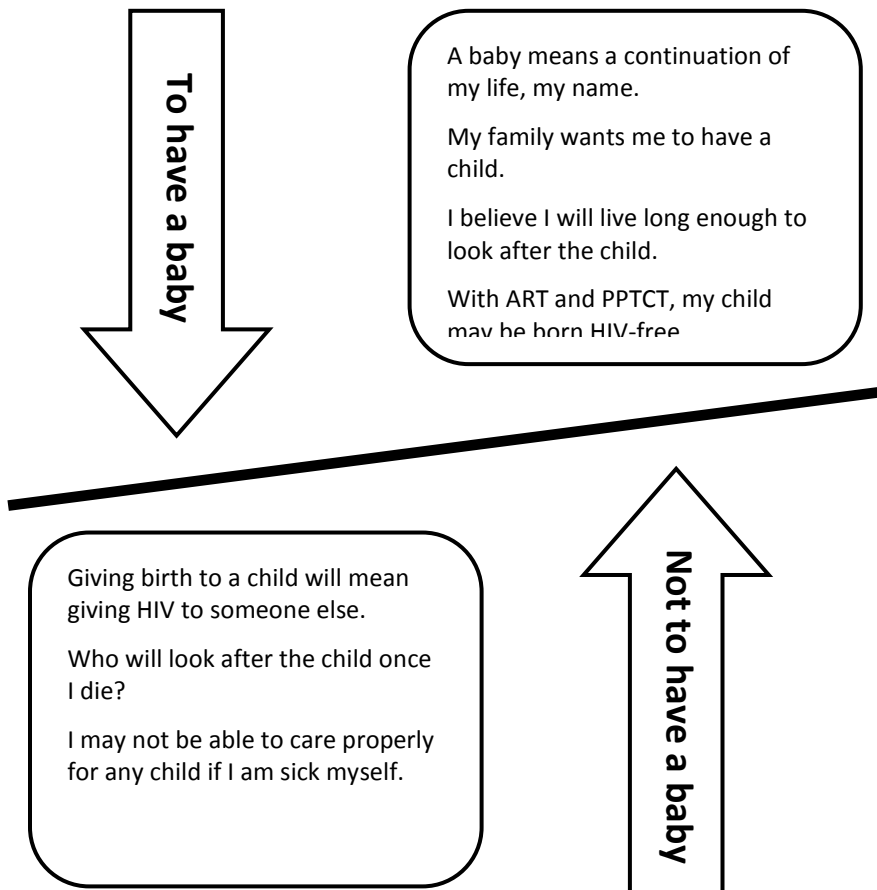
Availability of PPTCT and ART

PLHIVs who have access to PPTCT and ART feel more confident about parenthood. That is, they feel more confident about the chances that their children may be born without HIV, and that they will live long enough to parent them. ART counsellors may notice that as ARV medicine causes a client's health to improve, the client's hopefulness will also increase, and he/ she may feel more capable of sustaining the pregnancy.

Family Support

In India perceived family support or discouragement is a factor that tips the scale in either direction. If the discordant couple feels stigmatized by the family, or if they feel that the family will not support the child after their death, they may not want to bear children. When they feel the family will look after the child, they may be more likely to want to have children.

When you counsel a discordant couple, you should probe for the family attitude. Family members may advise the couple to channel their scarce resources to care for themselves and/ or other living children.



Stigma of Infertility

Sometimes couples may report that they want to have children because they believe the stigma of being infertile is worse than the stigma of being HIV-infected. This is more likely when the couple has not shared the HIV diagnosis with the family. Hindu couples may want to have a son who will light their funeral pyre. Couples of all faiths may want someone to continue the family name.

Completing the Family

Some couples may want to have children in order to complete their family. Some have stated that having a second or third child may at least provide the other children with some companionship after they (the parents) have died. Some couples may want to have children in order to cement their relationship.

Service-Provider's Attitude

An Indian study has shown that counselling by health providers does influence an HIV-positive women's decisions about child-bearing (Kalyanwala et al., 2007). As a health care provider, you do influence how your clients view this issue. You should be aware of the mistrust that clients may experience towards you. Many studies show that Positive people do not place any reliance on the ability of their health care providers to relate to their need to become a mother or a father. They also strongly believe that service providers lack the kind of knowledge and information that will help them, the clients, to handle their decisions. Some also expect negative statements from providers such as, "Why do you want to bring another life into the world? How will you look after another person when you can barely look after yourself?"

It is important to recognize your influence and to provide information in a supportive and non-discriminatory manner. Accepting that this decision is in the hands of the client and the partner is a difficult one. Regardless of the personal feelings of the counsellor or doctor, the client is entitled to accurate and updated information to make their decision. Name-calling and making decisions for the client are NOT counselling. Discriminatory attitudes may discourage PLHIVs from having children and they may also discourage them from interacting with us.

When we view clients as capable individuals, then we may begin to appreciate how and why they view their decision as most appropriate for their particular life-situations. For instance, some women experience shock and despair on first learning of their positive status. But later, they express a strong will to live for the sake of their children. For these individuals, having a child does not allow them to succumb to grief and despair. It becomes a strong facilitatory factor to take ART regularly. For others, the children they bear provide a strong counter-factor that enables them to cope with the dehumanizing effect of living with HIV; the child provides meaning to their life.

Harm Reduction for Discordant Couples who want a Child

When helping PLHIVs to plan a safe pregnancy, the service provider faces three distinct clinical challenges (Mathews & Mukherjee, 2009):

- ✓ to maintain the mother's health before, during and after pregnancy;
- ✓ to prevent vertical transmission from mother to child, and
- ✓ to prevent HIV transmission to the sero-negative partner.

Counselling, therefore, addresses when to get pregnant, PPTCT, pregnancy and post-pregnancy issues. For instance HIV infection raises the risk of childbirth complications such as fever and anaemia, particularly with a caesarean section delivery. For the child also there are risks of still birth, premature birth or low birth weight. As ICTC counsellors, you are likely to be very familiar with how to assist a client registered for PPTCT services. You may not be as knowledgeable about how to help a couple conceive a child with as little risk as possible.

Deciding to become pregnant need not become a choice between risking HIV transmission and fulfilling the need to have children. There are ways to reduce the risk of HIV transmission to the sero-negative partner and to the child. Some strategies for harm reduction are described below. Some of these fall into the expensive realm of reproductive technologies. Others are more low-tech but may carry a higher risk of transmission.

Counselling for discordant (or concordant-positive) couples who would like to conceive a child must address three challenges:

- **Maintain the mother's health before, during and after pregnancy;**
- **Prevent vertical transmission from mother to child, and**
- **Prevent HIV transmission to the sero-negative partner.**

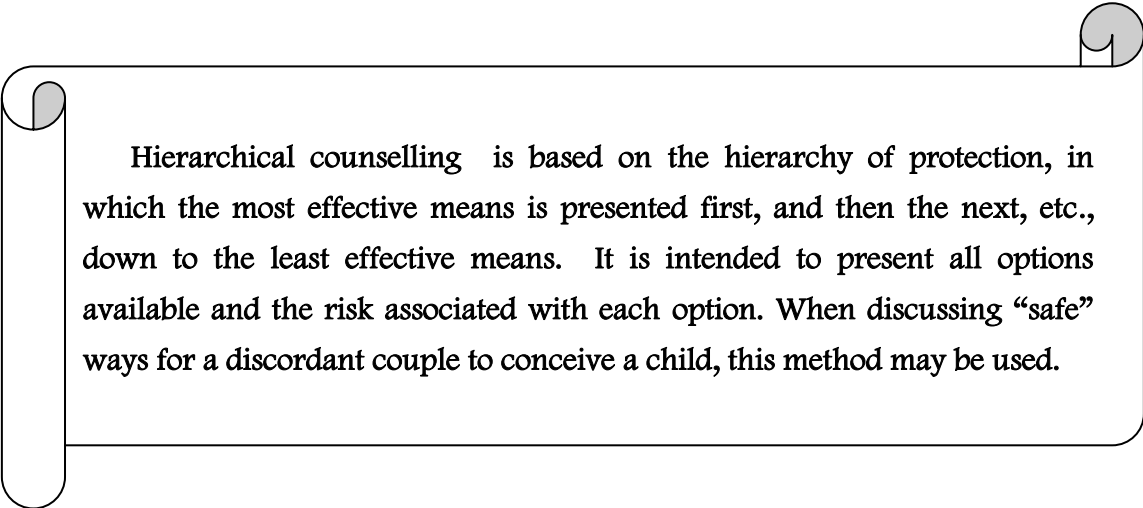
Artificial Insemination

Artificial intrauterine insemination is an effective way to minimize the risk of horizontal transmission for M-F+ couples. Here the man contributes his semen to a fertility doctor who then introduces it into the reproductive system of the female partner without the couple actually having sex. Insemination combined with another technique called sperm washing may lower transmission risk for M+F- couples.

However, access to such treatments may not be available to all clients especially to the population who come to ICTCs and ART centres: Cost may be an inhibiting factor. It should also be noted that these treatments are not guaranteed to prevent HIV transmission. However, your role as the counsellor is to make a relevant referral to a gynaecologist who is a fertility specialist.

Teaching Couples about Ovulation

One “lower-technology” and low-cost approach that may reduce the likelihood of horizontal transmission is teaching couples about ovulation and timing intercourse to fertile periods. This method offers a means for decreasing the number of unprotected sexual encounters: Sexual encounters without a condom are limited to the fertile period of the woman’s monthly cycle. There are limited published data examining the effectiveness of this approach. Remember, there is a risk of HIV transmission through even a single act of sex.



Hierarchical counselling is based on the hierarchy of protection, in which the most effective means is presented first, and then the next, etc., down to the least effective means. It is intended to present all options available and the risk associated with each option. When discussing “safe” ways for a discordant couple to conceive a child, this method may be used.

Treating Genital Infections

One easy way to reduce harm is to treat genital infections prior to attempting to conceive the child. Patients who wish to procreate should receive counselling, an exam and treatment prior to attempting

to conceive. If couples opt to use the ovulation (fertile) period for sexual contact, the service provider should strongly recommend to treat any genital infections present.

Checking Viral Load

Higher viral loads are associated with increased transmission rates. Therefore, if the sero-positive partner is on treatment with a viral load below detection limits, the discordant couple may be able to procreate naturally with minimal risk of infection to the negative partner. Persons whose viral load is still high may be counselled to delay attempts at conception until they are on stable treatment and, if testing is available, until the viral load is undetectable. However, there are some data that suggest that viral shedding in the genital tract does not necessarily correlate with serum viral load. The client should be made aware of the risk.

Male Circumcision

Circumcision may offer an additional strategy for harm reduction for sero-discordant couples where the man is uninfected. But as mentioned before this has cultural and religious overtones. It would be better for the counsellor to wait for the client to ask about this option rather than specifically recommend it. Further, if asked, the counsellor should present the facts of how male circumcision has been proven to reduce transmission risks but not completely eliminate it.

Indeed all the methods discussed above reduce transmission risks but do not completely eliminate them. This is one clear fact that you, as the counsellor, should discuss with the client, both individually and together.

Also note, all these strategies may be complicated by the fact that HIV-infected women tend to have lower fertility rates than uninfected women. During your counselling you should communicate with couples that overall fertility may be lowered and, therefore, they should set limits for the number of times they will engage in unprotected sex prior to achieving pregnancy.

Infertility is traditionally defined as the failure for a couple to conceive after frequent, unprotected intercourse over 12 months. Given the risk of unprotected sexual encounters, some experts have recommended that couples should be encouraged to try these methods up to a maximum of 12 months and, if unsuccessful, they should halt these attempts to conceive and should recommend to the couple to examine for any possible causes of infertility.

Approaches to reduce risk of horizontal transmission for HIV-affected couples who want to conceive children

<i>Infected partner</i>	<i>High technology</i>	<i>Low technology</i>
<i>Male</i>	Sperm washing + intra-uterine insemination, intracytoplasmic sperm injection	Screening and pre-treatment for STIs Delay until viral load controlled Limited, timed unprotected sexual encounters
<i>Female</i>	Artificial Insemination	Screening and pre-treatment for STI's Delay until viral load controlled Limited, timed unprotected sexual encounters Circumcision

Fertility Counselling for Discordant Couples as Harm Reduction

The following recommendations have been made by Mathews and Mukherjee (2009) for couples who wish to have children. They recommend that couple counselling in this situation should include

- ✓ The risks to the unborn child, the mother (particularly if she is positive), and the uninfected partner
- ✓ The options for reducing risk depending on the socio-economic circumstances of the couple, referrals to appropriate services, and relative risks associated with each option
- ✓ The fact that HIV infection may lower fertility and that attempts at procreation may be unsuccessful
- ✓ The need to wait until the infected partner is on ART with an undetectable viral load (where monitoring is available)
- ✓ In case of an infected woman, the need to exclude teratogenic ARV's, including efavirenz from her ART regimen.
- ✓ The need for genital exams for both partners and treatment for any diseases that may advance HIV transmission.
- ✓ The benefits for couples who share their plans with their providers: Close follow-up for necessary tests, early detection, enrollment in PPTCT programs

Decision-making about conception is a process. It may change over time, and with changed circumstances. The couple who yesterday did not want to have a child, may today change their mind in favour of having a child.

One key question is whether the pregnancy will affect the progression of HIV disease. The answer to this is negative. If a pregnant woman is on ART, her immune status in relation to other infections is not likely to suffer much.

Family Planning for Discordant Couples

Research in India shows that many discordant couples will report they do not have sexual relations with each other (at least immediately after being diagnosed). However, it is not possible to rely on this situation remaining unchanged throughout their later relationship. You, as the counsellor, have to prepare them for the day when they may choose to resume their sexual life. Here you must first assure them that it is normal and natural for them to want to have sex even when one partner is positive and the other is not. Also, they may need your reassurance that it is okay for one partner to be more eager than the other. However, resuming the sexual relation also carries with it the risk of viral transmission and the possibility of pregnancy. So as a counsellor, you should have accurate information to help them to manage both.

While helping a discordant couple to make good family planning choices, there are two key considerations:

- ✓ Preventing pregnancy
- ✓ Preventing infection

Only male and female condoms prevent both pregnancy and infection, and they should be used consistently for each and every act of vaginal or anal intercourse. Most other methods may also be used – but along with a condom is both pregnancy and infection are too be prevented.

Not all methods are suitable for every one. PLHIVs have a medical condition which may affect how well a family planning method will work or it may cause additional harm. In general, PLHIVs may be able to use most contraceptive methods. The exceptions are discussed below:

- Spermicides increase infection risk for uninfected women in M+F- couples. Further, spermicides or diaphragms with spermicides should not be used by women with HIV/ at high risk of HIV.
- The IUD is contradicted for an infected woman if the woman has gonorrhoea or chlamydia or is unwell with AIDS-related illness or if she is at risk of any of these.
- Rifampicin lowers effectiveness of contraceptive pills and implants.

- Some antiretrovirals such as protease inhibitors and NNRTIs may lower the effectiveness of hormonal methods.
- Female and male sterilization are not recommended for persons with advanced HIV disease.

NEGOTIATED SAFETY

It has been observed in some communities that some partners who have been together for a long time may consciously choose to abandon using condoms with each other. Kippax, Connell, Dowsett, and Crawford (1993) used the term "negotiated safety" to refer to this behaviour pattern. It is seen when both partners are HIV-positive or HIV-negative – that is among concordant couples. They choose this option based on the assumption that as they know the HIV status of their partner, they can manage their own risks. Such 'negotiated safety' also assume that the couple is monogamous or each partner always uses condoms with other casual partners. It requires a high degree of open communication between partners. This behaviour pattern is characteristic of concordant couples. The reason for describing it in this chapter is to highlight to you, the reader, that the field of HIV-related practice is dynamic and ever-changing.

Working with MSM Couples

It is easy when discussing sero-discordant couples to focus on male-female couples. Indeed the sections on pregnancy and family planning may contribute strongly to the idea that only male-female discordant couples exist or that they have issues. While few ICTC counsellors may actually see an MSM couple, much less an MSM discordant couple, it is important to recognize that they do exist and that they often have similar issues related to personal safety and intimacy. Moreover, as anal sex has high potential for HIV transmission, the likelihood of HIV passing from M+ to M- partner is even higher than the risk in a discordant male-female couple. The same couple counselling techniques and skills may be used also for MSM couples with suitable modifications.

One final note pertains to a behavioural phenomenon observed among some gay couples – namely barebacking. This refers to intentional condomless sex among some gay men who know that their partner is HIV-positive or who are unaware of their partner's HIV status and who choose to have sex without a condom despite the risks. This is seen as a sign of AIDS fatigue where an individual or a couple believes that the fear of infection is secondary. What may be more important for the individual could be the need to have sex without a barrier, or to recapture a sense of freedom. This is a situation which would require delicate handling by you, the counsellor.

Frequently Asked Questions



Who gets infected first? The husband or the wife?

There are different ways of looking at this question:

One is the programme view: Are women more at risk or men?

Indian data shows that this works both ways. For instance, a study of 27,681 couples who have tested at the Government Hospital of Thoracic Medicine at Tambaram, Tamil Nadu between the years of 1994 and 2008 found that 57.4% were sero-discordant (GHTM, n.d.). Further, 45.8% were M+F- and 11.6% were M-F+.

The second way of viewing this issue is in terms of physical and social vulnerability.

Biologically, women have a greater surface to transfer the virus. Socially, they are less in a position to avoid unwanted sex, or unprotected sex.

The third way of viewing this issue is in terms of questions from client couples: How will I know who got infected first: my spouse or I?

Here the question may be asked because one or both members of the couple wants to get into the blame game. There are various counselling techniques to deal with this situation.

What can happen when PLHIVs have unprotected sex?

- They can transmit HIV to their partners.
- They can get re-infected with HIV (that is super-infection).
- They can get infected with other STIs.
- If there is a woman in the relationship, she can get pregnant.

Frequently Asked Questions



What is the legal position regarding discordant couples?

The Supreme Court of India in the case of Mr. X vs Hospital Z (8 SCC 296, AIR 1998, SCW 3662) has stated that doctor-patient confidentiality must take into consideration the situation where an HIV-infected person may pose a risk of transmission to an uninfected spouse. Under these circumstances, a health care provider has a duty to inform the uninfected partner about the diagnosis.

Applying this to the ICTC situation, a counsellor must encourage the positive partner to share their status with their spouse. The counsellor, as described in the main write-up, may help the positive client on issues such as breaking the news. However, in event that the positive client does not disclose their test result with the partner, this duty falls on the counsellor. The client should be made aware of this duty to inform, and that the right to privacy is not absolute.

The same judgment also treated a PLHIV's 'right to marry' as a suspended right. However, when the Supreme Court reviewed its own judgment, it restored this right but reiterated that the sexual partner of a positive person has a right to know the situation they are getting into. (SCCL.COM 701, AIR 2003 SC 664, 2003[2] ALD 24 [SC])



Questions to ICTC Counsellors

Do we as counsellors overtly or covertly discourage positive persons from having more children?

Are we prepared with lists of services such as fertility doctors who are HIV-friendly or family planning centres?



References

- Adam, B.D., Husbands, W., Murray, J., Maxwell, J. (2005). AIDS optimism, condom fatigue, or self-esteem? Explaining unsafe sex among gay and bisexual men. *Journal of Sex Research*, 42 (3), 238-248.
- Allen, S., Meinzen-Derr, J., Kautzman, M., Zulu, I., Trask, S., et al. (2003). Sexual behavior of HIV discordant couples after HIV counseling and testing. *AIDS*, 17, 733-740.
- Allen, S., Tice, J., Van de Perre, P., Serufilira, A. Hudes, E., Nsengumuremyi, F. et al. (1992). Effect of serotesting with counselling on condom use and seroconversion among HIV discordant couples in Africa. *British Medical Journal*, 304, 1605-9
- Ateka, G.K. (2006). HIV status disclosure and partner discordance: A public health dilemma. *Public Health*, 120, 493-496.
- Balán, I.C., Carballo-Diéguez, A., Ventuneac, A., & Remien, R.H. (2009). Intentional condomless anal intercourse among Latino MSM who meet sexual partners on the internet. *AIDS Education and Prevention*, 21(1), 14-24.
- Beyeza-Kashesya, J., Ekstrom, A. M., Kaharuzza, F., Mirembe, F., Neema, S. & Kulane, A. (2010). My partner wants a child: A cross-sectional study of the determinants of the desire for children among mutually disclosed sero-discordant couples receiving care in Uganda. *BMC Public Health*, 10,247-258.
- Beyeza-Kashesya, J., Kaharuzza, F., Mirembe, F., Neema, S., Ekstrom, A. M., & Kulane, A. (2009). The dilemma of safe sex and having children: Challenges facing sero-discordant couples in Uganda. *African Health Sciences*, 9, 2-12.
- Boily, M.C., Buve, A., & Baggaley, R.F. (2010). HIV transmission in serodiscordant heterosexual couples. *British Medical Journal*, 340, 1149-1150.
- Carpenter, L. M., Kamalia, A., Ruberantwaria, A., Malambaa, S.S., & Whitworth, J.A.G. (1999). Rates of HIV-1 transmission within marriage in rural Uganda in relation to the HIV sero-status of the partners. *AIDS*, 13, 1083-1089.
- Chatterjee, Nilesh & Hosain, G.M.M. (2006). Perceptions of risk and behaviour change for prevention of HIV among married women in Mumbai, India. *Journal of Health, Population and Nutrition*, 24 (1):81-88.
- Centers for Disease Control and Prevention (2007). *Couples HIV Counseling and Testing (CHCT): Participant's manual*. Atlanta, GA, USA: Author.
- Centers for Disease Control (2004). STD surveillance 2004: Special focus profiles. Retrieved 7/25, 2006, from <http://www.cdc.gov/std/stats/adol.htm>
- Del Romero, J., Castilla, J., Hernando, V., Rodríguez, C., & Garcia, S. (2010). Combined antiretroviral treatment and heterosexual transmission of HIV-1: cross sectional and prospective cohort study. *British Medical Journal*, 340, 2205-2213.

- Emusu, D., Ivankova, N., Jolly, P., Kirby, R., Foushee, H., et al. (2009). Experience of sexual violence among women in HIV discordant unions after voluntary HIV counselling and testing: A qualitative critical incident study in Uganda. *AIDS Care*, 21 (11), 1363–1370.
- Freeman, E.E., & Glynn, J.R. (2004). Factors affecting HIV concordancy in married couples in four African cities. *AIDS*, 18, 1715–1721.
- Gangakhedkar, R.R., Bentley, M.E., Divekar, A.D., Gadkari, D., Mehendale, S.M., et al. (1997). Spread of HIV infection in married monogamous women in India. *JAMA*, 17, 2090-2092.
- Garnett, G.P., & Gazzard, B. (2008). Risk of HIV transmission in discordant couples. *Lancet*, 372, 270-271.
- Gray, R. H., Wawer, M.J., Brookmeyer, R., Sewankambo, N.K., Serwadda, D., et al. (2001). Probability of HIV-1 transmission per coital act in monogamous, heterosexual, HIV-1-discordant couples in Rakai, Uganda. *Lancet*, 357, 1149–53.
- Jewkes, R.K., Dunkle, K., Nduna, M. & Shai, N. (2010). Intimate partner violence, relationship power inequity, and incidence of HIV infection in young women in South Africa: a cohort study. *Lancet*, 376, 41-48.
- Jones, D.L., Chitalu N., Ndubani, P., Mumbi M., Weiss S.M., et al. (2009). Sexual risk reduction among Zambian couples. *Journal des Aspects Sociaux du VIH/SIDA*, 6 (2), 69-75.
- Kalyanwala, S., S. Lyengar, and S. Iyengar, and S. Janardhan, 2007: *Factors underlying the fertility intentions of people living with HIV/ AIDS in Karnataka*. New Delhi, India: Population Council.
- Kanniappan, S., Jeyapaul, M.J., & Kalyanwala, S. (2008). Desire for motherhood: exploring HIV-positive women's desires, intentions and decision-making in attaining motherhood. *AIDS Care*; 20 (6), 625-630.
- Lurie, M.N., Williams, B.G., Zuma, K., Mkaya-Mwamburi, D., Garnett, G.P., et al. (2003). Who infects whom? HIV-1 concordance and discordance among migrant and non-migrant couples in South Africa. *AIDS*, 17, 2245-2252.
- Matthews, L.T., & Mukherjee, J.S. (2009) Strategies for harm reduction among HIV-affected couples who want to conceive. *AIDS Behavior*, 13, S5–S11.
- McGrath, J.W., Celentano, D.D., Chard, S.E., Fullem, A., Kanya, M., et al. (2007). A group-based intervention to increase condom use among HIV serodiscordant couples in India, Thailand, and Uganda. *AIDS Care*, 19, 418-24.
- Mehendale, S.M., Ghate, M.V., Kumar, B.K., Sahay, S., Gamble, T.R., et al. (2007). Low HIV-1 Incidence among married serodiscordant couples in Pune, India. *Journal of Acquired Immune Deficiency Syndrome*: 41 (3), 371-373.
- Mehendale, S.M., Gupte, N., Paranjape, R.S., Brahme, R. G., Kohli, R., et al. (2007). Declining HIV incidence among patients attending Sexually Transmitted Infection Clinics in Pune, India. *Journal of Acquired Immune Deficiency Syndrome*: 45 (5), 564-569.
- Mehta, S.H., Gupta, A., Sahay, S., Godbole, S.V., Joshi, S.N., et al. (2006). High HIV prevalence among a high-risk subgroup of women attending Sexually Transmitted Infection Clinics in Pune, India. *Journal of Acquired Immune Deficiency Syndrome*, 41, 75–80.
- Moreau-Gruet, F., Jeannin, A., Dubois-Arber, F. Spencer, B. (2001). Management of the risk of HIV infection in male homosexual couples. *AIDS*, 15, 1025-1035.

- Mr X v Hospital Z Right to Marry. (2010). Retrieved August 16, 2010, from <http://www.lawyerscollective.org/hiv-aids/judgements/indian-confidentiality-x-vs-hospital-z>.
- Myer L, Carter RJ, Katyal M, Toro P, El-Sadr WM, et al. (2010) Impact of antiretroviral therapy on incidence of pregnancy among HIV-Infected women in Sub-Saharan Africa: A Cohort Study. *PLoS Med*, 7(2): e1000229. doi:10.1371/journal.pmed.1000229
- Myer, L., Morroni, C., & El-Sadr, W.M. (2005). Reproductive decisions in HIV-infected individuals. *Lancet*, 366, 698-700.
- Rispel L, Metcalf C, Moody K, & Cloete A. (2009). *Exploring coping strategies and life choices made by HIV discordant couples in long-term relationships: Insights from South Africa, Tanzania and Ukraine*. Amsterdam, GNP+.
- Solomon, S.S., Mehta, S.H. Latimore, A., Srikrishnan, A.K., & Celentano, D.D. (2010). The impact of HIV and high-risk behaviours on the wives of married men who have sex with men and injection drug users: implications for HIV prevention. *Journal of the International AIDS Society*, 13(Suppl 2):S7 -14.
- Stevens, P.E. & Galvoa, L. (2007). "He won't use condoms": HIV-infected women's struggles in primary relationships with serodiscordant partners. *American Journal of Public Health*, 97 (6), 1015-1022.
- Supreme Court of India - Right to Marry. (2010). Retrieved August 16, 2010, from <http://www.lawyerscollective.org/hiv-aids/activities/legal-services-sc-right-to-marry>.
- Thomas, B.E., Chandra, S., Selvi, K.J.A., Suriyanarayanan, D., & Swaminathan, S. (2009). Gender differences in sexual behaviour among people living with HIV in Chennai, India. *Indian Journal of Medical Research*:129, 690-694.

MODULES
MODULES
RELATED TO
RELATED TO
CARE & SUPPORT
CARE & SUPPORT

Nutrition Counselling

At the end of this unit, participants will be able to

- Explain the relationship between HIV and nutrition
- Assess and address issues related to nutritional status
- Identify appropriate nutrition actions to manage HIV-related symptoms
- Provide comprehensive nutrition counselling to clients

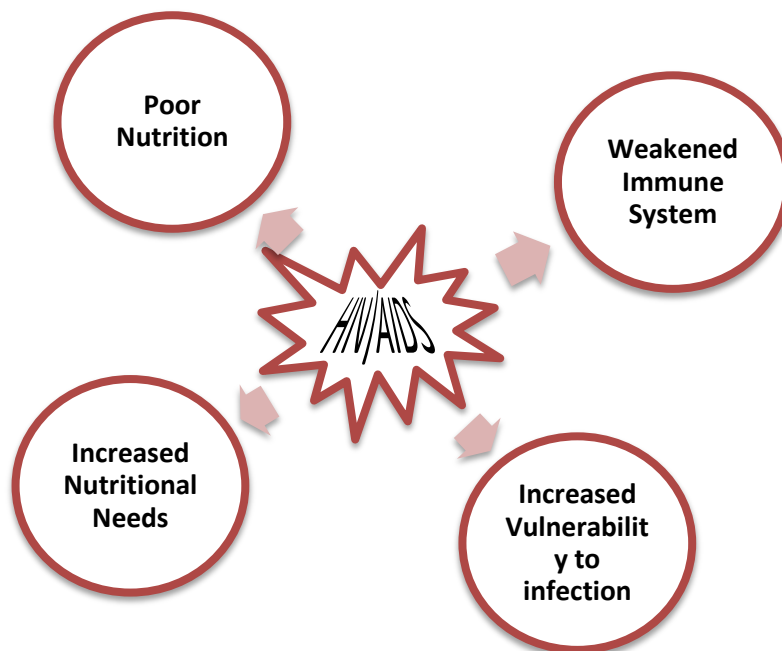
Good nutrition cannot cure AIDS or prevent HIV infection. However, People Living with HIV (PLHIVs) who eat properly are stronger and better able to fight infections. General health and nutritional status of an HIV-positive person can influence the time it takes for a PLHIV to develop AIDS as well as his/her overall quality of life and sense of well-being. As HIV begins to affect health right from the point of infection, nutrition becomes an important aspect of care for PLHIVs. Whether a person is on ART or not, good food is an important part of their life.

Thus the ICTC counsellor should encourage the client to build up healthy eating habits and to prevent the development of nutritional deficiencies.

Understanding the Link between Nutrition and HIV

HIV compromises the PLHIV's health and nutritional status. Poor nutrition in turn affects the PLHIV's health. This forms a vicious cycle:

- ✓ HIV can cause poor nutrition through reduced eating, greater energy requirements, and poor absorption of nutrients in the food.
- ✓ Poor nutrition, in turn, makes the immune system weak, increases the person's vulnerability to infection and makes the impact of the disease worse.



The figure illustrates this cyclical relationship.

- HIV destroys the PLHIV's immune response – that is his/ her ability to resist diseases. This makes him/ her vulnerable to frequent opportunistic infections (OIs).
- HIV and frequent OIs increase the body's use of energy and nutrients. This, in turn, increases the PLHIV's need for these nutrients.
- HIV and frequent OIs may also interfere with food intake and the way the body absorbs and uses nutrients.

- If the PLHIV's increased energy and nutrient needs are not met, he/ she may lose weight and become undernourished.
- This undernourishment can weaken the body's immune response even more.
- The weakened immune system results in repeated infections, which can make the PLHIV develop AIDS more quickly.
- Repeated infections further increase nutritional needs, leading to poor nutritional status, and so the cycle continues.

What the ICTC Counsellor can do

You, as the ICTC counsellor, can provide suitable nutrition counselling that helps in breaking this vicious cycle between HIV and malnutrition. Your messages can achieve this by helping PLHIVs to maintain and improve their nutritional status, boost their immune response, manage the frequency and severity of symptoms, and improve their response to medical treatment.

Ideally, nutrition counselling for PLHIVs should begin as early as possible in the course of the disease to help minimize weight-loss and slow progression of the disease to AIDS. However, in reality, nutrition care for PLHIVs suffers from the following:

- Delay because their HIV status usually becomes known only when they present with OIs.
- Food insecurity – that is many PLHIVs presenting at our ICTCs and ART centres do not have adequate resources to enable them to buy good food.
- Inadequate or wrong information on nutrition on the part of some counsellors.
- PLHIVs are sometimes not aware of their increased nutritional needs.
- PLHIVs may have symptoms such as mouth sores, nausea and vomiting which can further lead to poor nutritional intake.

Thus, it becomes important for the ICTC counsellor to address factors that can predispose him/ her to become malnourished. The counsellor can do this during follow-up counselling sessions at the ICTC itself or during home visits. During post-test counselling, the client is still grappling with the issue of learning their positive status. It is likely that most other information does not gain the client's attention when placed side-by-side with the news of the test.

Aspects of Nutrition Counselling

The counsellor should always remember that nutrition counselling should be simple and practical and should be tailored to the client's needs. It should consider the patient's socio-economic status, religious and cultural beliefs.

To assess and identify the client's needs the counsellor should collect the following information about the client

- Dietary intake (amount and kind of food eaten)
- Presence of HIV-related symptoms or illnesses (e.g., oral thrush, mouth sores, dental problems, vomiting, diarrhoea, depression, appetite loss, altered taste) that may affect food intake of the client
- Methods of food preparation
- Food access (availability) to the client – that is food security
- Sanitation and hygiene conditions in which food is prepared – that is food safety.

This information will help the counsellor to match counselling to the needs of the client. While obtaining this information the counsellor should suggest specific actions to the clients as per the identified needs. The counsellor may also use this information to make referrals to other services. We will discuss these aspects in the next few pages.

Counselling on Dietary Intake

Counselling on dietary intake simply refers to the question of “What to eat?” The counsellor should help the client to understand the need to have a diet which is diverse enough to provide him/her the necessary nutrients.

The daily diet for a healthy PLHIV adult should include all three food groups:

- **Energy-giving food** like whole cereals, sugar, starchy vegetables and fruit
- **Body-building food** like pulses, eggs, nuts, milk and milk products
- **Protective-food** like fruits, vegetables and water

A guide for daily food choices

- Cereals in the form of rice, *roti*, bread, *dalia*, and *upma* (6-11 servings) - that is energy-giving foods.
- Pulses like soyabean, *rajma*, and green gram *dal*, which provide protein, vitamins and soluble fibre (2-3 servings) – that is body-building foods.
- Milk, milk products and animal foods (2-3 servings) – that is body-building foods. These are rich in fat and cholesterol. So encourage clients to make a careful selection.
- Fruits (2-4 servings) and vegetables (3-5 servings) which are rich in minerals, vitamins, antioxidants and fibre - that is protective foods.
- Sweets and oil which should be consumed sparingly.

Note:

For Adults:

1 serving cereal = 1 *roti*/1 bread slice/ ½ *katori* rice.

1 serving pulse = 1 *katori* cooked dal

1 serving vegetables = 1 *katori* cooked vegetables

1 serving fruit = 1 medium-sized fruit

1 serving milk products = 1 cup milk/ 1 *katori* curd

1 serving meat = 1 egg/ 2 pieces of meat/ chicken approximately 100g per piece.

How Different Nutrients Help the Body

Nutrient	Function	Commonly Available Sources
Carbohydrates and Fats/Oils	Provide calories (heat required to raise the temperature of 1 Kg water by 1°C at 15°C), i.e. energy to maintain body temperatures, for metabolic purposes, to support growth and for physical activity.	Energy-giving foods include cereals: rice, wheat, <i>ragi</i> , jowar, tubers, roots, sugar, jaggery and honey, fruits, fats and oils.
Protein	Body building: Skin, bones, muscles organ tissue, blood, hormones and enzymes require protein.	<i>Dal</i> , nuts, egg, soyabean, milk and milk products, fish, meat.
Fibre (Soluble & Insoluble)	Not digested and absorbed. Insoluble fibre adds bulk to the stool and prevents constipation. Soluble fibre helps to improve cholesterol and blood sugar levels	Vegetables, wheat bran, whole grains provide insoluble fibre. Oats, whole pulses, all fruits with skin like apples, plums contain soluble fibre.
Fat		
Polyunsaturated Fat	Healthiest type. Should make up 10% of total calorie intake.	Fish, walnuts, corn, soya bean, sunflower and safflower oil
Monosaturated fat	Should make up 10% of total calorie intake.	Nuts, mustard, rapeseed, canola, olive oils, avocado and fish
Saturated Fat	Increases risk of cardiovascular disease. Should be less than 7% of the total calorie intake.	Fatty meat, poultry with skin, ghee, butter, whole-milk dairy foods, coconut and palm oils
Vitamins		
Vitamin A	Prevents infections. Necessary for eyes, skin, hair and	Egg, liver, milk and milk products, Green- and yellow-coloured vegetables and fruits

	mucous membranes.	
Vitamin B (<i>Thiamine, Riboflavin, Niacin, Folic acid, B12</i>)	Develops antibodies Necessary for healthy skin, limbs tongue, eyes, blood nerves and digestive system.	Bran, pulses, nuts, milk and milk products.
Vitamin C	Forms collagen that gives structure to bones, cartilage, muscle, blood vessels and capillaries, bones and teeth. Aids iron absorption and production of antibodies and t-cells	Fresh citrus fruits, vegetables like <i>amla</i> , guava, oranges, <i>mausambi</i> , capsicum, cabbage
Vitamin D	Needed for absorption of calcium.	Fish eggs, butter, exposure of skin to sunlight
Vitamin E	Antioxidant: prevents the ageing and destruction of body cells.	Whole grain, cereals, eggs, sunflower and olive oil, green leafy vegetables, nuts.
Minerals		
Iron	For Haemoglobin in the blood	Green leafy vegetables particularly <i>chulai</i> , liver, egg yolk, jaggery, organ meat.
Calcium	For teeth, bones and muscles	Milk and milk products, gingelly seeds, <i>methi</i> leaves, mint, almonds
Sodium	All cells need it, especially nerve cells	Salt
Iodine	For the hormone Thyroxin which is needed for normal growth.	Iodized Salt
Zinc	Antioxidant and anti-inflammatory, boosts, antibody production	Whole grains, yeast, nuts, sea food (lobster, salmon), pulses
Selenium	Antioxidant	Garlic, sea food, asparagus, spinach, eggs and mushroom

When counselling on dietary intake it is critical to remember that the dietary needs of a PLHIV are greater than that of a non-infected person. The tables below show the increased dietary requirements of an adult male and a female – the recommended dietary allowances (RDAs).

Changes suggested for an adult male

Nutrients	Normal	PLHIV
Energy(Kcal)	2400	2700
Proteins (g)	60	60
Fats (g)	20	Not to exceed 40
Micronutrients 1RDA	Iron, vit A, B1, B2, B3, B6, Folic acid & B12	In addition vit E, selenium, magnesium and zinc

Changes suggested for an adult female

Nutrients	Normal	PLHIV
Energy(Kcal)	2200	2500
Proteins (g)	50	50
Fats (g)	20	Not to exceed 40
Micronutrients 1RDA	Iron, vit A, B1, B2, B3, B6, Folic acid & B12	In addition vit E, selenium, magnesium and zinc

When counselling on dietary intake it is critical to remember that the dietary needs of a PLHIV are greater than those of a non-infected person.

The ICTC counsellor should ask the client to recall the 24-hour menu that he/she is following:

- *“Can you tell me what your daily meal is like on an average day (An average day is a day on which you might go to work or to school.)?”*
- *“Can you tell me what your meal is like on a special day (e.g., a Sunday or a religious festival)?”*
- *“Can you tell me what your meal is like on a day when you fast?”*

If needed, the counsellor should discuss how the client could modify existing meal patterns to make them more nutritious. Take care to make suggestions what are affordable to the client.

Further aspects of counselling on dietary intake include:

- Number of meals the client eats each day: *“How many meals do you eat each day?”* Normally the person should take 4-5 meals per day (breakfast, lunch, dinner and one or two snacks a day). But during acute illness the clients should be served small frequent meals on a 2 hourly basis (that is 5-6 small meals) as the bodily requirements for food increase. Palatable snacks like *sooji, idli, dhokla* or veg sandwich should be incorporated. Each meal should be made nutrient-dense as the appetite is poor.
- Assess whether the diet is diverse enough to provide the necessary nutrients – that is meals should contain foods from different food groups in the appropriate amounts and forms. Counsel the client to eat a variety of food items.
- Assess whether the client’s diet is nutritious or not. Counsel the client that diet can be made nutrient-dense by adding locally available ingredients such as milk powder to *Kheer*; adding honey/jaggery (*gud*) to drinks and food; adding vegetables to *roti*, rice and pulse preparations; adding *dal* to soups and *rasams*; adding *besan* to *paratha/chapati* to make *paustik roti*; adding peanuts to *upma, poha* or *pulao*.
- Check whether the client smokes or drink alcohol. Encourage the client to avoid alcohol or smoking as they affect the appetite as well as nutritional status of the client.

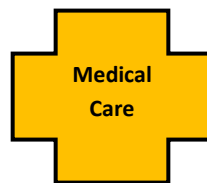
Eight critical nutrition practices to prevent malnutrition among PLHIVs

1. Regularly monitor weight.
2. Increase energy intake by eating a variety of foods, especially energy-rich foods. This is critical for illness periods.
3. Drink plenty of boiled or treated water.
4. Practice a healthy lifestyle by avoiding alcohol, tobacco, sodas, and other coloured or sweetened drinks (e.g., Pepsi, Limca and Coke).
5. Maintain hygiene and sanitation.
6. Exercise regularly.
7. Seek early treatment of infections and manage symptoms with dietary practices when possible.
8. Return to the usual eating patterns when HIV-related symptoms or illnesses resolve.

Counselling on Managing HIV-related Symptoms through Diet

Being infected with HIV can make it hard for PLHIVs to eat sometimes. They may develop common HIV-related symptoms that affect eating, digestion and absorption like nausea and vomiting, loss of appetite, constipation/ diarrhoea, fever, anaemia and mouth sores which further leads to weight loss.

The ICTC counsellor can help the PLHIV to select those foods and nutrition practices which help in managing the effects of HIV-related symptoms. During follow-up sessions at the ICTC or during home visits, the counsellor should explain the nutrition implication of the symptoms and should share the general recommendations for managing common symptoms provided in the following table. However, the counsellor should also strongly advise the client to seek medical help when symptoms persist.



General recommendations for managing HIV-related symptoms

<i>Symptoms</i>	<i>Management</i>
<i>Diarrhoea</i>	<ul style="list-style-type: none"> • Eat small amounts of food more often. • Eat bananas, mashed fruit, soft boiled white rice and porridge (<i>daliya</i>) to help slow down the diarrhoea. • Eat food at room temperature; very hot or very cold foods stimulate the bowels and make diarrhoea worse. • Drink a lot of fluids (soups, diluted fruit juice, clean boiled water and weak tea) • Avoid high-fat or fried foods • Avoid coffee and alcohol. • Avoid foods that cause gas or stomach cramps, such as beans, cabbage or onions. • Limit or eliminate milk and milk products such as yoghurt (<i>dahi</i>) to see whether the symptoms will improve. • Remove the skin from fruits and vegetables.
<i>Loss of Appetite</i>	<ul style="list-style-type: none"> • Eat small, frequent meals (5-6 meals/day) • Eat nutritious snacks • Add flavour to food and drink. • Drink plenty of liquids • Take light exercise and do light activity • Take walks before meals: Fresh air helps to stimulate appetite • Having family or friends assist with food preparation and sharing a meal provides a psychological ambience that aids appetite.
<i>Mouth Sores</i>	<ul style="list-style-type: none"> • Eat foods cold or at room temperature. • Eat soft and moist food such as porridge (<i>daliya</i>), mashed potatoes or mashed non-acidic vegetables or fruit • Avoid caffeine, alcohol and smoking, which can irritate mouth sores. • Avoid citrus fruits, tomatoes, spicy foods and very sweet, sticky or

	<p>hard foods.</p> <ul style="list-style-type: none"> • Soften your food by soaking it in liquid (milk, broth, juices, soup). • Drink fluids with a <u>clean</u> straw to ease swallowing. • Clean and rinse your mouth after each meal
<i>Nausea and Vomiting</i>	<ul style="list-style-type: none"> • Eat small, frequent meals (5-6 meals/day) • Eat bland food • Avoid food with strong or unpleasant odours • Avoid an empty stomach as this makes nausea worse. • Avoid lying down immediately after eating • Avoid coffee and alcohol • Drink plenty of liquids
<i>Constipation</i>	<ul style="list-style-type: none"> • Eat fibre-rich fruits (mangoes, guavas, jackfruit), vegetables (beans, peas, pumpkin, carrots, green vegetables) & sprouted food • Drink at least eight glasses of fluids a day, especially boiled water • Drink a cup of warm water in the morning before eating to help the bowels move • Do light exercises like taking frequent short walks
<i>Anaemia</i>	<ul style="list-style-type: none"> • Eat organ meat, fish and eggs. • Eat cereals like <i>ragi</i> and <i>bajra</i> • Eat variety of green leafy vegetables (raddish greens, mint, <i>chaulai</i>, cauliflower leaves and <i>sundaikai</i>). The best way for the body to utilize iron from plant sources is to combine food rich in Vitamin C, like <i>amla</i>, guava, oranges and lemons. • Take <i>jaggery</i> and dates between meals.

Counselling for Weight Loss

The ICTC counsellor should inform the client that weight change over a given period indicates how his/ her nutritional status has changed. Unintentional weight loss indicates poor food intake or disease that affects food digestion, absorption or utilization.

- Rapid weight loss (or gain) indicates a need for nutrition care and support.
- For an average adult serious weight loss is indicated by a 10% loss of body weight or 6-7 kg in one month. In most PLHIV it indicates the onset of AIDS and the need for extra nutrition.
- It is important to regain the lost weight as soon as possible and to restore the body's nutritional reserves. Educate the client that once the infection is over and the person is feeling better, he or she should start eating normally again.

Counselling on Food Preparation

It is not sufficient to just discuss type of food and quantities of food with a PLHIV. Often, people cook in a manner that causes them to lose the benefit of nutrients in the food: Nutrients like vitamin B and C are lost when foods are boiled or soaked in water and the water is thrown away. So the counsellor should help the client to use effective ways of food preparation to maintain the nutritional values of the food prepared. This can be done while still ensuring that food is tasty.

- **Enrich foods** by adding other foods that are high in energy and nutrients. This is called making food nutrient-dense
 - High energy: Oils, butter, *ghee*, sugar
 - High protein: Groundnut paste, milk, milk powder, eggs
- **Add sprouted seeds** to local foods to improve nutrient availability and digestibility
 - Sprouted foods are easily digested and absorbed and help the body digest and absorb other foods also.
 - Cereals such as wheat, *bajra*, *jawar* and maize can be sprouted, dried and milled into flour. This flour can be used to prepare *daliya*. These sprouted grains can also be dried in the shade and roasted lightly on a *tavaa*.
 - Legumes such as beans, cowpeas (*lobia*), chickpeas (*chhole*) and green peas can be sprouted and prepared as vegetables to eat with other foods.
- **Use fermented foods**
 - Fermented food is soft and easy to digest. It provides variety in texture. Fermentation increases the nutritive value of the food. Vitamin B, vitamin C and folic acid are increased during this process. Iron gets released from its bound form during fermentation and is easily absorbed.
 - Fermented foods include sour milk, yoghurt (*dahi*), sour porridge, *dhokla*, *idli*, bread.
- **Use fortified foods**
 - Some cereal flour and cooking oils are fortified with nutrients.
 - Always use Iodized salt. Make sure it is stored in a closed container as iodine is lost when the salt comes in contact with air for a long time.
- **Preserve nutrients during cooking**

- Steaming vegetables, fish, potatoes and bananas helps preserve nutrients in the food and is healthier than boiling or frying.
 - Wash vegetables before cutting them so that minerals and vitamins are not destroyed.
 - Peel vegetables thinly as vitamins and minerals are found just under the skin.
 - If vegetables are to be cooked in water, put them into the boiling water rather than heat the water and vegetables together.
 - Do not overcook the food as overcooking destroys many nutrients.
 - Use just enough water for cooking. Do not throw away the extra water. Use this extra water to cook some other food.
 - Cook rice in just enough water which gets absorbed during cooking (use 2 *katoris* of water for every one *katori* of rice)
 - Do not use cooking soda. Instead add tamarind or lemon juice to improve the flavour.
 - Cook in a pan which has a well fitting lid. When you cook in an uncovered pan most nutrients are lost.
- **Use spices**
 - Add spices to food or drinks to increase appetite. Some spices (e.g., ginger, garlic, cinnamon, cardamom and turmeric) can aid digestion.
- **Change the texture of food for sick people**
 - Mashing or pureeing food makes it easier to chew, swallow, and digest. We often do this for little children. But adults may also benefit.
 - Pounding meat before preparation makes it soft and easy to eat.
 - Marinate meat with yoghurt for a few hours to make it tender.
- **Reduce cooking time and fuel**
 - Soak beans overnight.
 - Hull cereals (remove outer covering) such as dry maize.
 - Ferment foods.

Counselling on Ensuring Food Security

During follow-up counselling or home visits, the ICTC counsellor should check if the client has access to food, including staples. Individual access to food is usually affected by lower earnings, reduced food production, lack of family support, effect of seasonality on food production and finally stigma associated with HIV.

For clients who have limited access to food, or who have just enough money to buy one meal a day, discussions and suggestions on a nutrient-dense diet or diverse diet will not be sufficient. With these clients the ICTC counsellor should discuss ways in which the client can ensure the availability of food at low or no cost.

Some suggestions are:

- Encourage clients to avail of any local nutrition schemes – those meant for PLHIVs as well as those for non-PLHIVs.
- Encourage clients to cultivate easily-grown vegetables in their own home gardens such as vegetables like cauliflower, cabbage, beans, cucumbers, peas, tomatoes, spinach, brinjal, raddish, carrot, ladyfinger, coriander, *methi*, broccoli and *pudina*. If ground space is available the creepers like beans, gourd, bitter gourd, sponge gourd (*tori*) and pumpkin can also be grown.
- Cultivate and use plants which are easily available and highly nutritious like *Chulai* (*Amaranthus*).
- In urban communities where space is limited, clients can try to grow small vegetables on a kitchen windowsill in a pot. Vegetables like brinjal, tomato, spinach, *methi*, *pudina* and coriander (*dhania*) can be easily grown in pots.
- In rural areas where client have more space they may cultivate trees like lemon, papaya, pomegranate and guava. Where possible, they can supplement their income by selling the extra produce.
- Clients from rural areas can also cultivate hens for eggs. But while doing so PLHIVs should take necessary precautions to prevent themselves from developing opportunistic infections. They

should avoid direct contact with the hens and should always wash their hands after working with livestock.

- PLHIV clients who do not have space for the household gardens can join and work in a community garden: PLHIVs can work with other people to form a group to collectively cultivate a single piece of land. Working in a community gardens can contribute to household food security of PLHIVs by providing direct access to food that can be harvested, prepared and fed to family members. The excess harvested products can also be sold and become a dependable source of income.
- Many PLHIVs report a therapeutic effect from gardening. This is a side benefit from this activity.

Points to remember:

- **Encourage the healthy actions that you want people to continue.**
- **Discourage the unhealthy or harmful actions that you want people to discontinue.**
- **Ignore/ Overlook the actions that neither help nor harm health.**

Counselling on Food Safety

Food can easily be contaminated by harmful germs or poison, if not handled, prepared and stored in a safe way. A person eating contaminated food may become ill (with food-borne illness) and experience symptoms such as stomach pains, nausea, vomiting and diarrhoea. The consequences of food-borne illness are more severe for people with low immunity such as PLHIVs.

During follow-up sessions or home visits you, as a counsellor, should identify food-safety issues affecting the client and suggest ways of ensuring proper food hygiene:

- Maintain clean surroundings and cooking utensils to stop food-borne illnesses from spreading.
- Protect food from rodents, insects and animals.
- Wash hands thoroughly before and after cooking.
- Use clean water for cooking.
- Keep raw and cooked foods separate to stop germs from spreading. This is particularly important for raw meat.
- Wash all fresh fruits and vegetables thoroughly.
- Cook food thoroughly to kill germs – but avoid over-cooking vegetables.
- Eat cooked food immediately.
- Store food carefully.
- Eating outside food is generally discouraged. This is particularly true for raw vegetables, fruits or curd. Fresh home-made food is safest because the client would have taken adequate care to ensure it is free from infective agents.

Note: This advice about keeping the food and cookware safe and clean is meant to protect client from the germs that they carry. HIV cannot spread through food and water. Tell the client to feel free to have their friends in their kitchen and to cook and share meals with them.

Benefits of Nutrition Counselling

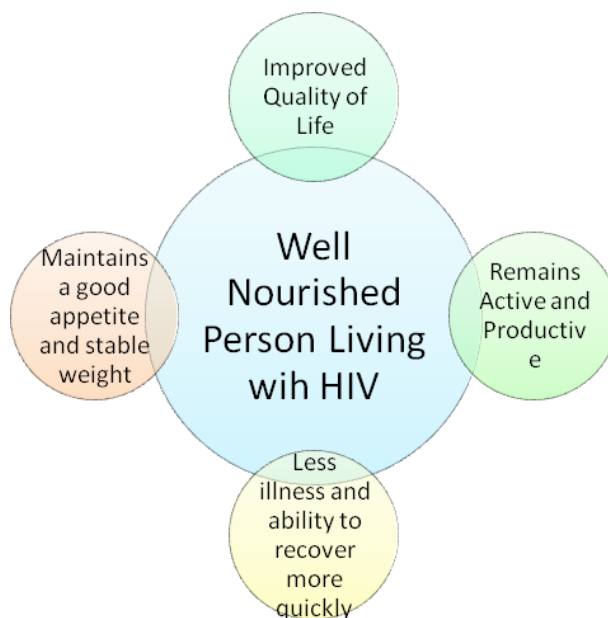
Effective nutrition counselling will improve the quality of life of PLHIVs. It is important to remember that nutrition counselling must span the entire spectrum of HIV/AIDS counselling and should include not only the person infected with HIV/AIDS but also the entire family.

PLHIVs who are well-nourished are likely to:

- ✓ Have a better quality of life, and be able to work;
- ✓ Enjoy good health, remain active, care for themselves and help with the care of children and other dependants;
- ✓ Have fewer illnesses and recover more quickly from infections, thus reducing costs for health care.
- ✓ Maintain a good appetite and stable weight.

CLHIVs who are well-nourished can:

- ✓ Attend school regularly, resulting in better education and development;
- ✓ Have more energy to play and have fun.





Questions to ICTC Counsellors

Can you think of some local customs that result in lowering the nutritional status of a PLHIV – for instance, rituals related to pregnancy or menstruation?

Are you sure you know when you should stop nutrition counselling and advise a client to see the doctor



References

- National AIDS Control Organisation, Ministry of Health and Family Welfare, Government of India & World Food Programme (2008). *Good nutrition in HIV: A guide*. New Delhi, India: Authors.
- National AIDS Control Organisation, Ministry of Health and Family Welfare, Government of India & World Food Programme (2008). *Manual for training on nutritional counselling*. New Delhi, India: Authors.
- National AIDS Control Organisation, Ministry of Health and Family Welfare, Government of India & World Food Programme (2008). *Good nutrition in HIV: Flipbook for counselling*. New Delhi, India: Authors.
- World Health Organisation & Food and Agriculture Organisation of United Nations (2009). *Nutritional care and support for People Living with HIV/AIDS: A training course*. Geneva, Switzerland: Authors.
- Regional Centre for Quality of Health Care (2004). *Food and nutritional counselling for PLWHA on antiretroviral therapy*. Kampala, Uganda: Author.
- East, Central and Southern African Health Community Secretariat, (2008). *A training manual for nurses and midwives*. Tanzania: Author

Home-Based Care

At the end of this unit, participants will be able to

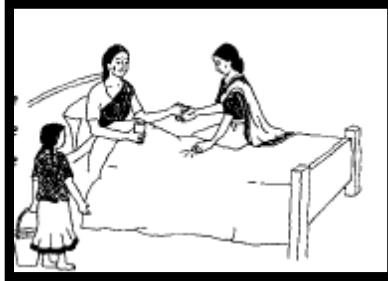
- Describe the importance of home-based care for PLHIVs.
- List simple measures for managing conditions such as diarrhoea and fever at home.
- State clearly the conditions under which home-based care is no longer sufficient.
- Demonstrate ways to care for a bed-ridden PLHIV in the home.
- Explain the properties of some common Indian herbs.

Home-based care includes both the things that PLHIVs do to take care of themselves and the care they receive from their family members in their own home. Home-based care can enhance the quality of life of PLHIVs and help to extend their productive lives for many years.

Home-based care is important for PLHIVs because

- ✓ Most ill persons prefer to stay within their own home even when ill.
- ✓ Home-based care is less expensive and can be given with more compassion and dignity in a familiar environment as compared to a hospital.
- ✓ PLHIVs do not have to travel long distances to seek care at a hospital.
- ✓ Home-based care helps to reduce the stigma attached to the disease and permits PLHIVs and their families to participate freely in community activities.
- ✓ The entire family has an opportunity to care for the individual and this promotes family unity.

- ✓ Some illnesses associated with HIV infection can be managed at home if PLHIVs are given basic information.
- ✓ Home-based care can delay the progression of HIV infection to AIDS by reducing the effect of HIV-related symptoms and illnesses on the PLHIV's body.



ICTC Counsellor's Role in Home-Based Care

To a large extent, how a PLHIV will manage his/her life depends on his/ her adjustment to the HIV illness conditions. As an ICTC counsellor, you have a good opportunity to prepare the client to live positively with HIV/AIDS during post-test counselling. While sharing the test results with the client, you should inform the client that he/ she can delay the progression from HIV to AIDS through a healthy lifestyle. He/ she can still have a healthy, happy and productive life by following certain simple, preventive measures:

- Visiting the ART centre (or the LAC) regularly – even when not immediately eligible for ART care, that is during the Pre-ART Care period.
- Making every effort to live a healthy and safe lifestyle.
 - ✓ Have a positive attitude towards self and others.
 - ✓ Take responsibility to work on problems instead of blaming others for them
 - ✓ Resolve feelings of guilt and shame.
 - ✓ Get adequate sleep.
 - ✓ Eat foods rich in protein, vitamins, minerals and carbohydrates.
 - ✓ Use clean water for drinking and cooking.
 - ✓ Exercise to keep fit.
 - ✓ Engage in work, if possible.
 - ✓ Use condoms during sexual intercourse.
- Avoiding unhealthy practices of smoking, drinking alcohol or using other drugs and having unsafe sex without condoms.

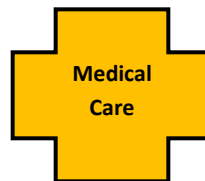
Most counsellors at ICTCs do convey these messages. But they also have the opportunity to do more.

Counselling needs of PLHIVs will vary from person to person. Counsellors should counsel clients with symptoms to seek medical help and give them appropriate messages to manage their symptoms. Clients who do not have any symptom should be counselled to live positively as well as to recognize and to treat infections as soon as they occur. The second part is important to prevent complications from developing. Many symptoms can be managed at home. But a good counsellor will also teach clients to recognize when home-based care is not enough.

Managing Common HIV-related Problems at Home

PLHIVs often develop common problems such as diarrhoea, weight loss, mouth sores, genital problems, general weakness and tiredness, common cold and cough. This section discusses how to manage some of these common problems at home.

Please carefully read the instructions – especially those regarding “**When to seek medical attention.**” If a client shows these signs, they should be immediately referred to the nearest health facility. We will highlight these instructions with the following symbol.

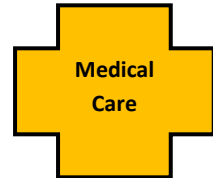


Diarrhoea

A PLHIV may develop diarrhoea because of contaminated food or water, worm infestation, viral infection of the intestines (HIV enteropathy) and some drugs. Treatment for diarrhoea should be initiated as early as possible: “Early home therapy” is needed to prevent dehydration and further damage.

When to seek medical attention

- ✓ In case of the following danger signs of dehydration, the client should seek medical care at once: Sunken eyes, dry lips, dry tongue, thirsty feeling, increased irritability, restlessness and lethargy, limited or no urine output, loose skin (Skin become so dry that it goes back slowly when pinched).
- ✓ In case the diarrhoea does not resolve.



What to teach the client

- ✓ No drugs are needed for diarrhoea if it does not last for long. Avoid taking self-medication.
- ✓ Replace fluids by drinking boiled water. If this is not possible, the client should use Zeoline solution. If not possible he/ she should filter the water or, at least, drink water from a safe source. Drink lots of liquids in the form of boiled water, tea, thin soup and juices.
- ✓ Take ORS. If possible, add half a cup (120ml) of fruit juice, coconut water or mashed ripe banana to the ORS solution.
- ✓ Do not stop eating. Consume soft or mashed foods like rice and porridge. Eat as much fruit and vegetables as possible, especially bananas, papaya and pumpkin. Eat smaller portions more frequently and make sure that food is fresh and not spoiled. Add good herbs such as cloves and ginger to food.



- ✓ Avoid spicy foods, acidic fruit (like oranges) and deep fried/very oily foods.
- ✓ Wash and dry the skin around the anus and buttocks after every bowel movement. Apply petroleum jelly (Vaseline) to dry skin.
- ✓ Teach the client when to seek medical attention.

Care for Children Living with HIV



- ✓ Give the child lots of fluids to drink like rice water with a pinch of salt, ORS, tender coconut water, butter milk, *dal* water, vegetable soup, unsweetened tea, and fresh fruit juice.
- ✓ Older children can be given *idli*, *idiyappam*, rice and *dal*, boiled potatoes, banana, bread and other easily digestible foods which are bland.
- ✓ Use a cup and spoon to feed small children because it allows fluid intake in small steady amounts (which reduces vomiting).
- ✓ Give careful skin care to very small infants. To prevent sores and rashes from wet nappies and underwear, leave the baby's bottom exposed to air till it dries. Potassium permanganate solution is a good antiseptic for cleaning infected sores. Add a pinch of crystals to a litre of clean water.



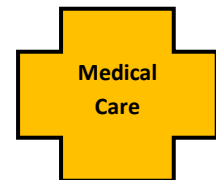
Mouth Sores (Candidiasis)

The normal organisms residing in the mouth can cause small, white or yellow patches on the inside of the mouth and tongue of a PLHIV. These patches usually come off easily with a small amount of bleeding when rubbed or scraped with a brush or fingernail. The infection may also result in burning pain, altered sensation and oral ulcers. It may be difficult to eat food because of these ulcers.



When to seek medical attention

Seek medical help if the problem does not respond to simple home-based care or if there is difficulty in eating and swallowing.



What to teach the client

- ✓ Manage mouth sores at home by scrubbing the tongue and the gums gently with a soft toothbrush or cloth at least three or four times a day, and then rinsing the mouth with a mild salt solution, a dilute mouthwash or lemon water.
- ✓ Suck a lemon, if not too painful, to slow down the growth of the fungus.
- ✓ Wash the mouth with tea made from *neem* or *tulsi* leaves.
- ✓ Apply Gentian violet solution three or four times a day. The solution is prepared by dissolving one teaspoonful of gentian violet crystals in half a litre of clean water.
- ✓ Chew garlic or eat yoghurt as this can also give some relief.



- ✓ Chop *tulsi* leaves, mix them with water and gargle.
- ✓ Avoid eating sweets and spicy foods.
- ✓ Maintain oral hygiene by rinsing the mouth with warm salt water, mint solution or a mouthwash solution after eating and in between meals.
- ✓ Maintain proper nutrition by eating healthy food. Protective foods rich in vitamins, especially oranges, lemons and tomatoes can prevent oral problems to a great extent.
- ✓ Avoid alcohol and smoking (and items containing alcohol and tobacco) as they increase risk of oral problems.

Care for Children Living with HIV

- ✓ Clean the mouth with soft, cotton swabs - using a brush will be painful and may cause bleeding.



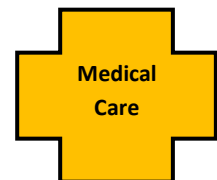
Fever

Fever means that the body temperature is too high/too hot. It is a sign that something is wrong in the body. A PLHIV may develop fever because of infections like tuberculosis, pneumonia, or typhoid. The person should see a doctor to treat the underlying cause of the fever. The measures discussed here are only to give symptomatic relief.



When to seek medical attention

- ✓ As fever is a sign of some underlying cause, it is important to seek medical help anyway.



What to teach the client

- ✓ Wipe the skin with a cool, wet cloth and place another cool, wet cloth (or sponge) on the forehead.
- ✓ If cold sponging does not help, then take a paracetamol tablet (For adults: 500 mg once in 6 hours). Do not take more than four tablets per day.
- ✓ Dress in light, cool clothing.
- ✓ Watch for any temperature rise and pattern of temperature rise - often in tuberculosis there is a low-grade fever with a rise in the evening.
- ✓ Drink more fluids - water, tea, broth and juice.



- ✓ Take infusions of good herbs like ginger (*adrak*), cinnamon (*dal chini*), and cloves (*lavang*). These herbs induce perspiration that helps in lowering the body temperature.
- ✓ One glass of water with 5-7 *tulsi* leaves and 2-4 peppercorns is useful in lowering fever.
- ✓ Rest till the fever subsides.
- ✓ Eat small meals frequently (5-6 meals/day) so that the body's increased nutrition needs are met regularly.

Care for Children Living with HIV

- ✓ Sponge the entire body of the child by wiping the skin with a wet cloth, especially the chest and forehead.
- ✓ If the doctor has prescribed liquid paracetamol, squirt the medicine slowly into the side of the child's mouth using a dropper or syringe or spoon.
- ✓ Praise the child after he/she takes medicines.
- ✓ Do not hide medicine in food as the child may start disliking that food item and may refuse to eat it in future. If the medicine tastes bad, tell the child in advance. Give him/her a spoonful of sugar that will allow the medicine to get down. Alternatively, give the child a social treat such as extra television time. Praise the child for taking medicine without a fuss.

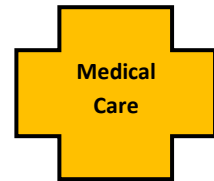


Nausea and Vomitting

A PLHIV may develop nausea and vomiting because of the HIV infection itself or infections like yeast, malaria and other OIs. Nausea and vomiting could also be because of reactions to some medicines.

When to seek medical attention

- ✓ Seek medical help if vomiting is frequent or continues for more than 24 hours with fever and dehydration or if the vomit blood in it.
- ✓ Seek medical help in case of danger signs of dehydration such sunken eyes, dry lips and loose skin.



has
as

What to teach the client

- ✓ Take small and frequent sips of fluid, weak tea, or ORS.
- ✓ Avoid an empty stomach as this makes nausea worse.
- ✓ Eat small, frequent meals (5-6 meals/day).
- ✓ Eat bland food.
- ✓ Take soups and stews which contain helpful herbs like cloves and ginger.
- ✓ Avoid food with strong or unpleasant odours.
- ✓ Avoid lying down immediately after eating.
- ✓ Do not take any medicines on an empty stomach.

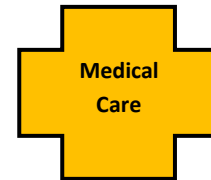


Cough and difficulty in breathing

Cough, difficulty in breathing, chest pain and increased production of sputum are common symptoms of problems like influenza, pneumonia and tuberculosis.

When to seek medical attention

- ✓ Seek medical help in case the following occurs with cough:
 - Sudden high fever with chills
 - Severe chest pain or discomfort
 - The color of sputum changes to grey, yellow or green
 - The sputum has blood in it
 - The person has severe difficulty in breathing



What to teach the client

- ✓ Take the correct and complete course of medicines as prescribed by the physician. Finish the whole course of antibiotics even if you feel better.
- ✓ Keep active by walking about, turning in bed and sitting up - this encourages the lungs to drain. Someone in the home can also massage or gently pat the client on the back over the lungs to encourage drainage.
- ✓ Hold a pillow to the chest or press the painful area with the hand while coughing - This can make the cough less painful.
- ✓ Cough and clear the lungs at least four times a day - This is an important way to clean the lungs of accumulated mucus and disease-causing micro-organisms.
- ✓ Drink lot of water along with medicines - to replace the fluid lost through the lungs and to keep the mucus from becoming too dry and sticky.
- ✓ Inhale hot water vapour (steam) to loosen the mucus several times a day.



- ✓ Practise a few home remedies like adding half a teaspoon of turmeric (*haldi*) powder in two tablespoons of ginger (*adrak*) juice with two tablespoons of honey and some lemon juice.
- ✓ Cover the mouth with a hand or cloth while coughing since many germs can pass to other people through the air.



- ✓ Spit into something that can be burned or buried into the ground so that no one else gets infected from the spit.
- ✓ Try and stay in a room which is cross-ventilated – that is one which has a passage for fresh air to come in and another for air to pass out.

Care for Children Living with HIV:

- ✓ For a very small child with difficulty in breathing the caregiver must check if he/she just has a blocked nose. Here the caregiver can clear the dry or sticky mucus from the congested nose using a wick made of cotton cloth, moistened in clean salt water (a quarter of a teaspoon in a cup of water).

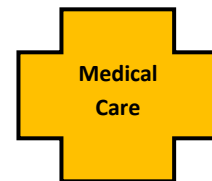


Weight Loss

A PLHIV can develop a significant weight loss if his/her increased nutritional needs are not met. This can happen as there is reduction in food intake and poor utilization of nutrients because of HIV. Weight loss can lead to weakness, lower immunity and faster disease progression.

When to seek medical attention

- ✓ If there is unexplained weight loss of 6-7 kilograms then the person should immediately seek medical help.
- ✓ Seek immediate treatment for any underlying illness like tuberculosis.



What to teach the client

- ✓ Regularly monitor body weight. For an average adult, serious weight loss is indicated by a loss of 10% of body weight in one month – or 6-7 kilograms in one month. So if there is unexplained weight loss of 6-7 kilograms then the person should immediately seek medical help.
- ✓ Eat 5-6 small meals daily. Eat snacks between meals such as peanuts, roasted *chana*, biscuits and fruit.
- ✓ Enrich meals by making meals 'nutrient-dense'. For example, add milk powder to *Kheer*, add honey/ jaggery (*gud*) to drinks or food, add vegetables to *roti* and rice, pulse preparations, add *dal* to soups and *rasams*
- ✓ Eat a variety of foods. Include favourite, well-liked foods. Select combinations of different cereals, vegetables and fruits.
- ✓ Continue to eat during periods of illness and infection.
- ✓ Increase food intake following periods of appetite loss or acute diarrhoea.
- ✓ Avoid alcohol and smoking
- ✓ Do not be too rigid about meal times - eat when hungry.

- ✓ Drink fluids after, and in between meals, not before and during meals.
- ✓ Use different cooking methods like boiling, steaming and baking.
- ✓ Use appetizers like *rasam* and *jaljeera* which will stimulate appetite.
- ✓ Take light exercise to stimulate appetite
- ✓ Rinse the mouth before eating. Maintain oral hygiene by regularly brushing teeth. Treat mouth sores as soon as possible.
- ✓ Eat food in pleasant surroundings, with family or friends.

Skin problems

Skin problems are common in PLHIVs. The most common causes of some of these problems include:

- Yeast infections (thrush, candidiasis)
- Other fungal infection (e.g. ringworm)
- Bacterial infections
- Shingles (herpes zoster)
- Scabies
- Poor hygiene
- Allergic reactions to medicines or skin irritants
- Bed sores (caused by lying in one position in bed)
- Eczema
- Kaposi sarcoma

What to teach the client



- ✓ Clean the skin frequently with soap and clean water and keep it dry between washing.
- ✓ Almost all skin problems involve the sensation of itching. Scratching the itching skin with fingernails can make things worse, either by breaking the skin or by introducing or spreading infection. This can be avoided by keeping nails short. Try to encourage people not to scratch any type of skin lesion or sore. However, rubbing with the flat of the fingers or gentle slapping can give some relief.
- ✓ Itching can be reduced in a number of ways, including the following:
 - Cooling the skin with water or fanning it.
 - Applying lotions such as calamine that are soothing and prevent the skin from becoming too dry
 - Not letting the skin get hot and not applying warmth to itching areas
 - Use safe traditional remedies that are available locally.

Herpes Zoster (*Nagin*)

Herpes Zoster is a viral infection. It begins as a painful rash with small blisters, usually on the face, limbs or trunk. Shingles on the face may affect the eyes, causing pain and blurred vision. The blisters often combine, resulting in a large eroded or broken area, and there may be an intense burning feeling in the affected area. Healing takes place over several weeks and leaves discoloured areas on the skin.

What to teach the client



The following measures may be helpful:

- ✓ Applying calamine lotion twice daily to relieve pain and itching promotes healing.
- ✓ Keeping the area dry and not letting clothes rub on them if possible.
- ✓ Wearing clean, loose-fitting, cotton clothing.
- ✓ Relieving pain with aspirin or paracetamol, though sometimes the pain may be very severe
- ✓ Preventing infection by bathing the sores with warm salt water three or four times a day or applying gentian violet solution once a day, or antibiotic skin creams or ointments if available.
- ✓ Watching for signs of infection of the shingles sores such as redness or pus. If infection occurs, treat as indicated for infected wounds above.

The pain usually diminishes after three or four days. Unfortunately some people develop a persistent pain and scarring over the affected area. Rubbing creams on the scars or painful areas may help; medicines for pain such as aspirin or paracetamol may also be needed.

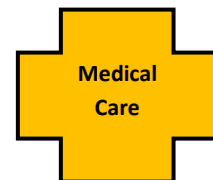
Genital problems

PLHIVs who do not use condoms during sexual intercourse may develop Sexually Transmitted Infections (STIs) with the following symptoms:

- ✓ Discharge (white, yellow, or greenish) from vagina or urethra or anus – the discharge may smell.
- ✓ Pain or discomfort during sex or when urinating
- ✓ Open sores in the genital, groin (inside the thighs), or rectal (around the anus) areas
- ✓ Rashes inside or around the genital area
- ✓ Warts in the genital or rectal areas
- ✓ Swollen glands in the groin

When to seek medical attention

Many people who have an STI do not develop any symptoms and may not be aware that they have an infection that can be passed on to their sexual partner/s. The symptoms described above require medical attention. The PLHIV should never be advised to self-medicate.



What to teach the client

- ✓ Safe sex - that is correct and continuous use of condoms - during sexual contact can prevent the development and transmission of STIs.
 - STIs can increase the risk of transmission of HIV to the non-infected partner and can also lead to re-infection with HIV if the partner is HIV-positive.
 - Testing and treatment of the partner is important for the complete cure and treatment of STIs in both partners.
- ✓ STIs can be fully treated with the appropriate and complete treatment.



- Take the full course of treatment even if you feel better. Incomplete treatment can lead to drug-resistance - that is the drugs can become ineffective against the causative organisms.
- DO NOT have sexual relations until treatment is complete.
- ✓ Genital hygiene is very important.
 - Keep the genital and rectal areas clean.
 - Wash the anus in a backward direction - that is away from the vagina.
 - DO NOT flush out the vagina after sex (that is a douche) or put anything inside (e.g., leaves or herbs) unless advised by a nurse or doctor.

Caring for a Bed-ridden Person at Home

As discussed previously, home-based care includes the things that PLHIVs might do to take care of themselves or the care given by their family members in their own environment *that is in their home*. Sometimes a PLHIV is too sick to manage their daily routine and they prefer to rest in bed. Their condition does not really require hospitalization but at this point they may require more special care from family members.



Here are some instructions that will help caregivers at home to provide care to such bed-ridden PLHIVs at home.

Movement

It is important to encourage the sick person to move as much as is comfortable for them.

- Encourage the sick person to move in bed or to get out of bed (if possible).
- Encourage the sick person to change his/her position every 2 hours.
- While helping him/ her to change their position in bed, lift the sick person gently but firmly. Do not drag the sick person, as this can break the skin.
- If possible help the bed-ridden patient to sit up in a chair from time to time.

Exercise

It is important to encourage the sick person to exercise.

- Encourage exercise twice a day and assist with movement of ankles, knees, hips, wrists, elbows, shoulders and neck.

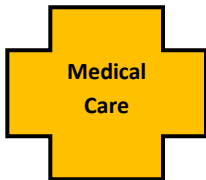
- Hold the limb above and below the joint while moving it. Support as much of its weight as you can.
- Bend, straighten and move the joints gently and slowly as far as they normally go.
 - **Exercise the wrists:** Bend the wrists gently and slowly without causing pain. Apply pressure gradually. Repeat the exercise several times.
 - **Exercise the elbows:** Gently lift the forearm up and down. Repeat the exercise several times.
 - **Exercise the shoulders:** Gently lift the arm up and bring the hand above and behind the head. Move the arm from side to side. Repeat the exercise several times.
 - **Exercise the knees:** Gently bring the knee up and to the side. Repeat the exercise several times.



Skin care

- Take special care of the PLHIV's skin
 - Look everyday for damaged skin on the pressure points, that is the back, shoulders and hips. These may show up as a reddish area on a light-skinned individual and shades of purple or blue on a darker –skinned individual.
 - Put extra soft material to support the bony areas, such as a soft cotton towel, under the sick person.
 - Keep the bed clothes clean and remove all wet clothes and wet bed sheets.
 - Give a regular sponge bath to the sick person. This will help to maintain the skin as well as to make the sick person feel good: To give a sponge bath, dip a soft cloth in the warm water and wring out the excess. If needed, a mild soap can be used in the water. Wipe the skin gently, starting from the more clean area to the less clean area, that is from face to feet. Pay special attention to the skin creases and bony areas.
 - Massage the sick person with petroleum jelly (Vaseline) or oil, if not contraindicated.

All of these measures will help in preventing complications that a bed-ridden PLHIV can develop like stiff joints, muscle fatigue, bed sores.



In case bedsores or ulcers develop, report these to a trained health worker and seek advice on treating the sores.

Remember: While caring for the sick person, let the PLHIV do as much as he or she can do. Also inform caregivers that at times the sick person might direct strong emotions (such as anger and blame) towards you. Often they do this because they are generally frustrated with their own situation. The caregiver should allow the sick person to express his/her feelings and frustrations freely and try not to overreact to the person's emotions. The caregiver should try to find out if there is something they need and how to help them.



Common foods or herbs that can be used as medicines

Traditional Indian medicine relies on the use of herbs and other plants. ICTC counsellors can suggest to clients the use of common herbs to provide relief from symptoms related to HIV.

These, however, cannot cure HIV. They only bring symptomatic relief.



Basil/ *Tulsi*

- Basil (*Tulsi*) is best known for its effect on the respiratory system.
- One glass of water with 5-7 *tulsi* leaves and 2-4 peppercorns is useful in lowering fever. *Tulsi* in a juice or powdered form can also be taken with honey. *Tulsi* is very effective in relieving stomach pain and in deworming. It has anti-inflammatory effects. The powdered form can be applied over wounds, swelling and painful areas. For mouth sores, chop the leaves, mix this with water and gargle.

Carrots

- Raw carrots have two uses. They contain beta-carotene (Vitamin A) which is an important vitamin to help the body fight HIV. They also help clear the digestive system of worms and parasites.

Cayenne Pepper/ *Lal mirchi*

- Cayenne pepper (*lal mirchi*) improves appetite, fights infections and inflammation of the intestines.
- PLHIVs can add a pinch of this spice to cooked or raw foods.

Cloves

- Cloves improve appetite, help digestion, diarrhoea, nausea and vomiting.
- They may be added to soups, stews, warmed fruit juice and tea.

Garlic

- Garlic is a powerful plant that helps to fight different types of illness or problems. It helps digestion and sensations of weakness. It is effective in fighting diarrhoea, throat and ear infections.
- Garlic is most effective when eaten raw. But it is also useful when cooked.
- Garlic can also be used to make a tea: Pour some boiled water in a mug containing a tea bag of green tea and two or three crushed cloves of garlic. Let it brew for 3-5 minutes.

Ginger (*Adrak*)

- Ginger improves digestion, relieves diarrhoea and improves the appetite. It is often used to treat coughs, sore throat and nausea.
- Ginger can either be added to food, chewed on raw, or made into tea by crushing ginger in water and boiling it for 10 minutes (Strain before drinking).

Lemons

- Lemons or limes fight bacteria, help digestion and dry mouth sensation.
- PLHIVs may add lemon/lime juice to foods and drinks, or suck on a piece of raw lemon/lime.

Mint

- Mint helps digestion and soothes mouth sores.
- PLHIVs may use it as a tea or gargle with it in case of mouth sores.
- Chewing mint leaves helps in digestion.

Neem

- The *neem* tree is a very useful one and its various parts have uses - that is the bark, leaves and flowers have medicinal values. The leaves and the bark of the neem tree are very effective in controlling infections, deworming, and in disinfecting and healing wounds.

- Application of warm, boiled *neem* leaves water solution to the affected area helps in relieving itching in case of allergic rashes or in case of any other skin problems. It can also be used to bring down fever.
- *Neem* oil can also be applied to relieve itching.
- Cut a fresh twig from the *neem* tree, remove the leaves and boil the bark in water. It can be drunk as a tea, or the bark can be chewed.

Parsley

- Parsley (*Dhania/Ajmoode*) stimulates the stomach and makes the person feel hungry. It is rich in Vitamin C. Traditionally it is used as a food garnishing.
- The finely chopped leaves can be added to salads or cooked food.

Pumpkin seeds

- Pumpkin seeds are a rich source of protein. They help the digestive system clean itself of worms and parasites.
- PLHIVs can dry the seeds in the sun and eat a handful a week to keep the stomach clean.
- Pumpkin seeds when roasted can be eaten as snacks but they are more nutritious when eaten raw.

Aloe Vera

- Aloe vera (*Kumari*), when taken internally, has a mild laxative effect and detoxifies the body. It helps in deworming, gives relief in case of abdominal pain caused due to digestive disorders and is good for liver disorders.

When to Discuss Home-based care with Clients and Caregivers

During the post-test counselling session the client may be too busy absorbing the emotional shock of diagnosis and may not be ready to listen to information about home-based care. So you may wonder when to discuss all this information on home-based care with clients or care givers.

At the Post-test Session

- During post-test counselling you, as the ICTC counsellor, should first help the client to accept the diagnosis.
- You may also try to motivate him/her to live positively with HIV. Try to convey a strong impression of hope. Explain that positive living can enable the client to live a long and healthy life. Further, encourage them to register for Pre-ART Care. Explain that when required (that is when the person is eligible for ART), they will be enrolled into anti-retroviral treatment which will help to control the progression of HIV in the body.
- But also encourage them to undertake small measures at home that can keep them healthy.
- Repeat the message of hope and invite them to come back to you for follow-up counselling. In the language of counselling, this is called “keeping the door open.” Make sure that your client knows when you are available to talk and listen.

Repeat the message of hope and invite them to come back to you for follow-up counselling. In the language of counselling, this is called “keeping the door open.” Make sure that your client knows when you are available to talk and listen.

At the Follow-up Session

- As the disease progresses, the PLHIV has time to understand and absorb the situation. He/she may visit you for follow-up. Further, you may have the opportunity to make home visits on Saturday afternoons. During these occasions you can discuss with the client and the family members the information presented in this module. During home visits you may also be able to make suggestions on care of bed-ridden patients.
- One thing you will have to reassure clients and family members about is the fact that HIV does not spread through casual contact.
- At this stage the client may become interested in learning more about specific physical and emotional symptoms that may be troubling them at that time. Assess the informational needs of the client and provide information accordingly. Do not attempt to give all the information in one big fat capsule. Just as the write-up emphasizes 5-6 small meals a day, in a similar manner, it is better to give smaller amounts of information as per the ability of the client to absorb the information but encourage them to come back when they need help.
- Further, be prepared to repeat the information when required. Also, when clients do come back remind them of their past successes in managing their symptoms. Using their own experiences will be helpful in conveying the message of hope.
- Also, encourage and empower family members to participate in providing necessary care and support to the PLHIV.

Remember, each PLHIV and each family is unique and their needs are different.



Questions to ICTC Counsellors

Are you confident you know when to stop giving advice on home-based care refer the client for medical attention?



References

World Health Organisation Regional office for South-East Asia (1996). *Handbook on home-based care*. New Delhi, India: Author.

World Health Organisation (2006). *Symptom management and end of life care: A guide for caregivers*. Geneva, Switzerland: Author.

World Health Organisation (2006). *Patient self management and care giver booklet for HIV management: A guide for HIV positive patients, family members, caregivers and treatment supporters*. Geneva, Switzerland: Author.

National AIDS Control Programme, Ministry of Health, Tanzania (1999). *Trainer's guide for home- based care providers*. Tanzania: Author.

Path international (n.d.). *Community home-based care: Training guide*. Washington DC, USA: Author.

**MODULES
TO ENHANCE
ICTC WORK**

Use of IEC Materials at the ICTC

At the end of this unit, participants will be able to

- State the importance of using IEC materials
- List the types of IEC materials available and their uses.
- Demonstrate how to use the ICTC flipbook and an IEC film.

IEC stands for Information, Education and Communication. It is a process through which people are informed as well as educated about vital issues through specific means of communication. IEC materials are materials that are available to help in this process.

This module focuses on how ICTC counsellors can improve their usage of IEC at their respective ICTCs.

Advantages of IEC

For the counsellor:

- It serves as a memory aid for the counsellor to ensure that all points get covered.
- Pictures are worth a thousand words.
- The client's attention is attracted and sustained.
- It triggers discussion and helps bring up questions from clients
- Helps compare similarities and differences (e.g. ways in which HIV can and cannot be transmitted)
- It helps show stages or steps (e.g. using a condom)
- It helps show changes (e.g. spread of HIV in the human body)
- It helps show something that cannot be seen in real life (e.g., the virus)

For the client:

- It makes something small, big enough to be visible (e.g. HIV)
- It makes complicated concepts easy to understand (Structure of HIV)
- Pictorial depiction helps the client relate to things being discussed
- It helps clients who cannot read to understand things more easily: Less literate clients who are not used to technical discussions may be more comfortable.
- It helps client's retain information provided better and for longer
- It helps clients contextualize information being provided
- Sometimes the topics we discuss in our counselling are very sensitive and it is difficult for the client to maintain eye-contact. Having IEC materials in front of them helps them to avoid being embarrassed.

Opportunities to use IEC

Messages during waiting time

IEC begins outside the counselling room. Often the posters are displayed only in the counselling room.

In the waiting area, display posters, charts, video films and brief reading materials which trigger some interest, curiosity and questions in the minds of clients or which give some sort of information to the client - They will prepare the client for receiving more information and counselling.

Messages in waiting areas should be relevant to the clients. For instance, it makes no sense to display posters on Post-Exposure Prophylaxis, Universal Safety Precautions and WHO Clinical Staging in waiting areas.

Messages during counselling session

Messages during the counselling session should provide clear information on HIV during the counselling session.

The counsellor could use different IEC for better understanding of the client (e.g., leaflets, education materials, flipbooks, wall charts, penis model, samples of condoms, lubricants) along with other requisite information like the address of the ART centre, TB centre, etc.

Take-home messages after counselling session

Messages to take home could include how to get to the ART centre or the DMC for TB services.

Take-home leaflets are available in some SACS.

Referral slips could have a pictorial representation/map along with the written address of the centre. Also it is strongly recommended to display this on the wall/ desktop.

IEC that can be used at the ICTC

FLIPBOOKS

Help explain a complex issue/ introduce a sensitive topic

POSTERS

Help communicate a thought/idea

WALL CHARTS

Help communicate basic information/ processes

FLASHCARDS

Act as a visual aid to focus on/explain a particular issue

VIDEO FILMS

Help generate discussion or provide information in the absence of a facilitator

BOOKLETS

Act as a reminder media to reinforce information provided during counselling

LEAFLETS

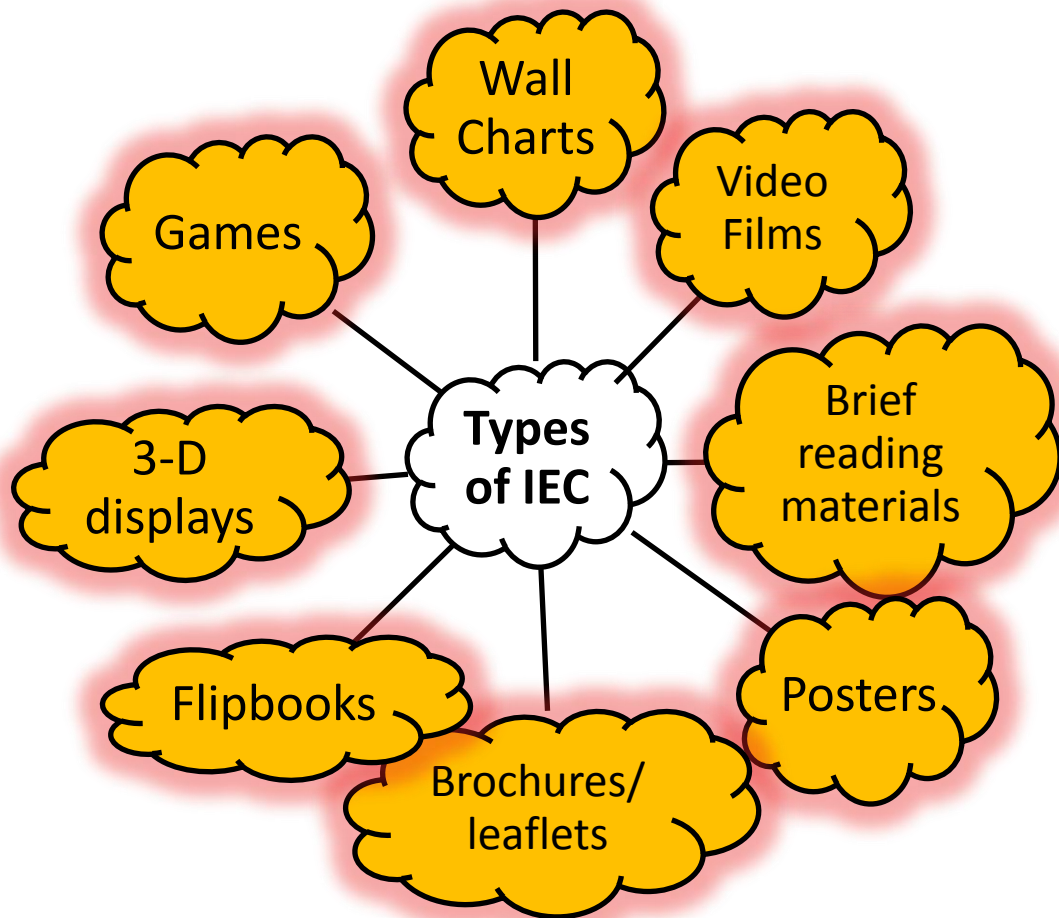
Act as a reminder media to reinforce information provided during counselling

MODELS

Help demonstrate a process through simulation

We will discuss each of these in detail.

Note: Some instructions are applicable in group settings. These have been marked with an *.



Films

1. Play the film in advance to see if the film and the equipment you are using is working properly.
2. Familiarize yourself with the contents of the film and prepare yourself for questions that might follow.
3. Ensure that the clients are seated comfortably and everyone can clearly see and hear.
4. Give a brief introduction to the film before playing it.
5. Prepare a guide or questions for reflection to be used at the end of the film or when stopping at the relevant points.
6. Stop at relevant points to generate discussions and also address queries that the clients may have (If the film permits the same).



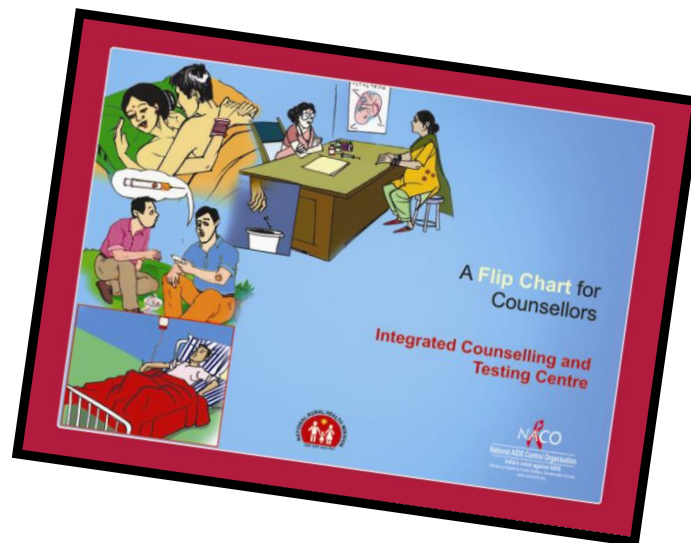
7. Conduct a discussion after the film concludes. Start by asking simple questions about the film, e.g. what were the names of the characters, what was the story, what happens when someone does or says particular things in the film? (This will help us to understand whether clients have understood/ heard/ seen the film.) Try and relate it to their personal or real-life experiences by asking reflective questions, e.g., *Does this happen in reality with people like us? What do we*

do then? What advice can we give the characters in the film? What did you learn from this story/ film session/ discussion?" (This helps in knowing what the client has learned and remembers as main messages)

8. Reinforce and emphasize major learnings at the end.
9. In case you are playing the film/ video in the waiting area, you need to take note of the following:
 - ✓ Ensure that the display screen is at a proper height and is comfortably visible to all.
 - ✓ Play the film in advance to see if the film and the equipment you are using is working properly.
 - ✓ Ensure that the film/ video is in a loop so that it keeps playing continuously. If unable to do this, check the video or DVD player periodically, and restart the film when it stops.
 - ✓ Ensure that the volume is at an appropriate level, i.e. not too loud or too soft.

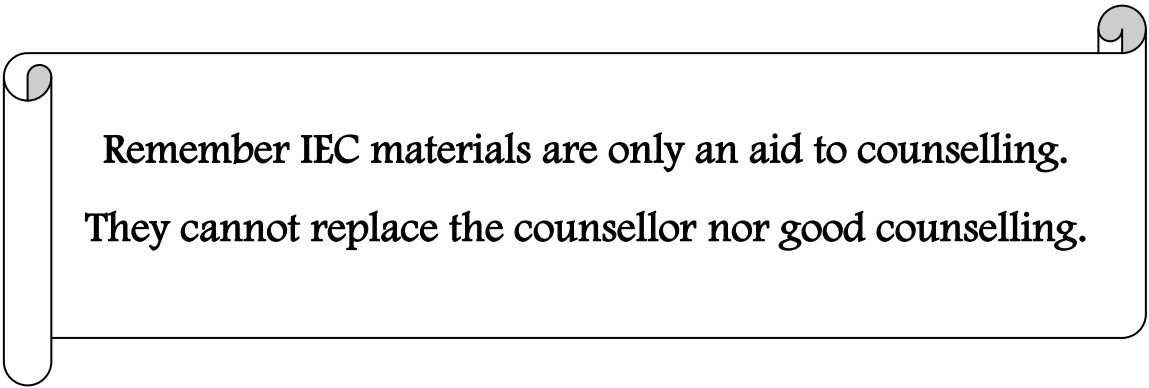
Flip Books / Flash Cards

1. An introduction needs to be given on the topic to be discussed.
2. Familiarize yourself with the contents in advance so that you do not have to read the text, but can narrate the story/ theme in your own words. This will allow you to look at the client rather than down at the material while counselling.
3. Introduce the characters (if there is a story) in the material to the participants and give a background to the story /theme.
4. Use appropriate gestures/emotions while narrating to engage the client(s)
5. Make eye contact with the client while counselling and observe their reactions.
6. Observe the client's reactions. If he or she looks confused/ puzzled/ blank, encourage questions



7. Be seated with the client(s) at the same level and ensure that the flip chart is visible to all.*
8. Slip one of your hands in between the leaves and use the other to point at characters.
9. Ensure that the flip chart does not touch your lap. Keep rotating it in all directions so that everyone gets a good view of the visuals*.

10. Stop in between and encourage / ask questions. Relate it to the client's experiences.
11. Ask the client, "What did you learn from this story/ session/ discussion?" (This helps in knowing what the client has learned and remembers as main messages).
12. Reinforce and emphasize major learnings.
13. Ask the client if they have any questions about the issues addressed in the flipbook



**Remember IEC materials are only an aid to counselling.
They cannot replace the counsellor nor good counselling.**

Wall charts

1. Hang the chart in such a way that it can be seen by all. Ask people towards the back if things are visible to them.*
2. An introduction needs to be given on the topic to be discussed
3. Start by asking the client, "What do you see in this chart?" (This helps in knowing what client already knows, or his/her perceptions and build on what client already knows or understands from the visual). Then the counselor can highlight the theme.
4. Each chart has a central theme. That needs to be highlighted.
5. Follow the sequence of pictures/ themes given.
6. Make sure you are standing in such a way that your body is not covering the chart.*
7. Use a stick or a pointer to point at relevant pictures/ themes.



8. Encourage questions.
9. Make eye contact with the client(s) while counselling and observe their reactions.
10. Observe the client's reactions. If he or she looks confused/ puzzled/ blank, encourage questions.

11. Ask the client, “What did you learn from this poster/session/ discussion?” (This helps in knowing what the client has learned and remembers as the main messages).
12. Reinforce and emphasize major learnings.



Posters

1. Posters are more commonly used for general viewing, but can also be used during counselling sessions to stress upon the relevance/ importance of the topic being discussed.
2. It is best to usually put up posters in sequence (if any) such as Risk Behavior, Modes of transmission, Myths and Misconceptions, Counselling and Testing, ART, Living with HIV, etc.
3. Posters should be put up at eye level so that people do not have to strain to see them.
4. Think in advance about what the poster is meant to do and who will see it.
5. Study the poster beforehand in detail.
6. Do not look at the poster all the time while discussing with the client. Focus more on the client, pointing occasionally towards the poster
7. The poster should be facing the client



Source: World Health Organisation.

8. Start by asking the client, “What do you see in this chart?” (This helps in knowing what client already knows, or his/her perceptions and build on what the client already knows or understands from the visual). Then the counselor can highlight the theme.

9. Make eye contact with the client while counselling and observe their reactions.
10. Observe the client's reactions. If he or she looks confused/ puzzled/ blank, encourage questions.
11. Along with displaying posters in your counselling room also display them in the waiting area.
12. Ask the client, "What did you learn from this poster / discussion?" (This helps in knowing what the client has learned and remembers as main messages).
13. Reinforce and emphasize major learnings.

Handouts/ Leaflets

1. Study the handout beforehand thoroughly.
2. Give it to the client and go over it with him or her.
3. Ask the client to study it.
4. Start by asking the client, "What do you see in this handout?" (This helps in knowing what the client already knows, or his/her perceptions and builds on what the client already knows or understands from the visual). Then the counsellor can highlight the theme.
5. Ask the client if they have any questions and answer any question that he or she may have.
6. Observe the client's reactions. If he or she looks confused/ puzzled/ blank, encourage questions.
7. Give the client the booklet and suggest sharing it with others.

Booklets

1. Familiarize yourself with the contents of the booklet in advance. This will help you explain the booklet better to the client and also effectively answer any questions that might come up.
2. Explain to the client what the booklet is about and take him or her through it.
3. Point to the pictures and not the text. This will help the client remember what the illustrations represent.
4. Observe the client's reactions. If he or she looks confused/ puzzled/ blank, encourage questions.
5. Summarize major learnings.
6. Ask the client if they have any questions on the issues addressed in the booklet
7. Give the client the booklet and suggest sharing it with others.



Models



1. Explain that you are using a model or a dummy to simulate something that happens in real life and that model is for representational purpose only. (For example in real life, the condom has to be put onto a penis and not a representational model of the same!).
2. Demonstrate use of the model clearly mentioning each stage. For instance if you are using a penis model to demonstrate condom use, mention each stage in detail and in sequence.
3. Mention both male and female condoms and explain the use of water-based lubricants and the risks of oil-based lubricants
4. Stop to ask after each stage to see if the client has understood/ has any questions.
5. Observe the client's reactions. If he or she looks confused/ puzzled/ blank, encourage questions.
6. After the demonstration, ask the client to repeat the demonstration, explaining each stage (if applicable).
7. Discuss any concerns that the client may have.

Games

Games are an interactive way of getting a message across about health and behaviour change. The message is delivered but the client also has an opportunity to have fun while learning the information. This writer has seen simple games such as a Dart board and a Snakes and Ladder game used to convey important messages. However, they involve a smaller group. They may also be very appropriate for younger clients.

1. The counsellor should first study the game and understand the key points it is trying to convey.
2. Keep all the materials handy – for instance, dice and counters.
3. Make sure that you have sufficient time to play the game.
4. Explain to them the reason for the game – namely to learn a little more about HIV.
5. Play the game and pause occasionally when you reach a key message to discuss it. Doing so too often reduces the fun of the game.
6. At the end of the game, ask the client what they thought about the game and if there is anything they would like to clarify.
7. There is a temptation to preach. The counsellor should avoid this.



Frequently Asked Questions



Why does NACO or SACS not allow me to use a film that I have found on my own?

There are several reasons:

Need for common or standard messages

There is a need for common or standard messages. This makes it easier for different personnel in the system to reinforce the key messages. Clients should hear the same message at the ICTC (counsellor/ORW), ART centre, TB centre, STI clinic and TI project.

Avoiding negative messages

Fear-based messages or negative messages should be avoided. They often produce a short-term behaviour change. In some cases, they may even back-fire. Some films and posters provide negative messages.

Need for relevant messages

Messages should also be timely and relevant. For instance, a World AIDS Day event announcement should not be up on a notice-board 6 months later. Sometimes films are made to meet a certain need. They may not be appropriate to the ICTC setting (e.g., a film for medical personnel on the action of ARV drugs).

ICTC Outreach

At the end of this unit, participants will be able to

- Make a quarterly plan for conducting outreach on Saturday afternoons
- List Do's and Don'ts of community outreach
- Assess their own performance in outreach activity

The Operational Guidelines for Integrated Counselling and Testing Centres (2007) mention that, *“On Saturdays in the afternoon session, counsellors will undertake outreach work and visits to the homes of HIV-positive clients facing severe crisis. TA/DA will be paid to the counsellors for the outreach activities/ home visits as per the state government rules.”* After these guidelines were written, outreach by ICTC counsellors was expanded as per the NACP III priorities to focus on the High Risk Groups (HRGs) and bridge populations.

Outreach by ICTC counsellors includes:

1. Visits to TI project sites/ hot spots
2. Visits to sites where there are many migrants/ truckers
3. Visits to other NGOs
4. Visits to key villages
5. Home visits to PLHIVs

Type of ICTC Outreach Activities

Visits to TI project sites/ hot spots

A hot spot is a place where members of TI communities gather to practise their commercial activity (in case of sex workers) or to engage in those habits that place them at risk (in case of IDUs and MSMs). Visits to TI project sites or to hot spots are done to increase familiarity with members of High Risk Groups at the projects and their issues. They are also intended to increase referrals and to do on-spot education related to HIV in general, and HIV testing.

The advantage of TI site visits is two-fold:

- ✓ The counsellor will learn the reality of the TI client's life situation.
- ✓ TI clients will feel more comfortable approaching the ICTC for testing.

Visits to sites where there are many migrants/ truckers

These visits are meant to increase familiarity with members of Bridge Populations at the sites where they gather. It is also intended to increase referrals and to do on-spot education related to HIV in general, and HIV testing.

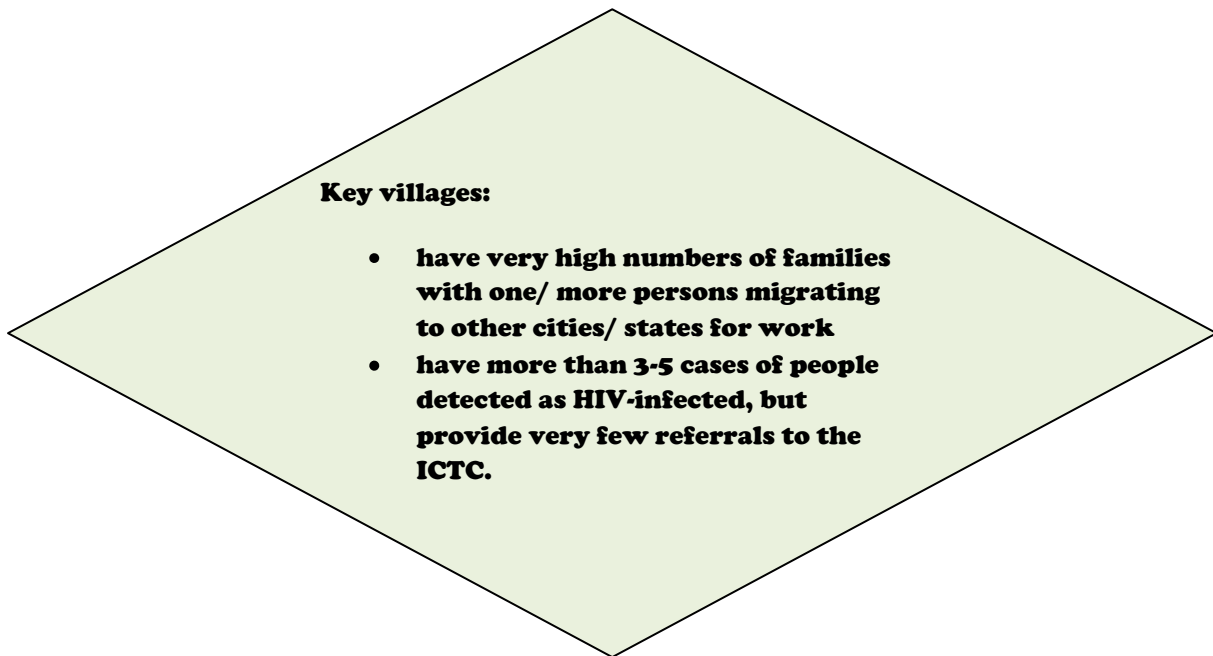
Visits to other NGOs

Here the counsellor will interact with NGO personnel to explain the services available at the ICTC in order to generate referrals. But it is also a source of feedback on how the general community perceives the ICTC services.

Visits to key villages

Key villages:

- have very high numbers of families with one/ more persons migrating to other cities/ states for work
- have more than 3-5 cases of people detected as HIV-infected, but provide very few referrals to the ICTC.



Visits to key villages are a team effort involving the District Supervisor and the Outreach worker. The tasks which should be accomplished by the team led by the District Supervisor include:

- Meeting young people (youth club members/NYKS), leaders/members of SHG, ASHAs, AWWs, *gram panchayat sarpanch*/members. If the Link Worker Scheme is operational in the district, the counsellor should also interact with Link Workers
- Holding a *gram sabha* and explaining issues related to HIV/AIDS to motivate persons to take up HIV counseling and testing.
- Ensuring that HIV-positive pregnant women in the village have access to prenatal care and transport for timely institutional delivery through assistance by the ANM/ASHA/GP.

- Explaining to the community to refer persons having cough for more than 2 weeks for TB and HIV tests.
- Explaining the need to identify children who are stunted and malnourished or who have diarrhoea or fever, and to refer them for HIV testing and/or early treatment.
- Motivating AWWs to ensure good nutrition to Children Living with HIV and pregnant women.

Outreach does not include going on health camps. Nor does it include attending conferences or meetings on behalf of the Dean of the Hospital. This does not include lectures in schools and colleges.



Home visits to PLHIVs

The aim of this is to follow up with clients who have tested positive. There are three scenarios:

Clients who test positive

One is following up with clients who have tested positive at the ICTC. The counsellor must ensure that clients are coping well with their test result, and that they have made contact with the nearest ART centre. The counsellor must also use this opportunity to motivate spouses of the Positive Person to get tested for HIV if they have not already done so (When they are motivated and come in for testing, the information should be noted in Column 16, 18, 19, 20 of the ICTC Register for General Clients). Here it is important to realize that the counsellor cannot ask for a telephone number at the Post-Test Session (that is after finding out about the person's positive result) as this is a sign of discrimination. Contact details should be gathered at the Pre-Test Session from all clients. At the Post-Test Session, the counsellor should prepare the client for the possibility of a home visit a few months later. As you will learn in another training session, many positive people do not follow up at the ART centre. A good practice would be to prepare the positive client to expect a phone call 6 weeks after the test date to check whether they made contact with the ART centre and address any problems they may have faced.

Clients who Miss or who are LFU

A second scenario is tracing someone who has MISSED a regular visit to the ART centre/ LAC, or, even more seriously, someone who is Lost-to-Follow-Up (LFU). Information about LFU and MISSED clients would be provided by the ART centre or the LAC. If a particular ICTC has been designated as an LAC, then those counsellors would also be able to appreciate the importance of home visits.

Positive pregnant women

The third scenario concerns visits to pregnant women whose positive HIV status is detected early during pregnancy. It is important to sustain their interest in an institutional delivery where they can be administered nevirapine prophylaxis. These follow-ups will become even more critical as new PPTCT regimens are introduced beyond the single-dose nevirapine administration. During home visits, the counsellor can provide nutritional counselling, infant-feeding counselling, and motivate the spouse to get tested. When the spouse is motivated and presents for testing, the information should be noted in Column 19, 20, 21 of the ICTC Register for Pregnant Women.

After delivery, the counsellor can use the home visit to follow up the mother and baby and ensure that the baby undergoes Early Infant Diagnosis. Enter the data in Column 34, 35, 36 of the ICTC Register for Pregnant Women. Enter the relevant data in the ICTC Post-natal Follow-up Register.

In high prevalence districts, some ICTC counsellors may be assisted in these tasks by Outreach workers. But the presence of an Outreach worker does not reduce the responsibility of the counsellor for outreach.



➤ **What to Observe During Home Visits**

- ✓ General impression of community
 - Is the community close-knit/ supportive/ nosey and curious/ comprised of transient neighbours such as migrants
 - Is the client's home located in a healthy environment where food is sold in a hygienic manner?
 - Are there medical resources available such as a chemist shop?
 - Are there resources for the client to entertain him/ herself and relax (e.g., garden, community space, cinema, community library, temple courtyard, coffee shop)?
- ✓ Physical exterior of home
- ✓ Physical layout
 - Does the client have privacy to keep his medicines, medical files, etc.?
 - Is there a quiet space for the client to rest when sick?
 - Is there sufficient ventilation in case the client has tuberculosis?
 - Does the home have a toilet and bathroom? Is it inside or outside? If outside, is it shared with neighbours?
- ✓ Family members and their interactions – positive as well as negative
- ✓ Presence of children
- ✓ Gender relations and norms – sense of equality

Some Do's and Don'ts

- Always leave a note of where you are going for field work so that your superiors know where you are. This is important for your safety in case there is an accident.
- Eat your meal before you leave the ICTC, so you do not feel hungry.
- Find out the weather conditions before you leave. Do not attempt to be a hero by trying to go for field work in adverse conditions like extremely heavy rains.
- Decide beforehand whether you would like to accept a cup of tea in your client's home. Stick to this decision. Here it should be mentioned that it is considered rude to refuse hospitality. But the counsellor may also be worried about drinking food or water that is unsafe. Tea is generally considered safe.
- Inform clients that you might pay a home visit. But also ask them how they would prefer you to structure your visit. Some of them may prefer that you introduce yourself as a friend of the family.
- Do not wear flashy jewellery when you go on field work.
- Take off your shoes when you enter someone's home.
- As you may be visiting the homes of people who are ill, it is important to do some self-care when you return home: Wash your hands and face when you return home. Change your clothing. These simple actions will reduce the possibility of cross-infection by opportunistic infections.
- Prepare a kit with IEC and condoms
- Inform the local police station if working in an FSW site

How to evaluate the effectiveness of ICTC Outreach

There are different criteria for this

1. The simplest is whether you have completed the activity. On the Outreach Planning Sheet, there is a simple scoring system at the bottom of each monthly table. For each *completed* outreach activity, the counsellor should mark 5 points. If there is a fifth Saturday in a month, outreach activity need not be planned for that *fifth Saturday* only.

But this is only the first step.

2. The next level of recording the type of activity during the Outreach visit. Here, the counsellor should capture what she/he actually did. For a home visit, it could be patient education and motivation. For a village visit, it could be number of contacts as well as education and referral invitations to the ICTC. For a TI visit, it could be number of contacts as well as awareness-building of ICTC services. These are only examples. Counsellors can mention many other things.

However, Outreach work must show results.

3. The only real way to know if Outreach work is successful is in terms of the number of referrals that are generated from the visits, the number of persons contacted who follow-up. Further, it is not sufficient to be satisfied with one or two referrals. A good counsellor would be able to see an increasing number of such referrals and follow-ups.



Reference

National AIDS Control Organisation (2007). *Operational guidelines for Integrated Counselling and Testing Centres*.
New Delhi, India: Author

SELF-DIAGNOSTIC TOOL ON OUTREACH

- 1) My ICTC is in a Category A / B./ C. D. district *(Please circle the right number)*
- 2) Please mention the name of the district _____
- 3) In the last two months, I have gone for Saturday outreach ___ times *(Please put the number)*
- 4) As part of outreach, I did the following
(Please put the number. If you have not done this activity write 0)
 - a) Visited ___ TI projects *(Please mention the type MSM/FSW/IDU)*
 - b) Visited ___ hotspots
 - c) Visited ___ NGOs *(Please mention the name _____)*
 - d) Visited ___ key villages
 - e) Visited ___ positive clients
- 5) The result of my outreach was *(Please put the number)*
 - a) ___ referrals from TI projects
 - b) ___ referrals from hotspots
 - c) ___ referrals from NGOs
 - d) ___ referrals from key villages
 - e) ___ follow-up visits from positive clients
 - f) ___ partners of positive clients motivated for testing
- 6) I maintain a record of my field work : Yes / No *(Please circle the right answer)*

NAME OF COUNSELLOR _____

DATE _____

OUTREACH PLANNING SHEET

IMP: Each visit should have a contact person/ client address

J/F/M/A/M/J/ J/A/S/O/N/D 2011/12/13/14	First Saturday	Second Saturday	Third Saturday	Fourth Saturday
Visits to TI project sites/ hot spots				
Visits to sites where there are many migrants/ truckers				
Visits to other NGOs				
Visits to key villages				
Home visits to PLHIVs				
SCORING For each completed outreach activity, give yourself 5 points. If there is a fifth Saturday in a month, outreach activity need not be planned for that day only.				
KEY OUTCOMES Here you should briefly mention highlights of the activity completed.				

District Supervisor's Signature: _____

(in absence of District Supervisor, any other SACS official can sign this sheet)

OUTREACH PLANNING SHEET

IMP: Each visit should have a contact person/ client address

J/F/M/A/M/J/ J/A/S/O/N/D 2011/12/13/14	First Saturday	Second Saturday	Third Saturday	Fourth Saturday
Visits to TI project sites/ hot spots				
Visits to sites where there are many migrants/ truckers				
Visits to other NGOs				
Visits to key villages				
Home visits to PLHIVs				
SCORING For each completed outreach activity, give yourself 5 points. If there is a fifth Saturday in a month, outreach activity need not be planned for that day only.				
KEY OUTCOMES Here you should briefly mention highlights of the activity completed.				

District Supervisor's Signature: _____

(in absence of District Supervisor, any other SACS official can sign this sheet)

OUTREACH PLANNING SHEET

IMP: Each visit should have a contact person/ client address

J/F/M/A/M/J/ J/A/S/O/N/D 2011/12/13/14	First Saturday	Second Saturday	Third Saturday	Fourth Saturday
Visits to TI project sites/ hot spots				
Visits to sites where there are many migrants/ truckers				
Visits to other NGOs				
Visits to key villages				
Home visits to PLHIVs				
SCORING For each completed outreach activity, give yourself 5 points. If there is a fifth Saturday in a month, outreach activity need not be planned for that day only.				
KEY OUTCOMES Here you should briefly mention highlights of the activity completed.				

District Supervisor's Signature: _____

(in absence of District Supervisor, any other SACS official can sign this sheet)

OUTREACH PLANNING SHEET

IMP: Each visit should have a contact person/ client address

J/F/M/A/M/J/ J/A/S/O/N/D 2011/12/13/14	First Saturday	Second Saturday	Third Saturday	Fourth Saturday
Visits to TI project sites/ hot spots				
Visits to sites where there are many migrants/ truckers				
Visits to other NGOs				
Visits to key villages				
Home visits to PLHIVs				
SCORING For each completed outreach activity, give yourself 5 points. If there is a fifth Saturday in a month, outreach activity need not be planned for that day only.				
KEY OUTCOMES Here you should briefly mention highlights of the activity completed.				

District Supervisor's Signature: _____

(in absence of District Supervisor, any other SACS official can sign this sheet)

A Thousand Worries

I am worried that I might get lice.

What if the TI people think I am interfering?

What will people say if they see me at a project for FSWs?

What if I get TB or some other transmittable illness?

But I don't know anything about drug users.

What if the community or village people ask me why I have come?

Time Management at the ICTC

At the end of this unit, participants will be able to

- List activities that deserve priority by way of suitable time investment
- Discuss ways of managing their time working at the ICTC
- Describe strategies to reduce the impact of time-wasters at the ICTC

We all have the same amount of time in a day. At some point in our life, we have all wished to have a little bit of extra time. As ICTC counsellors, you may have wished for extra time to complete your work - counselling, maintaining registers, doing outreach work, attending to the instructions of the medical officer or just to breathe. You may also wish that your work becomes less, so that you can spend quality time on those tasks are important. However, we all know we are not going to get that additional amount of time. So the big question is *how to complete the work on time without reducing the quality*. One answer to this is effective time management.

Time management is a very important professional skill. When we think of successful role models, this is one of the key qualities that comes to mind. Time management means using time effectively. It is about managing and controlling your actions as per the available time.

Good time management is a combination of commonsense, basic techniques and good working habits. It develops over time. You may develop the techniques and working habits for a particular situation or job. But once you master them, you can tailor them to another situation.

Time management involves an analysis of what want to do in your work and life, how do you do it presently and a plan to manage your time in relation to these activities. It also requires a commitment from you to change how you have done things till now.

Effectiveness versus Efficiency

Please note that effectiveness is different from efficiency. Efficiency is completing a task with the least possible amount of wasted resources - effort, money or time. Effectiveness refers to the quality of the work. Efficient workers perform all tasks given to them in a said amount of time; they give importance to completing the tasks. While those who are effective, select the right tasks from the given tasks and achieve them in the most fruitful way. They think about the importance of the task against the overall objective of the course of their tasks. People who manage time well keep a good balance between the two. See the following observations from NACO and SACS officials on Effective versus Efficient counsellors.

"I met a male counsellor in the North-East. He was very busy in his hospital-based ICTC. I asked him how he managed his time. He explained he had observed that many patients referred for testing came from the surgery departments. Realizing that pre-surgery testing is not likely to yield many positive clients, and further may only serve to create stigma, he tried to educate the surgeons. Along with the SACS, he ran another full site sensitization where the surgeons were informed about the priority to be given to people with high-risk behaviours. Surgeons were encouraged to screen out people with no risk behaviours. This reduced the number of unnecessary testing cases and the counsellor was able to focus his energy on the critical cases."

"One of the most efficient counsellors I have seen was a counsellor in a very busy ANC department in the South. I was impressed with how she managed. She would work in groups of 6 or 7. First she would do thorough education for one group, take all their details and then send them for testing. Meanwhile another group would gather. She had all her tools handy – the ICTC flipbook, the penis model and her OPD films. She used all of them to get her message across."

"I was very surprised to learn from one counsellor about her outreach work on Saturday. She told me she went to a nearby orphanage. I wondered how this fitted in with NACO's priorities of reaching Most-at-Risk Populations. She just appeared to be spending time on Saturday doing 'some' outreach. But was it going to produce results?"

"While discussing my official visit to one state, I learned from my NACO colleague that he had earlier visited the same private hospital in that city that I visited. At the time of his visit five months before mine, the ICTC counsellor had not done any outreach work. He had instructed her to do so. I was happy to share with my colleague that the ICTC counsellor at this private hospital was indeed doing some Saturday outreach at an MSM-TI project and this had increased the referrals from here as well as the positivity rate from testing in her centre. She was indeed able to provide service to people who needed it"

Why you need to know about time management

Being a professional, you should be able to provide the maximum results possible. It is possible to be busy the whole day, work hard and continuously- even to the detriment of your health – and yet produce low outputs like clients referred to the ART centre but not reaching, low testing among HRG groups in the ICTC area or positive, pregnant women not turning up for delivery at hospitals. You may even say that you have been working hard all the time.

Actually this is a familiar phenomenon which has been named the Pareto principle or the 80:20 Rule. According to this rule most people typically 20% of their expected results with 80% of unfocussed work. This underlines the scope you have to generate better results if you work smarter.

Most counsellors are already working hard. But they may benefit from learning to work in a smarter manner.

Some of the questions which can help you to understand your results are

- *“Am I reaching people who are at risk?”*
- *“Am I devoting more time to people who need me?”*

Some counsellors complain about the work load at their ICTCs, mainly in terms of the high number of clients coming to the ICTC and the number and volume of other work. They also share concerns regarding their inability to provide quality counselling to clients. This leads to them experiencing job stress. On the other hand, a few counsellors are situated in ICTCs with few clients. Their problem is boredom and a sense of not contributing or feeling worthwhile. Even they can improve the quality of their work time.

To summarize, the advantages of time management are

- ✓ Having more time for important tasks such as counselling positive clients
- ✓ Completing more tasks
- ✓ Reduced stress
- ✓ Time for relaxation
- ✓ Professional excellence
- ✓ Personal improvement

How to manage time

One mantra for time management is planning your time in advance. You must

- Understand your tasks
- Identify their frequency
- Know how much time you require to complete the task
- Allot time to perform the task
- Execute your plan

A time map will help you planning your time once you know your tasks.

The tasks at the ICTC

Let us look at the major tasks at the ICTC and their frequency. You will realize that you have routine daily tasks, weekly tasks and monthly tasks.

Daily tasks

- Pre-test counselling
- Post-test counselling
- Daily record maintenance such as the Register for Clients and Stock Register – and once the systems are in place, daily entry into the SIMS.

Weekly tasks

- Dealing with the weekly OPD load
- Outreach on Saturday afternoon

Monthly tasks

- Attending the monthly review meeting conducted by the district supervisor
- Sending the monthly reports to SACS every month

Apart from these, there may be some unexpected tasks like attending a seminar, preparing some reports or attending to SACS officials during their monitoring visits to the ICTC.

Planning your time at the ICTC

Time plans can be macro (large time period) and micro (short time period). In the ICTC, we can consider Monthly and Weekly plans as macro and Daily plan as micro.

Creating a monthly plan

One of the easy ways to build a time plan is to fill in a monthly calendar with those time commitments that cannot be shifted.

This will include monthly tasks such as

- ✓ Monthly review meeting
- ✓ Reporting deadlines. The ICTC monthly report is due on the 3rd of the month to the SACS. Here you have to allot time for smaller tasks associated at the month end – tallying last month's figures and getting the MO's signature

You can also block off weekly engagements in the same calendar:

- ✓ Saturday outreach work.
- ✓ Heavy OPD days
- ✓ ANC days
- ✓ LAC days (for those ICTCs functioning as LACs).



Further, you should consider setting aside some time each day to fill your registers and other records. It is best to set aside a half hour every day to go over the registers rather than pile everything for the end of the month. For instance, one common observation is that the stock register is not filled on a daily basis as it should be. Are you filling your stock register every day? If you are not, then you should consider doing so because this will avoid you having to tax your memory at the end of the month.

Once you fill in these regular tasks, you then have an idea of when you may schedule a follow-up visit or when you may invite self-generated referrals from a TI projects. Of course your calendar is not yet full. You probably have many tasks that you need to add. The monthly plan can help you identify

those slots where you can fit in some not-so-important tasks. The plan can also give you an idea of how each day will look.

Creating a daily plan or a daily time map

A daily plan will help you in planning how you will carry-out your daily tasks. This requires you to have a fair idea about your daily tasks, how much time each of them requires and where you can place them on your daily schedule. It should also match with the time schedules of your hospital. You can have a daily time map fixed for you and keep the same until you want to make modifications. A sample daily time map is given below.

Daily Time Map

Time	Activity
9.00 am – 9.15 am	Preparing the room, checking monthly plan, keeping IEC and other materials handy for use
9.15 am – 11.15 am	Group counselling for ANC clients
11.20 am – 1.00 pm	Pre-test counselling
1.00 – 1.30 pm	Lunch , reading the news paper
1.30 pm – 3.30 pm	Post-test counselling
3.30 pm – 4.30 pm	Follow-up counselling and filling up registers, Contacting the ART centre or the DMC to check if there are Lost-to-Follow-Up clients (You can choose to contact one centre on one day and the other centre on the other day)
4.30 – 5.00 pm	Any other work
5.00 pm	Leaving office

Some Time Management Techniques

Key to effective time management is executing your plan systematically. This requires you to master some basic time management techniques.

Organizing

“Organizing is the process (by) which we create environments that enable (us) to live, work, and relax as exactly as we want to. When we are organized, our homes, offices and schedules reflect and encourage who we are, what we want, and where we are going” - Morgenstern in Organizing from the Inside Out.

Organization is not the same as neatness. When you organize things in a way convenient to you, you will be able to reach them easily and can save time searching for them. Organizing time is similar to organizing space. When you organize your activities, you get more time to do them.

Prioritizing

Prioritization is an essential skill for all professionals. It means to decide which task should be finished before the others. If you do not make such a decision, you may first complete the more enjoyable task, the task that takes the least time, the easier one, the familiar task or the task which makes you feel good. These tasks may not always be the important ones. If you do not recognize the priority level of different activities, you will find yourself fire-fighting – that is trying to complete important tasks at the very last moment. For instance, Do you find yourself running around for the MO's signature on the 3rd of every month? Is there a way to get the report signed on the 2nd or on the 1st?

Prioritizing involves the following steps

1. Decide what to do
2. Decide when to do it
3. Decide how to do it
4. Reevaluate your priorities

➤ **Deciding what to do**

One way to prioritize is the ‘Eisenhower Method’ (after US president Dwight D. Eisenhower who was said to have used this method). This method helps to decide the priorities based on the importance and urgency of the activities.

<i>Priority Matrix</i>		
	<i>Urgent</i>	<i>Not urgent</i>
<i>Important</i>	1st priority. Should be done immediately and personally.	Priority can be 3. Should be done personally. May do after you complete the urgent tasks. But should be allotted adequate time.
<i>Not important</i>	Should be the 2nd priority. If possible may delegate to your team member or involve others also.	4th Priority. May be delegated to team members. But should be completed before the deadline. May be allotted to the time slot when you have low energy.

While this may not sound relevant to your work at the ICTC, it has implications in designing your outreach programmes and demand-generation activities. An outreach programme high should be given priority than a general health camp.

➤ **Deciding when to do**

Some tasks in your list come with their assigned time, like pre-test counselling for ANC clients. Mostly clients come for pre-test counselling in the morning. However, there are some other tasks, like preparing reports, whose timings you can decide. Ask yourself “What is the best use of my time right now?” Ask this question whenever there is any question about what to do next.

You may also need to prioritize the activities within one category. For example, if you plan outreach visits, you need to prioritize between home visits to a PLHIV, visit to a village where some HIV-related crisis has occurred and TI project visits. Accordingly, you can decide on which Saturday you will go to each of these places.

➤ **Deciding how to do**

This is a caution to the perfectionist. Perfectionism is the enemy of time management, prioritization, efficiency and effectiveness. People who are perfectionists often start a task, but do not finish it or they take too long doing it, because they feel it still needs to improve. You need to minimize this self-destructive behaviour and focus on the results.

Addressing procrastination

“Procrastination is the act of putting off something until later by either not starting it, starting it at the last minute, or starting but not finishing”– Tullier.

If you procrastinate, it does not mean that you are a bad person. However, procrastination is not harmless, as it affects others also.

People delay doing things for different reasons, including

- Desire for attention
- Fear of change, failure, making a mistake and inadequacy.
- Uncertainty
- Lack of deadlines, information or interest.
- Over-commitment
- Resentment
- Unpleasant/boring tasks

To address procrastination, you should be aware of when you procrastinate and why. Keeping a procrastination log will help you in the same

You can stop procrastination by putting new thinking and new behaviours in to the areas identified as problematic. For instance, if you do not begin tallying the monthly data for reporting just because nobody is pushing you to do it, request one of your colleagues or friends to keep on reminding you about the deadline. Some other useful tips are given below.

- ✓ Break big tasks to manageable and small chunks. For example, preparation of monthly report can be broken down by tallying figures of general walk-in clients and provider-referred clients, ANC clients, consumables and staff details.
- ✓ If you have trouble in starting, start anywhere For instance, begin outreach with your first visit to the nearest TI project, then plan to visit one which is more distant. This will give you a good feeling about completing something.
- ✓ Do the hardest, most unpleasant task first. Once it is done, you may experience a sense of satisfaction of having taken the bitter medicine and then become relaxed enough to complete other tasks in the list.
- ✓ Aim for uninterrupted quality work time for half an hour. Most likely this may be available in the afternoon after clients leave the ICTC.

- ✓ Set your own time limits and increase your pace accordingly. For example, if you plan to record client information for the day in one hour, the next week aim at doing this in 50 minutes, in 40 minutes in the third week and so on.
- ✓ Fix and have a regular time to refresh your mind. Go around the area and meet people whom you like to connect with, or take a short walk around the hospital garden. Then you can come back with fresh energy.
- ✓ Remove distractions. Some counsellors switch off their cell phones while counselling and check missed calls every hour or so.
- ✓ Celebrate small achievements. If possible, celebrate these with your colleagues. You can find many occasions like a positive, pregnant lady delivering at the hospital, an exposed baby who tests negative in the confirmatory diagnosis, submitting your monthly report a day early, or receiving positive comments from a DAPCU or SACS officer visiting your ICTC.
- ✓ Display your activity plans on your work wall and put tick marks for things done.
- ✓ Think about the outcomes, rather than the process
 - “If you teach about condom use, the person can be saved from HIV”
 - “If you meet the FSWs in the area, HIV testing among them will increase”

Addressing time-wasters

Not all people are able to manage their time optimally. To prevent failures in time management, you must be alert about time-wasters. These are activities that take up large amounts of time without adding value to your work. Time wasters are of two categories

Internal time wasters

These are things you can control and change. You can look for behaviors such as

- Personal disorganization
- Lack of discipline such as not being present at the ICTC regularly
- Having too many personal and outside office activities
- Poor maintenance of office atmosphere and equipments like the computer
- Acting without plans, especially follow-up of clients and outreach
- Not having deadlines

You can change or control these time-wasters on your own. For example, if you find yourself disorganized, try to put things in an order. Start keeping a note of tasks you have to do and mark when you can do them.

External time wasters

These are caused by someone else and not always controllable by you. These can include

- Interruptions from others during counselling sessions.
- People coming late for appointments
- Dealing with problems of others in the hospital.
- Lack of computer or registers
- Lack of IEC materials
- Unclear instructions from superiors such as Chief Medical Officer, DAPCU officials or ICTC Medical Officer
- Lack of support from colleagues like Lab Technician, Medical Officer or staff nurse in the labour room

Managing Time Wasters

Managing time-wasters requires time and effort. Some time-wasters may be deep-rooted habits. Since it took a long time to develop the habit, you need to consciously try to change them. For the

same, you have to carefully identify which time-wasters you are practicing and figure out how you are going to change them. Some hints are provided below

- Make sure you know your priorities, and make sure what you do contribute to them
- Plan your time. Include time for unexpected tasks, urgent works, interruptions, etc
- Never promise what you can't deliver
- Use waiting time for something productive (e.g., waiting in the Dean's waiting room)
- Make optimum use of equipments and maintain them properly
- Organize your workplace so that you can easily find what you need.
- Listen and communicate effectively
- Distractions from other staff and clients are a major time-waster during counselling sessions and works that require concentration. Here are few tips to manage them
 - Allow a stated time each day for interruptions / unplanned events
 - Rearrange your furniture so that you are not facing the door
 - Remove extra chairs from your room. Close the door.
 - Avoid people who continuously take advantage of you

Some additional tips

- A plan – what you are going to achieve and what are the activities and their timelines.
- A To Do List
 - You can carry a small notepad and pen and note tasks you have to do.
 - Keep a to-do-list on your table and mark off tasks completed one by one. The achievements will give you satisfaction, while the un-marked ones will keep you in pace.
- An organized work place
 - It is the key to help you with your stationery, files, communication aids, etc. Patient education materials, condoms, penis model, referral cards, details of ART centers, etc should be within your easy reach.
 - Keep details of important contacts under the glass table-top or in a small notebook or on your cell phone for easy reference. Details of places where you constantly refer clients may be posted with a map outside your door. This will remind clients to go, and also prevent people who interrupt you for lost directions.
- Punctuality. Be on time to your workplace. Being late will ruin all your time plans.

ANNEXURES

Annexure 1: Steps in making Paper Bag Puppets

Step 1: Fold the paper bag. Once folded, you should be able to move the folded bottom by putting your fingers inside.



Step 2: Draw the outline of the face of the character you want to make on a separate cardboard or paper plate. The breadth of the picture should be bigger than the base of the paper bag.



Step 3: Paint the picture and wait until it is dry. Make sure that the eyes and mouth are clearly visible



Step 4: Cut out the face.



Step 5: Paste the picture on the base of the paper bag.



Step 9: Beautify the puppet (if required). This can be done by painting the bag with appropriate colours, making the body of the character and pasting it on the paper bag.



Annexure 2: Sample Stories

THE SELF

A flea decided to move with his family into the ear of an elephant. So he shouted, "Mr. Elephant, sir, my family and I plan to move into your ear. I think it only fair to give you a week to think the matter over and let me know if you have an objection."

The elephant, who was not even aware of the existence of the flea went his placid way, So after conscientiously waiting for a week, the flea assumed the elephant's consent and moved in.

A month later Mrs. Flea decided the elephant's ear was not a healthy place to live in and urged her husband to move. The flea decided to wait a month at least so as not to hurt the elephant's feelings.

Finally, he put it as tactfully as he could: "Mr. Elephant, sir, we plan to move to other quarters. This has nothing at all to do with you, of course, because your ear is spacious and warm. It is just that my wife would rather live next door to her friends at the buffalo's foot. If you have any objection to our moving, do let me know in the course of the next week."

The elephant said nothing, So the flea changed residence with a clear conscience

The universe is not aware of your existence! Relax!

de Mello, A (1998) The Prayer of The Frog: A book of story meditations (1st Vol.) Anand, India: Gujarat Sahitya Prakash.

EDUCATION

The family settled down for dinner at the restaurant. The waitress first took the order of the adults, then, turned to the seven-year-old.

“What will you have?” she asked.

The boy looked around the table timidly and said, “I would like to have a hot dog.”

Before the waitress could write down the order, the mother interrupted. “No hot dogs,” she said. “Get him a steak with mashed potatoes and carrots.”

The waitress ignored her, “Do you want ketchup or mustard on your hot dog?” she asked the boy.

“Ketchup”

“Coming up in a minute,” said the waitress as she started for the kitchen.

There was a stunned silence when she left.

Finally the boy looked at everyone present and said, “Know what? She thinks I’m real!”

de Mello, A. (1996). The Prayer of The Frog: A book of story meditations (2nd Vol.). Anand, India: Gujarat Sahitya Prakash.

Annexure 3: Optional Article on Vulnerability of MSMs

Article Reprinted with Permission from Guilford Press

AIDS Education and Prevention, 19(4), 346–364, 2007

© 2007 The Guilford Press

STRUCTURAL VIOLENCE AGAINST *KOTHI*-IDENTIFIED MEN WHO HAVE SEX WITH MEN IN CHENNAI, INDIA: A QUALITATIVE INVESTIGATION

Venkatesan Chakrapani, Peter A. Newman, Murali Shunmugam, Alan McLuckie, and Fredrick Melwin

This qualitative investigation explored the experiences and contexts of stigma and discrimination among HIV-positive and high-risk *kothi*-identified men who have sex with men (MSM) in Chennai, India, and ramifications for HIV prevention. MSM were recruited through community agencies ($n = 10$) and public sex environments ($n = 8$), along with three key informants. In-depth, semistructured interviews were conducted, audiotaped, and transcribed. Narrative thematic analysis and a constant comparative method were used to identify themes. Findings revealed multiple intersecting social and institutional contexts and experiences of stigmatization, discrimination, and violence across police, community, family, and health care systems, as well as illuminating consequences for MSM. Multisystemic structural violence places *kothis* at extreme vulnerability for HIV infection and AIDS. Public mass media antidiscrimination campaigns, education and training of health care providers and police, funding of indigenous MSM community organizations, and decriminalization of consensual sex between same-sex adults may help to combat stigma, discrimination, and violence against MSM, which is fundamental to effective HIV prevention.

From the Kama Sutra to numerous ancient temple carvings, it is evident that men who have sex with men (MSM) and *hijras/aravanis* (transgendered women or male-to-female transgendered persons) have existed in India for thousands of years. Strong condemnations of same-sex behaviour or attractions are also notably absent from Hindu religious doctrine. In general, Indians tolerate, accept, and respect a wide range of difference in cultures, religions, languages, and customs. Despite Indian society's general climate of acceptance and tolerance, however, there appears to be limited public knowledge and understanding of men who have sex with men (MSM) or same-sex sexual orientation. Furthermore, Indian and international human rights organizations have documented human rights violations against sexual minorities (People's Union for Civil Liberties, Karnataka [PUCL-K], 2003), the transgendered community (PUCL-K, 2001), and HIV/AIDS peer outreach workers from MSM and sex worker communities (Human Rights Watch, 2002) in India.

Discriminatory practices, which may occur outside of the conscious awareness of persons who constitute the key institutions of society, may emerge from family, community, medical, and legal systems. Indirect forms of oppression, such as stigmatization and discrimination, are engaged by individuals or groups as methods of social control to prioritize and enforce their particular beliefs, worldviews, and their power within a society (Galtung, 1969; Link & Phelan, 2001). Power-wielding groups may have little awareness that the privileging of their own belief systems occurs at the direct expense or marginalization of other social groups, such as MSM. As Galtung (1969) wrote, "Personal violence shows ... Structural violence is silent ... Structural violence may be seen as about as natural as the air around us" (p. 173). Link and Phelan (2001) have indicated that indirect forms of oppression evolve into direct forms of oppression, such as violence and abuse, when stigmatized groups do not accept their assigned nondominant status. Thus, it is hypothesized that key institutional forces may be complicit, if not actively engaged in stigmatizing and discriminating practices against MSM. Overall, stigma and discrimination against MSM may need to be explored as a product of structural societal forces, as opposed to traditional models that focus on stigma as an individual-level phenomenon (Galtung, 1969; Parker & Aggleton, 2003).

The silence and secrecy associated with institutional stigma and discrimination may provide ideal conditions for escalation of the AIDS epidemic (Mann, 1987a; Mann, 1987b; Mawar, Sahay, Pandit, & Mahajan, 2005). The fact that HIV was first identified among female sex workers in Chennai and later spread to the general population may fuel the still popular presumption that the HIV epidemic in India is "predominantly heterosexual" (National AIDS Control Organization [NACO], 2005a). Nevertheless, institutional silence may be evidenced in MSM being largely overlooked in HIV prevention and treatment in India. Out of 455 HIV serosurveillance sites operated by NACO across the vast landscape of India in 2003, only three sites specifically collected data from MSM (NACO,

2005b). This lack of epidemiological data appears to be emblematic of inadequate national HIV prevention and care programs for MSM in India (Chakrapani et al., 2002) and may be a manifestation of structural factors, including institutional stigma and discrimination.

Limited investigations have focused on stigma and discrimination faced by MSM and *hijras* in India (Chakrapani, Babu, & Ebenezer, 2004), even less so among persons in these communities living with HIV. In fact, a recent UNAIDS (2001) report on stigma and discrimination faced by people living with HIV (PLHIV) in India included only one and a half pages with scant information on “gay and other homosexually active men.” The authors noted that “[d]espite numerous attempts over several months, eliciting the voluntary participation of HIV-positive gay men in this study proved unsuccessful” (UNAIDS, 2001, p. 56).



FIGURE 1. Map of India.

The purpose of this investigation is to explore the lived experiences and contexts of stigma and discrimination among HIV-positive and high-risk *kothi*-identified MSM in Chennai, India, and ramifications for HIV prevention.

METHODS

Two qualitative studies were conducted in Chennai, a metropolitan city of 6 million people. Chennai, formerly known as Madras, is located on the Bay of Bengal in the southeast Indian state of Tamil Nadu (Figure 1). The studies were conducted in collaboration with three community-based organizations: Social Welfare Association for Men (SWAM), Sahodaran (Brother), and Allaigal (Waves). These organizations primarily serve *kothi*-identified MSM, including those who are HIV-positive and those who engage in sex work. Prolonged engagement (Lincoln & Guba, 1985) over the course of 6 years on the part of the research team with these agencies and the populations they serve greatly facilitated study implementation and interpretation of the findings.

Previous experiences of the research team suggested that MSM, and even more so HIV-positive MSM in Chennai may be reluctant to meet in groups owing to fears of disclosure to both their own and the larger community and the criminalization of sex between men in India (Chakrapani et al., 2002). Accordingly, individual, in-depth semistructured interviews were conducted by trained interviewers. Furthermore, all recruitment was conducted by word of mouth only in order to avoid potential risks to participants and research

staff that might result from inadvertently advertising the study outside of select venues or invoking police involvement.

In Study 1 ($n = 10$), peer-driven and snowball sampling techniques were used to recruit HIV-positive *kothi*-identified MSM. SWAM staff informed known HIV-positive MSM who belong to their friendship network about the study and asked about their willingness to participate (peer-driven sampling). Additionally, some HIV-positive MSM referred other HIV-positive MSM, who then contacted the research staff (snowball sampling). To ensure exploration of issues faced by married MSM, research staff specifically included married MSM among those invited to participate. In Study 2 ($n = 8$), outreach staff recruited potential participants from in and around public sex environments (PSEs; i.e., “cruising areas”) in Chennai. Potential participants were invited to take part in a one-time anonymous interview. Additionally, three key informants with expertise on the *kothi* community were recruited from community agencies serving this population.

For both studies, interview venues were chosen according to the convenience of participants and the safety of participants and research staff. All the HIV-positive *kothi*-identified MSM were interviewed in a private room in the offices of SWAM or Allaigal. MSM recruited from PSEs were interviewed at SWAM or in safe places near the cruising sites. Some of these men preferred not to come to the offices of an MSM-identified agency. No interviews were conducted in PSEs owing to risks to participants and staff. Written informed consent was obtained from all participants, including consent for audiotaping of the interview. The investigation received approval from the Ethics Review Board of University of Toronto and the Community Advisory Board of SWAM.

Interviews were conducted using a semistructured in-depth interview guide in Tamil with scripted probes. Interview questions were modified or added over the course of the study in an iterative process to explore and reflect on emerging findings, a technique called progressive focusing (Schutt, 2004). The interview guide was translated into Tamil and back-translated into English to ensure accuracy. Interviewers were native Tamil-language speakers who received extensive training in interviewing and research ethics. All interviews and communications with participants were conducted in Tamil, except for two key informants who preferred to be interviewed in English.

The interviews of HIV-positive MSM and key informants (Study 1) were from 45 to 90 minutes. Interviews with MSM from cruising areas (Study 2) were conducted for about 30 minutes because most of these interviews took place near the cruising areas. An honorarium of 200 Indian rupees (U.S.\$ 4.50) was given to all HIV-positive MSM as recommended by SWAM’s community advisory board. No monetary incentives were given to MSM recruited in cruising areas; rather, snacks were provided after the interview. Key informants did not receive incentives. Interviews were tape-recorded and transcribed verbatim in Tamil and translated into English for data analysis. Three participants who agreed to be interviewed did not want their interviews to be audiotaped owing to concerns about confidentiality; notes were taken immediately following these interviews.

Multiple readings of the transcripts were performed by two independent investigators. Line-by-line review of the transcripts was conducted and first-level codes (descriptors of important components of the interviews), including in vivo codes (using the language of participants), were noted in the margins (Charmaz, 2006; Glaser, 1978). Next, text corresponding to each of the first-level codes was reviewed by at least two investigators. Using focused coding and a constant comparative method (Charmaz, 2006; Glaser & Strauss, 1967), first-level codes were refined and organized into categories. Finally, theoretical coding was undertaken to identify higher level codes, relationships among categories, and to ensure saturation of categories (Charmaz, 2006). Member checking was conducted with key informants to increase credibility of the findings (Lincoln & Guba, 1985). Peer debriefing (Lincoln & Guba, 1985) was undertaken with MSM community leaders and health care researchers to increase trustworthiness of the findings. The results correspond to the emergent categories; all quotations are drawn from the interviews.

RESULTS

UNDERSTANDING THE *KOTHI* CONTEXT

Kothi-identified MSM, as part of their self-defined role, ostensibly do not engage in sex with one another. *Kothis*’ gender expression is feminine and they are attracted to masculine partners, who they call *panthis*. *Panthis*, however, do not self-identify as such; the label is used by *kothis*. *Kothis* are generally receptive partners in sexual encounters with *panthis*, who are assumed by *kothis* to be predominantly heterosexual. Men who engage in both insertive and receptive anal sex are labeled “double-deckers” by *kothis*. Nevertheless, some *kothis*

report that behaviorally they fit in the double-decker category or that they may engage in various sexual behaviors to please their *Panthis* partners. *Kothis* are generally of lower socioeconomic status and some *kothis* engage in sex work for survival. The construction of sexuality among *kothi*-identified MSM is thus complex, and may differ from that of middle-class, educated, gay-identified MSM in India (Chakrapani et al., 2002). The findings of this study are best interpreted in the context of *kothi* identity and may not be transferable to other groups of MSM in India.

PARTICIPANTS

Participants in Study 1 included 10 HIV-positive *kothi*-identified MSM and three key informants, who were service providers to *kothis*. Participants in Study 2 were eight high-risk *kothi*-identified MSM of unknown HIV serostatus. Participants across the two studies ranged from 19 to 52 years of age, with a mean age of 28.2 years. Key informants ranged from 29 to 40 years of age. All participants were of lower socioeconomic status, with an average monthly income of 1,500 rupees (U.S.\$34) or about \$1 per day. Five participants were unemployed at the time of the interview and half ($n = 9$) indicated working occasionally as sex workers, predominantly receptive partners in sexual encounters with *panthis*. Four participants reported being married (to women).

Multiple Contexts of Stigma, Discrimination and Violence. The experiences and consequences related to stigma, discrimination, and violence against *kothi*-identified MSM occurred across multiple social and institutional contexts and are presented in four categories: the police, community members, family, and the health care system. These categories are further structured into subsections that include direct and indirect forms of oppression. A fifth category describes the impact of direct and indirect oppressive forces on the lives of *kothi*-identified MSM.

The Police: Direct Forms of Oppression

Verbal and Physical Harassment. Participants reported being verbally harassed by police. *Kothi*-identified MSM may frequent PSEs in Chennai to locate potential male sex partners or male clients if they are sex workers. These *kothis* face problems from police who regularly monitor these public spaces. *Kothis* are of lower socioeconomic status and many *kothis* can be recognized by their feminine mannerisms; police often use abusive language and insult them. In particular, participants who reported frequenting the same PSEs over time in search of potential male sexual partners explained that policemen may easily recognize them. These men reported being physically accosted and beaten by police for no specific reasons. As a participant reported, "That policeman said to me, 'Why are you standing here? I know who you are;' and before I reacted he started to beat me with a *lathi* [police stick] on my back and legs."

Sexual Assault and Rape. In addition to physical abuse, participants reported being sexually assaulted by police. One participant described that while in a deserted public area he was forced by a policeman to perform oral sex on the policeman. Another participant who was an HIV-positive MSM reported an incident in which a policeman took him to the police station and forced him to have sex with him:

Policemen took me to police station and during the night one policeman asked me to come to the bathroom. He had sex with me in the back. I did not have condoms at that time since I was only in my underwear. I also could not talk about condoms; even if we just show condoms they will beat us on our hands with the *lathi*.

This sexual assault by policemen also presents a direct risk of sexually transmitted disease (STD) and HIV transmission to both parties.

Blackmail and Extortion. Participants reported instances in which policemen had taken away driver's licenses or identity cards and written down the addresses of *kothis* who come to cruising areas. The police then ask them for money or for periodic payments under threat of informing family members that the participant is engaging in public sex or sex for money with other men. A participant explained:

He [the policeman] took away my driver's license and said that if I want to have it back I need to give him 200 rupees. I had no other option and gave it. I was only standing in that place when he found me. He might have been noticing me for many days before he came to me to get money from me.

Some MSM who are frequent visitors of a particular cruising area have to regularly pay the beat policemen so the men can remain at the site. *Kothis* who engage in part-time sex work may be particular targets, because

they are seen as able to afford to pay: “Police usually get about 20 rupees almost daily from me . . . even if I go somewhere else I might need to pay money to the policemen on that beat,” explained a participant.

The Police: Indirect Forms of Oppression

Arrest on False Allegations. In addition to outright abuse, participants reported circumstances where police officials abused their powers when in contact with *kothis*. Police may target *kothis* because as a marginalized group within society they hold little power or influence to challenge such systemic abuses. One participant described the experience of being arrested on false charges:

Policemen want to book some cases to show that they are doing their job. Hence once in a while we become easy targets for them to book cases. They may book us under petty crimes like pickpocket or chain snatching and will ask us to pay money to be released from or not to be booked in such cases.

Another participant reported that he had been arrested by a policeman, who alleged that one of his *aravani* (*hijra*, or male-to-female transgender) friends may have been involved in a theft that occurred in the area. Because this *kothi* was a frequent visitor to that area and known to be a *kothi* because of his feminine mannerisms, he was an easy target for the police.

Refusing to Offer Protection to MSM. In addition to reporting rampant abuses of police powers, participants also described the policemen as being derelict in their duty to serve and protect *kothis*. *Kothis* who reported physical or sexual abuse from “rowdies” explained that often they don’t report the incidents to police because they have lost faith in them. A *kothi* described a policeman’s reaction to a request to file a report: “Since you are a *pottai* [derogatory term] he must have done that. Why should we protect you? I’m not appointed by the government to protect people like you.” Thus, in addition to violence and extortion on the part of police, *kothis* are also at heightened risk from others since they cannot rely on police protection.

Harassment of Outreach Workers from MSM Community Organizations. Police were also reported to indirectly discriminate and oppress *kothis* by harassing and obstructing community outreach workers providing services to *kothis*. A key informant explained:

The outreach workers face problems from policemen if they have condoms with them. Outreach workers are even afraid to carry educational materials that show pictures of STDs. Some policemen don’t even look at the identity cards shown by the outreach workers. They will say, “I know who you are . . . don’t fool me by showing this [identity card].”

These activities on the part of the police pose substantial obstacles to outreach workers and directly obstruct their ability to implement HIV prevention activities in the field.

The Community: Direct Forms of Oppression

Kothis who frequent PSEs described being victimized by community members referred to as rowdies or ruffians. Ruffians are reported to engage in forms of violent oppression that include verbal abuse, physical violence, sexual assault, blackmail and extortion.

Violence by Rowdies. A participant explained, “We call those *panthis* who give us trouble *beelis*. *Beelis* beat us for no reason and may also take away money from us. Many times they also forcefully have sex with us and do not allow us to use condoms.” Another participant reported, “We can not report this to police since they join hands with one another,” referring to collusion between police and rowdies.

A participant reported that a rowdy:

had a large knife with him and cut me on my leg, maybe to scare me. He also later forced me to have sex with him. On another day, a rowdy demanded money from me and told me if I did not give him money he will cut me with a blade.

Another participant recounted an incident of violence from a rowdy:

One rowdy was angry that we come to his area and also earn money through sex work. Hence he threw a large stone in the face of my *kothi* friend and walked away. I took my friend to [government hospital], but there we did not have the guts to tell them that a rowdy did that. We

said that he tripped over a stone and injured himself. What shall we say if we want to file a case?
... That we are homosexual men and also do sexwork?

As participants explained, the actions of rowdies are enabled by a system that does little if anything to protect MSM, a system in which police are often as feared as the rowdies. Some male sex workers who regularly stand in a particular site to find clients explained their inability to use condoms with ruffians:

They [ruffians] have sex with us. We cannot talk about condoms with them. They will beat us and show us a knife. They have hurt me using blades. They also take away our money.

Thus, the risk of HIV transmission is ever-present with rowdies.

Blackmail by Rowdies. A participant explained attempts at blackmail by rowdies: "That rowdy by some way got my home phone number and threatened me that he will tell my family members if I do not give him money periodically. Finally, I got rid of him only after changing our phone number." *Kothis* do their best to protect themselves in a dangerous social context. Nevertheless, harassment, extortion and violence against *kothis* on the part of rowdies, powerlessness to report the events for fear of repercussions, and inability to gain the protection of police were recounted.

THE COMMUNITY: INDIRECT FORMS OF OPPRESSION

Rejection by Heterosexual Friends. In addition to experiencing direct oppression in the form of violence from ruffians, *kothis* may experience indirect forms of oppression from members of the community who are well known to them. Participants reported not disclosing that they are HIV-positive and/or MSM to most of their heterosexual ("general") friends. A participant explained, "How can I tell our general friends that I am a homosexual and HIV-positive? They would break the friendship immediately and may also spread the news to others. We cannot show our face outside."

Another participant recounted that his heterosexual friend would reject him and feared stigmatization from being associated with an MSM:

I once asked my "ordinary" [heterosexual] friend what he would do if he found out I am a homosexual. He said he would leave me at once. He also asked me what others would think of him if he was a friend of a homosexual. He said he did not want to face that risk.

Kothi-identified MSM may feel unable to reveal their sexuality to heterosexual friends, as well as their HIV status. Heterosexual friends of some MSM may not want to continue friendships with known *kothis* owing to fear of stigma by association and discrimination from others in the community. Confronted by the very real prospect of being ostracized from their established peer support networks, many *kothis* may remain secretive about being MSM or HIV-positive. Silence or denial may decrease the likelihood that *kothis* will engage resources and practices consistent with safer sex and deters utilization of resources for HIV/AIDS care and other health concerns.

Rejection by Other Kothis. HIV-positive participants also described stigma and discrimination from within their own *kothi* community. A participant recounted an incident of having his confidentiality compromised while reaching out for support to another *kothi* :

I cried when I was told I was HIV-positive. Another *kothi* saw this and asked why I was crying. At that moment I told him I was positive, without thinking about the consequences. Then that *kothi* spread the news to everyone.

Another participant who reported being open about his HIV status to his *kothi* friends narrated an incident that occurred in the drop-in center of a community organization:

Usually I also assist in cooking in the drop-in center kitchen. After I was known to be HIV-positive, I was asked not to participate in any cooking activities. One *kothi* said, "Do you think others would like to eat the food cooked by you? They will throw away the food once you go that side." I was very saddened to hear those comments.

Some *kothis* evidence lack of knowledge about HIV transmission and endorsement of myths, and may discriminate against other *kothis* who are HIV-positive.

Another dimension of discrimination within the *kothi* community occurs around marriage. Although many *kothi*-identified MSM get married, some *kothis* mock these marriages and may even target married *kothis*. A married *kothi* explained his fear of being targeted by other *kothis*:

I was very afraid of going out with my wife after we newly married. I was worried about what other *kothis* would say. Will they laugh at me? Whether they will come and talk to me when I was with my wife? What if they tell my wife about me? I was going mad with all these thoughts.

Kothis may experience stigma and discrimination within their own communities, which may manifest as unwanted disclosure of their being HIV-positive, discrimination as a result of living with HIV, and fears of being “outed” (i.e., revealed as an MSM) to their wives. Marriage by *kothis* to women, in turn, is strongly linked to family pressures to adopt the expected male role and fears of rejection from the family.

The Family: Direct Forms of Oppression

Participants reported stigmatization as well as violence from within their own families, who might otherwise represent an invaluable source of support.

A participant reported the repercussions of his father finding out about his sexuality: “By some way my father came to know about my same-sex behavior. From then onwards, he started to hate me and beat me then and there.”

Kothis may leave the family home to escape the abuse and violence inflicted by family members in response to discovering their sexual orientation. A participant reported experiencing violence from his siblings: “My brothers had beaten me black and blue after they came to know about me. Later I had to run out of my family to settle in Chennai.” Another participant indicated that his family “verbally abused me for bringing shame to the family name.”

The Family: Indirect Forms of Oppression

In addition to leaving home to escape direct violence, many *kothis* consider leaving their family to avoid the conflict and stress arising from the clash of traditional Indian family values and their sexuality. A key area of conflict within the family may arise from the social pressures for men to marry regardless of their same-sex orientation. A participant described the stress within the family by saying that “there were frequent quarrels between my father and mother regarding my behavior. Once I got sick of it and ran away from my home and stayed in a market area.” Upon leaving the family system *kothis* are likely to face other stressors, including poverty. A participant reported that after leaving home he “survived by exchanging sex with other men for money.” Faced with the need to satisfy their basic survival needs, some *kothis* may place themselves and others at increased risk for HIV infection.

Regardless of whether or not *kothi*-identified MSM leave the family home they are likely to be held responsible by family members for the stress and conflict within the family system as a result of their failure to fulfill their expected male roles and transgression of male gender norms. A participant describes this process: “When I returned to my home after some time, I came to know that my father had passed away. My entire family hated me, since I was thought to be responsible for my father’s death.”

Kothis are also the target of blame by family members for bringing public shame to the family, owing to their sexual orientation. Participants explained that for some family members, their being HIV-positive might be more acceptable than being gay. For example, a participant reported: “[M]y father told me that he could tolerate that I was HIV-positive but asked me not to tell others that I got it by having sex with men.” Although HIV is stigmatized, the stigma attached to homosexuality among some families may be even greater.

The Health Care System: Direct Forms of Oppression

Health Care Providers. Participants reported discrimination and stigmatization by health care providers, which took the form of derogatory labeling, demeaning interactions, outright insults, breaches of confidentiality, and refusals of service. Together these forms of direct oppression appear to contribute to substandard care of *kothis*.

Kothis may be uncomfortable reporting symptoms that might disclose they had sex with other men for fear of provider repercussions. Furthermore, some providers are negligent in asking about sexual histories and outright insulting and/or incompetent in working with MSM.

A participant reported being asked by a physician in a derogatory way, “Are you a man? . . . You have a moustache and why do you want to have sex with other men? Try women.” This illustrates lack of sensitivity and knowledge in working with MSM. An HIV-positive participant described discrimination experienced at a government (public) hospital: “As soon as you are found to be HIV-positive they [physicians] send us to [another facility]; they don’t even touch us then.”

A participant described his embarrassment in recounting anal STD symptoms to his doctor:

Once I had pain in the back [anus] and was afraid to tell the doctor when I went to [a government hospital]. I came back without telling. Then my friend took me to a private doctor known to him. I told him about the pain and he prescribed some tablets for it . . . No, he did not see the back.

Some MSM may not reveal their anal STD symptoms for fear of being revealed as having sex with men. Furthermore, physicians may not conduct proper clinical examinations even if symptoms, such as those suggestive of anal STDs, are reported by the patient.

The Health Care System: Indirect Forms of Oppression

Health Care Providers. *Kothis* also report that some medical practitioners, agency staff, and programs engage in indirect oppressive practices through being poorly educated about HIV transmission or treatment, engaging in negligent professional conduct that fails to adequately explore risk factors, hiring staff who are incompetent in working with MSM, and/or designing programming that fails to account for the needs of MSM and/or denies equal accessibility to MSM. A participant shared an incident in which a private medical practitioner neglected to inquire about any sexual history or details of his anal symptoms when he mentioned that he had an ulcer “in the back.” “[The doctor] then asked, ‘Did you wash your legs [a euphemism for washing buttocks] in a pond?’ I said ‘yes.’ No . . . he didn’t ask anything about my sexual activities.” This suggests possible embarrassment on the part of this physician in asking about same-sex behavior even though it was relevant in the clinical context. Consequently, one cannot be sure about the accuracy of the clinical diagnosis and provision of proper treatment for STD symptoms.

Participants also expressed that safer sex information for HIV-positive persons is either not given at all or different messages are given by different providers. A participant reported:

Tell me . . . when one has become HIV-positive should they no longer have sexual feelings? We are also human beings; why is this not discussed by doctors? They tell us, ‘Do not have sex.’ Many do not even talk about it [sex].

Another participant explained,

I told that doctor that I had sex last month. He gave back my [outpatient case] sheet and asked me to get out. I was told later that he actually slapped one patient for having had sex. I was fortunate [giggles]. He is no longer in [name of government hospital].

Participants recounted confusion at inconsistent safer sex information from different providers. As a participant reported:

The doctor told me not to have anal sex but that I can have oral sex . . . that too with condoms. That nurse told me I should not be having sex at all, since I should not infect others. The counselor was telling me to reduce the sex[ual activity]. He didn’t even talk about condoms.

Participants explained that even less information on sex with women is given to self-identified MSM, and their need for information about how to address women, including their wives.

Often, no, always, they [outreach workers] talk about male-male sex but not much information is given on sex with women or STDs in women; and many *kothis* are married too. How can they tell their wife that they have HIV? They cannot use condoms with their wife . . . I do not know.

Even providers or counselors who do address sex between men may omit discussion of sex with women, perhaps having judged that these men are not sexually active with women. MSM as well may be reluctant to raise the issue of sex with women, or that they are married, for fear of greater stigmatization and blame, and fear of compromising their confidentiality.

HIV-Positive Support Groups. Entire programs ostensibly engaged in HIV prevention or HIV treatment may be perceived as oppressive by *kothis*. For example, some HIV-positive participants indicated awareness of support groups and organizations, but were wary of attending groups designed to primarily serve HIV-positive heterosexuals: "Someone told me there is one [support group] in Chennai for ordinary [heterosexual] positive people. What will be the use in going there?" Another participant expressed his fear of being discriminated against: "Will they understand us? Maybe they will not talk to us when we go there." A participant described his experience attending a group for HIV-positive heterosexuals: "There one can talk about medical issues, but how can I talk about my personal life? They do not talk about that." Another participant, however, expressed optimism that other groups for persons living with HIV would understand the issues faced by MSM: "They will understand us [MSM]; they are also suffering from HIV and face discrimination, hence they could understand our condition too."

A key informant suggested the benefits of HIV-positive MSM having the option to attend any HIV-positive group: "They should be given options . . . should be able to go there [to mainstream groups] and use their services, as well as should have their own support groups so that they can talk about the sexuality issues . . . can move back and forth between the groups and then can ultimately choose where they want to be, after experiencing both." Nevertheless, participants' generally perceived that mainstream HIV-positive support groups, ostensibly serving heterosexuals, would not be able to serve their needs.

Consequences of Stigma and Discrimination in the Lives of *Kothis*

Depression and Suicidality. Some HIV-positive participants described waiting for their feelings of sadness, depression, and alienation to abate by themselves. The latter is understandable given reality-based fears of discrimination from many constituencies who they might otherwise reach out to for support: health care providers, family, *kothi* friends, heterosexual friends, and HIV-positive support groups. Nevertheless, some participants who described suicidal feelings after finding out they were HIV-positive reported positive experiences in seeking support from other *kothis*:

I would have committed suicide. I told my suicidal feelings to another *kothi*. He said why die now, when anyway we will be dying owing to AIDS in the future. Then, I also thought what was the point in dying; as long as I live let me remain jolly.

Another participant explained: "When we [*kothis*] are together, we laugh, tease one another, and chat a lot . . . we would be very happy. Once I have to leave to my home I would feel very lonely; I could not share these things in my home." Although some HIV-positive *kothis* described fears and experiences of being ostracized by their own community, other *kothis* expressed their experience of the *kothi* community as a primary source of emotional support.

Nondisclosure of HIV Status / Lack of Social Support . HIV-positive participants expressed fears of rejection and isolation that prevented them from revealing their serostatus to nonsexual friends and family. "I cannot tell this to my *panthi* [nonsexual masculine] friends," noted one participant. "They cannot understand . . . if I tell my general [heterosexual] friends then they will tell my family." Another participant explained, "I do not want to tell my *kothi* friends. If one knows then everyone will come to know; I have seen how some [HIV-] positive *kothis* have suffered from problems created by other *kothis*."

Reasons for not disclosing one's HIV status to family members included fear of bringing shame to one's family, not making the family suffer, and fear of rejection. Some HIV-positive participants expressed shame about their sexual orientation. In particular, some respondents reported feelings of guilt about their sexual orientation, which reemerged after learning of their HIV status. As a participant reported, "It is because I'm born like this I got this infection." Anti-gay stigma and HIV/AIDS stigma may be mutually reinforcing and inextricably linked for some MSM. A participant described wanting to protect his family from shame: "What will the neighbors speak of my family? They could not show their face outside." Another participant asked, "But why should we tell our family that we are positive? That will only make them suffer."

Another HIV-positive participant explained his fear of being further rejected by his family: "Already my brothers do not talk to me because of my feminine nature and if they came to know I am also positive then they will just drive me away." HIV-positive *kothis* may experience reality-based fears and concerns that prevent them from disclosing their HIV status to family members. Participants described both wanting to protect themselves from rejection from within their own families as well as wanting to protect their families from stigma and discrimination from the larger society. Thus, stigma and discrimination operate in multiple ways that present

obstacles to HIV-positive *kothis* in reaching out to their families, who might otherwise represent an important source of psychosocial support.

DISCUSSION

Kothi-identified MSM face stigma, discrimination and violence across multiple social and institutional contexts in Chennai. Experiences of victimization appear to be exacerbated for HIV-positive *kothis*, who face additional stigma and discrimination within the health care system (which they are more likely to have to interact with as a result of being HIV-positive), within the larger *kothi* community, and from mainstream HIV and AIDS support groups. As difficult as it may be to contend with stigma and discrimination from within one context, such as law enforcement, the family or the health care system, the multiple overlapping contexts of stigma and discrimination faced by *kothis* present monumental challenges not only for HIV preventive intervention, but for overall health and survival. This network of “ubiquitous social structures,” as depicted in Figure 2—across legal, community, family and health care systems—is emblematic of structural violence (Galtung, 1969), which places MSM at extreme vulnerability for HIV and AIDS.

The present findings suggest interlocking subsystems of discrimination and victimization of *kothi*-identified MSM—including police, community members, family members and health care providers—that are embedded in structural factors, and which must be understood beyond an additive or individual-level model. For example, rowdies are able to extort money from *kothis* because of *kothis*' reality-based fears of rejection from family if their sexual orientation and/or HIV status became known. Rowdies can engage in unmitigated exploitation and violence against *kothis*—on an ongoing basis—because police, who might otherwise be called on to protect people from such violence, themselves engage in violence, rape, harassment, and blackmail of MSM. Without police enabling, the behavior of rowdies might otherwise be punished and reduced. The social context in which disclosure of one's sexual orientation to family is tantamount to family and community rejection also enables the threat of blackmail and extortion, which otherwise might prove less likely to be effective threats.

Interlocking subsystems that support direct and indirect victimization of *kothi*-identified MSM are enabled and fomented by structures embedded within Indian society. A legal system that criminalizes sex between consenting male adults provides an example of a structural-level factor that creates conditions which enable discrimination and stigmatizing practices. Inequality and discrimination that is codified within the legal system establishes social conditions that facilitate the disempowerment and marginalization of MSM. Apparently commonplace police harassment of MSM and health care workers, for example, is supported as MSM represent easy targets for “filing a case,” which provides a demonstration to the public that the police are doing their jobs. These unjustifiable arrests also function to avert concerns regarding possible public complaints and media attention if MSM “cruising areas” on police beats appear to be uncontrolled or unchecked. As long as male-to-male sex is criminalized, there exists state-sponsored justification and motivation for police harassment and violence against MSM, and the likelihood of individual MSM coming forward to report or combat such violence and abuse is greatly diminished as they are always at risk for arrest and for being blamed themselves. The extensive harassment of MSM suggested by the present study is supported by a recent investigation in which two thirds of 62 MSM HIV prevention outreach workers surveyed in Chennai reported at least weekly harassment from police and rowdies (Safren et al., 2006). Our study suggests that while police violence against MSM may occur on an immediate personal level, which may be more visible, such personal violence is “called into action by expectations deeply rooted in the structure” (Galtung, 1969, pp. 179–180) of Indian society—or structural violence—which is more difficult to pinpoint and control. Nevertheless, the present findings suggest that HIV prevention research and interventions for MSM in Chennai must target this structural level.

The sexual and physical harassment and violence faced by *kothis* from both rowdies and police also may be understood as punishment for transgressing traditional gender boundaries and as an affirmation of the masculinity of the perpetrators. Perhaps paradoxically, such violence and victimization may enable sexual activity between *kothis* and police or rowdies; the perpetrator is perceived as male and not homosexual, even as he is engaging in sex with another man, because of the violent nature of the encounter and his role as the insertive partner in anal or oral sex.

Interwoven systems of stigma and discrimination also present tremendous obstacles to families who might otherwise serve as important sources of support for HIV-positive *kothis*. Our findings suggest that for some families it may be easier to accept their son's being HIV-positive than to accept his sexual orientation. Nevertheless, being HIV-positive is seen as a sign of sexual immorality; not only the individual, but the entire

family risks being stigmatized by the larger community. Courtesy stigma (Goffman, 1963), or stigma by association, has been documented in regard to both gay men (Herek, 1999; Sigelman, Howell, Cornell, Cutright, & Dewey, 1991) and PLHIV (Alonzo&Reynolds, 1995; Herek, 1999) and appears to be a potent phenomena among *kothis*. Many *kothis* may be reluctant to bring shame to their families by revealing their HIV status, in addition to fears of being rejected by their families, which obviates even the possibility of disclosure and family support. Families as perpetrators of both indirect and direct discrimination and violence on a personal level also form part of the superordinate system of structural violence in enacting oppressive social codes that disenfranchise and victimize MSM.

In a similar vein, stigmatization and discrimination against *kothis* within mainstream HIV-positive support groups that largely serve heterosexuals may reflect fear of stigma by association. PLHIV may experience particular vulnerability to stigma and may actively resist association with homosexuality, which may threaten the construction of “innocent victim.” As a result, PLHIV who might otherwise serve as resources and provide social support for *kothis* living with HIV and AIDS may be constrained by structural forces that threaten their own survival in a system of oppression against all PLHIV. Fear of stigma by association, and the power of structural violence, also appears to be manifested among heterosexual friends of *kothis* and HIV-positive *kothis*, which often precludes *kothis*’ seeking social and emotional support from heterosexual friends.

Finally, discrimination against *kothis*, and HIV-positive *kothis*, in particular, occurs within the health care system. Disparaging comments, outright refusal of service, lack of appropriate clinical examination and lack of appropriate safer sex counseling suggest a health care system that is largely inadequate in serving MSM. It is not surprising that MSM may choose not to volunteer information about sexual behaviors and STDs in a hostile context, which further obviates the possibility of receiving appropriate care and safer sex counseling. Health care providers may limit the possibility of appropriate care by denying and even supporting crucial structural impediments to health (Farmer, Nizeye, Stulac, & Keshavjee, 2006). Police harassment of HIV/AIDS outreach workers further contributes to a system that presents myriad obstacles to HIV prevention. In fact, HIV prevention targeting MSM and sex workers is itself treated as a subversive act, which may be met with systematic and coordinated violence. As a consequence, key opportunities for HIV prevention among both HIV-positive and high-risk HIV-negative MSM are squandered. The health care system as an instrument of stigma and discrimination, along with the legal system, may become an agent of structural violence (Padilla, Vasquez del Aguila, & Parker, 2007)—in direct antithesis to the mandates of public health and safety—thereby placing MSM at increased vulnerability to HIV infection.

A small but increasing number of U.S. studies have addressed the association between stigma and discrimination, respectively, and HIV risk among gay men (Herek, 1999; Meyer, 2003), and ethnic minority MSM (Fullilove & Fullilove, 1999; Ramirez-Valles, Fergus, Reisen, Poppen, & Zea, 2005), and stigma and discrimination as obstacles to HIV preventive intervention (Fullilove& Fullilove, 1999; Herek, Capitano&Widaman, 2003; Ramirez-Valles et al., 2005). A related embryonic, yet vital, area of research is focused on the role of structural factors in producing HIV risk (e.g., Blankenship et al., 2006; Parker, Easton, & Klein, 2000; Rhodes et al., 2005) and, specifically, the role of structural violence in HIV risk and prevention (Farmer et al., 2006; Lane, 2004). The paucity of such research in India (Godbole&Mehendale, 2005) may be owing to lack of awareness regarding the tremendous challenges faced by MSM and the fact that structural factors are less obvious and less easily studied as determinants of health than personal factors (Farmer et al., 2006; Lane, 2004). Furthermore, neither health care professionals nor researchers are exempt from the constraints of structural violence or stigma by association.

In the context of multiple subsystems engaged in indirect and direct stigmatization and discrimination against MSM in India, the importance of gay-affirmative community-based organizations, such as SWAM, Sahodaran, and Allaigal in Chennai, and the Humsafar Trust in Mumbai, cannot be overstated. These community-based organizations serve as vital points of resistance in a system of structural violence, through combating stigma, promoting and facilitating access to care and education, and engaging MSM as active agents in community and advocacy networks in India. On a more micro level, community engagement also may mitigate the negative effects of stigma, such as depression and low self-esteem (Ramirez-Valles et al., 2005), which may be associated with increased HIV risk behaviors (Diaz, 1998; Meyer, 2003). Indigenous, gay-affirmative community-based organizations, while scarce, remain bastions of support and advocacy, and islands of HIV/AIDS outreach and education for MSM in Chennai. All too often they operate on shoestring budgets, given difficulties in procuring federal or local governmental funding—another manifestation of structural violence against MSM. Community-based organizations serving MSM in India also represent vital nodes for international collaboration and

structural interventions, and access to stakeholders from MSM communities, who are crucial to the implementation of culturally competent and ethical HIV prevention research and effective preventive interventions.

Further investigations of stigma and discrimination faced by MSM in India, and the superordinate context of structural violence, should address institutional contexts of discrimination and oppression; sociocultural constructions and expectations regarding gender roles and norms, Indian male sexuality and masculinity; and a critical understanding of Indian history and postcolonial influences as reflected in present societal institutions and cultural practices. It is important that such studies give voice to multiple stakeholders across diverse MSM and transgender communities in different geographical locations, including specific attention to the experiences of MSM living with HIV and AIDS, which may shed further light on the experiences of MSM in India and support culturally syntonetic structural interventions for HIV prevention and social change.

Limitations to this study include the small purposive sample; caution should be exercised in drawing inferences about other MSM, particularly those who are not *kothi*-identified, and MSM from other geographical locations in India. The purpose of this study was to explore in depth the lived experiences of HIV-positive and high-risk *kothis* in Chennai; and we were successful in recruiting individuals from these highly vulnerable populations from several different venues, which increases the transferability of the findings. Additionally, because of the risks that PSEs pose to participants and research staff, and the fact that men attending these sites may not wish to come to a community agency setting, the interviews of these men were limited in duration as compared to those of the agency-based participants. Nevertheless, many common themes emerged across the two samples, as well as some concerns that appear to be intensified for HIV-positive MSM. An additional strength of the present investigation is that it involved training and funding of Indian researchers, interviewers and outreach staff, many of whom are part of the MSM community or provide services to MSM.

RECOMMENDATIONS

The present findings suggest that challenging the Indian government to uphold human rights and to combat stigmatizing and discriminatory practices against MSM may be a central component in reducing HIV and AIDS vulnerability among MSM in India (Mawar et al., 2005). Direct challenges to Indian federal laws that effectively criminalize sexual relations between consenting same-sex adults are central to resisting structural violence, which promotes extreme vulnerability to HIV and AIDS among MSM. Decriminalization of same-sex behaviors would also be a first step toward enacting and enforcing anti-hate crime legislation that would hold individuals accountable for violence and abuse targeting *kothis* and other MSM.

Antidiscrimination education campaigns in the mass media targeting the general public also may be an important intervention to combat stigma and discrimination associated with MSM and HIV/AIDS. Furthermore, designing and implementing specific education and sensitization programs for health care providers, both to counteract ignorance and end outright prejudice and discrimination, is also essential to supporting HIV prevention and treatment among MSM. The implementation of collaborative efforts with the health care system will need to be conducted in a manner that acknowledges cultural taboos related to sexuality (Brahme et al., 2005) and that influences medical staff (Elamon, 2005). Additionally, extensive education and wide-spread monitoring of police is a vital component of reducing vulnerability among *kothis*. The establishment of connections between each of these subsystems with community-based programs that serve MSM communities may promote awareness of the needs of MSM and specifically protect community outreach workers from harassment and abuse.

Given the importance of grassroots community-based organizations to the health and survival of *kothis*, government and international efforts to stabilize funding and offer technical support to organizations led by *kothis* and other MSM may be an effective method to promote empowerment, HIV prevention, and human rights. Access to stable funding from the government for MSM community groups may be facilitated by stakeholders within the health care system through tapping the growing will of the Indian government to implement programming that recognizes the threat of a growing AIDS epidemic (Godbole & Mehendal, 2005).

Overall, this investigation suggests a system of structural violence against *kothi*-identified MSM that creates extreme vulnerability to HIV infection and AIDS. To marshal effective HIV prevention, interventions must combat stigma, discrimination, and violence against *kothis* and other MSM in India. In the multisystemic context of structural violence, HIV preventive interventions that merely address the individual level—for example, safer sex education, HIV/AIDS knowledge, condom use and sexual negotiation skills—are unlikely to be effective

(Newman et al., 2006). HIV prevention also must target the structural level, including social, economic, political, legal, and medical systems, which otherwise are likely to promote continued morbidity and mortality among MSM in India.

REFERENCES

- Alonzo, A.A., & Reynolds, N.R. (1995). Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. *Social Science and Medicine*, 41(3), 303–315.
- Blankenship, K.M., Friedman, S.R., Dworkin, S., & Mantell, J.E. (2006). Structural interventions: Concepts, challenges and opportunities for research. *Journal of Urban Health*, 83(1), 59–72.
- Brahme, R.G., Sahay, S., Malhotra-Kohli, R., Divekar, A.D., Gangakhedkar, R.R., Parkhe, A.P., et al. (2005). High risk behaviour in young men attending sexually transmitted disease clinics in Pune, India. *AIDS Care*, 17(3), 377–385.
- Chakrapani, V., Babu, P., & Ebenezer, T. (2004). *hijra* s in sex work face discrimination in the Indian health-care system. *Research for Sex Work*, 7, 12–14.
- Chakrapani, V., Kavi, A.R., Ramakrishnan, R.L., Gupta, R., Rappoport, C., & Raghavan, S.S. (2002). *HIV prevention among men who have sex with men (MSM) in India: Review of current scenario and recommendations*. Retrieved March 4, 2005, from http://www.indianglbthealth.info/Authors/Downloads/MSM_HIV_IndiaFin.pdf
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: Sage.
- Diaz, R.M. (1998). *Latino gay men and HIV: Culture, sexuality, and risk behavior*. New York: Routledge.
- Elamon, J. (2005). A situational analysis of HIV/AIDS-related discrimination in Kerala, India. *AIDS Care*, 17, 141–151.
- Farmer, P., Nizeye, B., Stulac, S., & Keshavjee, S. (2006). Structural violence and clinical medicine. *PLoS Medicine*, 3(10), 1686–1691.
- Fullilove, M.T. & Fullilove, R.E. (1999). Stigma as an obstacle to AIDS action: The case of the African American community. *American Behavioral Scientist*, 42(7), 1113–1125.
- Galtung, J. (1969). Violence, peace and peace research. *Journal of Peace Research*, 6, 167–191.
- Glaser, B. (1978). *Theoretical sensitivity*. Mill Valley, CA: Sociology Press.
- Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory*. Chicago: Aldine.
- Godbole, S., & Mehendale, S. (2005). HIV/AIDS epidemic in India: Risk factors, risk behaviours & strategies for prevention & control. *Indian Journal of Medical Research*, 121, 356–368.
- Goffman, E. (1963). *Stigma: Notes on the management of a spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall.
- Herek, G.M. (1999). AIDS and stigma. *American Behavioral Scientist*, 42(7), 1102–1112.
- Herek, G.M., Capitanio, J.P., & Widaman, K.F. (2003). Stigma, social risk, and health policy: Public attitudes toward HIV surveillance policies and the social construction of illness. *Health Psychology*, 22(5), 533–540.
- Human Rights Watch. (2002). *Epidemic of abuse—Police harassment of HIV/AIDS outreach workers in India*. 14(5). Retrieved March 5, 2005, from <http://www.hrw.org/reports/2002/india2/india0602.pdf>
- Lane, S.D. (2004). Structural violence and racial disparity in HIV transmission. *Journal of Health Care for the Poor and Underserved*, 15(3), 319–335.
- Lincoln, Y.S., & Guba, E. (1985). *Naturalistic enquiry*. Newbury Park, CA: Sage.
- Link, B.G., & Phelan, J.C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27, 363–385.
- Mann, J.M. (1987a). AIDS—A global perspective. *Western Journal of Medicine*, 147(6), 693.
- Mann, J.M. (1987b). The World Health Organization's global strategy for the prevention and control of AIDS. *Western Journal of Medicine*, 147(6), 732–734.
- Mawar, N., Sahay, S., Pandit, A., & Mahajan, U. (2005). The third phase of HIV pandemic: Social consequences of HIV/AIDS stigma & discrimination & future needs. *Indian Journal of Medical Research*, 122, 471–484.
- Meyer, I.H. (2003). Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: Conceptual issues and research evidence. *Psychological Bulletin*, 129(5), 674–697.
- National AIDS Control Organization. (2005a). *An overview of the spread and prevalence of HIV/AIDS in India*. Retrieved January 2, 2005, from http://www.nacoonline.org/facts_overview.htm
- National AIDS Control Organization (NACO). (2005b). *HIV estimates (2003)—National AIDS Control Organization: A note on HIV estimates 2003*. Retrieved February 5, 2005, from http://www.nacoonline.org/facts_hivestimates.htm
- Newman, P.A., Venkatesan, C., Row Kavi, A. & Kurien, A.K. (2006). HIV-1 prevalence in young adults in south India. *The Lancet*, 368(9530), 1115.
- Padilla, M.B., Vasquez del Aguila, E., & Parker, R.G. (2007). Globalization, structural violence, and LGBT health: A cross-cultural perspective. In I.H. Meyer & M.E. Northridge (Eds.), *The health of sexual minorities: Public health perspectives on lesbian, gay, bisexual and transgender populations* (pp. 208–241). New York: Springer.
- Parker, R., & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: A conceptual framework and implications for action. *Social Science & Medicine*, 57, 13–24.
- Parker, R.G., Easton, D., & Klein, C.H. (2000). Structural barriers and facilitators in HIV prevention: A review of international research. *AIDS*, 14(Suppl. 1), S22–S32.
- People's Union for Civil Liberties, Karnataka. (2001). *Human rights violations against sexuality minorities in India*. Retrieved March 3, 2005, from <http://www.pucl.org/Topics/Gender/2003/sexual-minorities.pdf>
- People's Union for Civil Liberties, Karnataka. (2003). *Human rights violations against the transgender community: A study of kothi and hijra sex workers in Bangalore, India*. Retrieved March 5, 2005, from <http://www.altlawforum.org/PUBLICATIONS/PUCL%20REPORT%202003>
- Ramirez-Valles, J., Fergus, S., Reisen, C.A., Poppen, P.J., & Zea, M.C. (2005). Confronting stigma: Community involvement and psychological well-being among HIV-positive Latino gay men. *Hispanic Journal of Behavioral Sciences*, 27(1), 101–119.
- Rhodes, T., Singer, M., Bourgois, P., Friedman, S.R., & Strathdee, S.A. (2005). The social structural production of HIV risk among injecting drug users. *Social Science and Medicine*, 61(5), 1026–1044.
- Safren, S.A., Martin, C., Menon, S., Greer, J., Solomon, S., Mimiaga, M.J., et al. (2006). A survey of MSM HIV prevention outreach workers in Chennai, India. *AIDS Education and Prevention*, 18(4), 323–332.
- Schutt, R.K. (2004). *Investigating the social world—The process and practice of research* (4th Ed.). Newbury Park, CA: Sage.

Sigelman, C.K., Howell, J.L., Cornell, D.P., Cutright, J.D., & Dewey, J.C. (1991). Courtesy stigma: The social implications of associating with a gay person. *Journal of Social Psychology, 131*(1), 45–56.
 UNAIDS. (2001). *India: HIV and AIDS-related discrimination, stigmatization and denial*. Geneva, Switzerland: PAIS: Author.

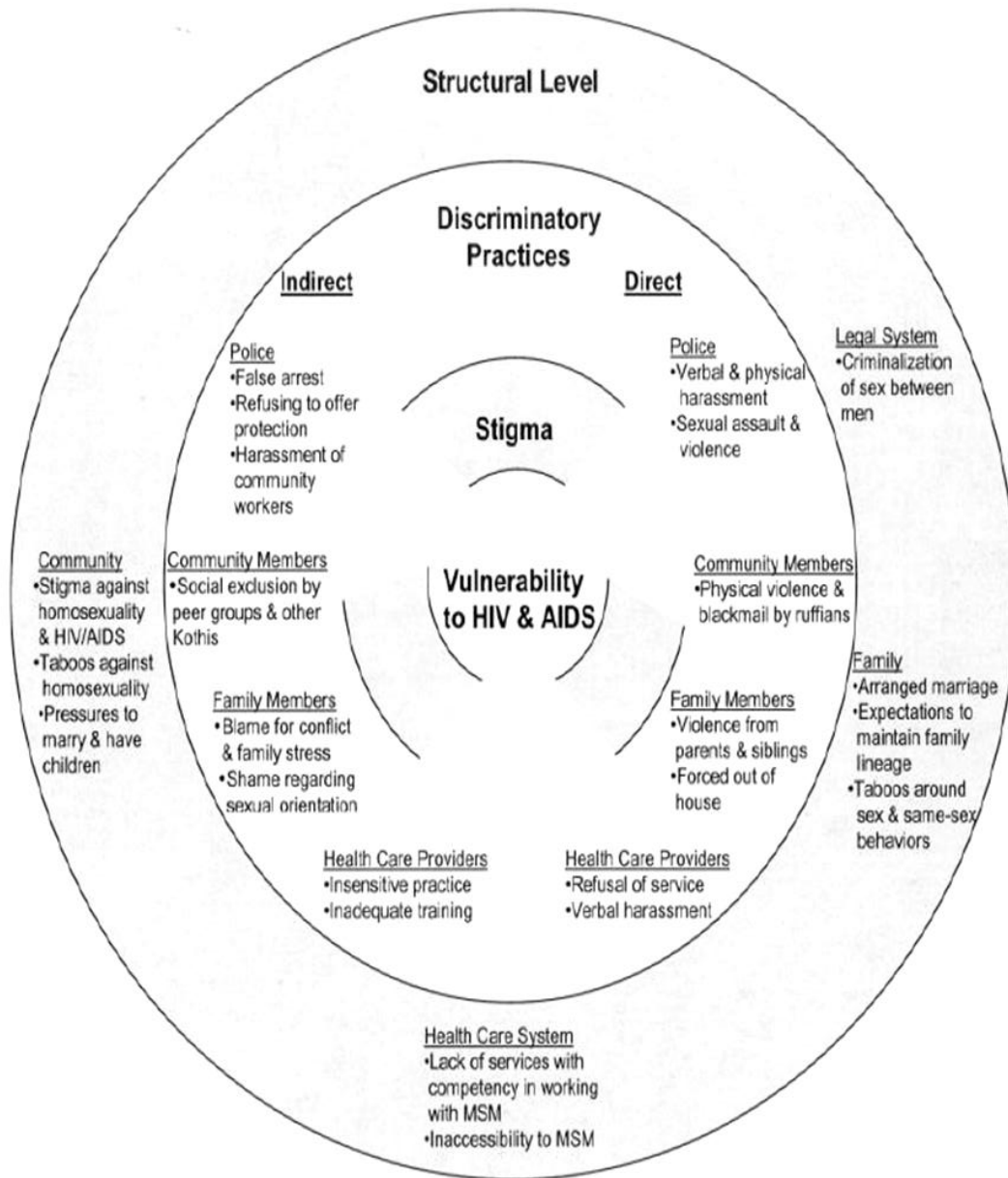


FIGURE 2. A Conceptual Model of Structural Violence and Vulnerability to HIV and AIDS among Kothi-identified Men who have Sex with Men in Chennai, India.