

KERALA STATE AIDS CONTROL SOCIETY (KSACS)

GUIDE LINE FOR TREATMENT CARE TEAM (TCT)

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A guide line for Treatment Care Team (TCT)

Preamble

Kerala State AIDS Control Society (KSACS) is providing various services to support People Living with HIV/AIDS (PLHIVs). National AIDS Control Society (NACO) has selected KSACS as the role model in AIDS awareness campaigns and ranked top in implementing the programmes followed by West Bengal, Andhra Pradesh, Mizoram and Arunachal Pradesh. 'Prathyasakendrams' are one of the major sources of care and support services for the HIV infected and affected people in the Kerala. For the last many years these centres are providing support to the PLHIVs in terms of psycho-social support services, skill development programmes and referral services with the assistance of volunteers in this field. Though they are doing remarkable initiatives in this sector, following challenges and gaps are still remaining to be addressed.

- ✚ Bystander support to PLHIVs in hospitals, home based care and support to those who are orphans or neglected from their own families
- ✚ Official proceeding from hospital/police station regarding the ownership of the dead body of orphans/out of state people in funeral and follow up
- ✚ Rehabilitation of PLHIVs
- ✚ Bystander support to PLHIVs those who are mentally impaired /violent in some cases
- ✚ Continuous counselling, care and support, supply of medicine, food and financial support to PLHIVs those who are living alone
- ✚ Blood supply in emergencies
- ✚ Follow up /handholding support to reduce the stigma(personal, family and social)

In this context, KSACS is aiming to strengthen the activities of 'Prathyasakendram' and district level networks and giving an opportunity for the new PLHIVs to come forward and develop capacity to provide care and support to the PLHIVs who are isolated from the mainstream. Volunteers are available in all Prathyasakendrams for providing hospital services. However, it is essential to support these volunteers financially for maintaining their livelihood. More over, it is essential to build the skills of these volunteers in order to improve their performance.

In these circumstances, KSACS is planning to select ten volunteers in each district through empanelment process, named as Treatment Care Team (TCT) and provide training to them to deliver the services based on the guidelines developed by KSACS.

History of Care and support in HIV/AIDS sector

HIV is believed to have originated in non-human primates in sub-Saharan Africa and transferred to humans during the 20th century. The epidemic is officially reported in human being on 5th June 1981. In January 2006, the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO) estimate that AIDS has killed more than 25 million people since it was first recognized, making it one of the most destructive pandemics in recorded history. It is estimated that about 0.6% of the world's population is infected with HIV.^[3] In 2005 alone, AIDS claimed an estimated 2.4–3.3 million lives, of which more than 570,000 were children.

HIV primarily infects vital cells in the human immune system such as helper T cells (specifically CD4⁺ T cells), macrophages and dendritic cells. HIV infection leads to low levels of CD4⁺ T cells through three main mechanisms: firstly, direct viral killing of infected cells; secondly, increased rates of apoptosis in infected cells; and thirdly, killing of infected CD4⁺ T cells by CD8 cytotoxic lymphocytes that recognize infected cells. When CD4⁺ T cell numbers decline below a critical level, cell-mediated immunity is lost, and the body becomes progressively more susceptible to opportunistic infections.

Eventually most HIV-infected individuals develop AIDS (Acquired Immunodeficiency Syndrome). These individuals mostly die from opportunistic infections or malignancies associated with the progressive failure of the immune system.^[7] About 9 out of every 10 persons with HIV will progress to AIDS after 10-15 years.^[8] Treatment with anti-retroviral, increases the life expectancy of people infected with HIV. After the diagnosis of AIDS, the current average survival time with antiretroviral therapy (ART) (as of 2005) is estimated to be more than 5 years.^[9] Without ART, death normally occurs within a year.^[10] It is hoped that

current and future treatments may allow HIV-infected individuals to achieve a life expectancy approaching that of the general public. Considering this, proper treatment, care and support definitely help to extend the life span of PLHIVs. This is one of the main reasons to think about the Treatment Care Team (TCT) in this sector.

Treatment

HIV infection is not the end of one's life. People can lead a healthy life for a long time with appropriate medical care. ART effectively suppresses replication, if taken at the right time. Successful viral suppression restores the immune system and halts onset and progression of disease as well as reduces chances of getting opportunistic infections – this is how ART is aimed to work. Medication thus enhances both quality of life and longevity.

Adherence to ART is critical

Adherence to ART regimen is therefore very vital in this treatment. Any irregularity in following the prescribed regimen can lead to resistance to HIV drugs, and therefore can weaken or negate its effect.

ART is accessible to all

ART is now available for free of cost in our country due to government initiatives to all those who need it. Public health facilities are mandated to ensure that ART is provided to PLHAs. Special emphasis is given to the treatment of sero-positive women and infected children.

Care and Support

The care, support and treatment needs of HIV positive people vary with the stage of the infection. The HIV infected person remains asymptomatic for the initial few years; it manifests by six to eight years. As immunity falls over time the person becomes susceptible to various opportunistic infections (OIs). At this stage, medical treatment and psycho-social support is needed. Access to prompt

diagnosis and treatment of OIs ensures that PLHAs live longer and have a better quality of life.

NACP-II, focus was given on low-cost care, support and treatment of common OIs. Apart from further improving the availability, accessibility and affordability of ART treatment to the poor, NACP-III plans to strengthen family and community care through psycho-social support to the individuals, more particularly to the marginalised women and children affected by the epidemic. They also have plans to improve compliance of the prescribed ART regimen, and address stigma and discrimination associated with the epidemic.

To achieve this objective, 350 Community Care Centres (CCCs) are planned to be set up during the programme period (2007- 2012) in partnership with PLHA in high prevalence and moderate prevalence districts. These centres will be established based on the epidemiological profile and PLHA load of the districts, and will be linked to the nearest ART centre.

These centres will provide counselling for drug adherence, nutritional needs, treatment support, referral and outreach for follow up, social support and legal services. Respective State AIDS Prevention and Control Societies (SACS) will ensure access of high risk groups to community care centres through linkages between TIs and the centres. By strengthening local responses, NACP-III seeks high levels of drug adherence and compliance of the prescribed ART regimen. This approach to care, support and treatment also creates awareness about the prevention of HIV infection and, thus, is a very significant part of NACP-III in achieving NACO's mission of containing and reversing HIV/AIDS incidence in India.

Care and Support for Children

Approximately 50,000 children below 15 years of age are infected by HIV every year. So far, care and support response to these children is at a very minimal level. NACP-III plans to improve this through early diagnosis and treatment of HIV exposed children; comprehensive guidelines on paediatric HIV care for each level of the health system; special training to counsellors for counselling HIV positive

children; linkages with social sector programmes for accessing social support for infected children; outreach and transportation subsidy to facilitate ART and follow up, nutritional, educational, recreational and skill development support, and by establishing and enforcing minimum standards of care and protection in institutional, foster care and community-based care systems.

Consultation Workshop on development of Treatment Care Team & preparation of Guideline

Workshop focused on the following key points

- Experience sharing of care and support in present scenario
- Objectives of the TCT
- Criteria for the selection of TCT members
- Selection process of TCT members
- Expectation of the TCT members from KSACS
- Roles & responsibilities of TCT members
- Identifying the anticipatory challenges of TCT
- Training needs

Experience sharing of care and support in present scenario

In the experience sharing session, participants shared the following facts:

- Staff of Prathyasa had to attend patients
- There is no financial support to help the staff to meet the TA and other incidental expenses during the travel and in hospitals
- In certain cases Prathyasa staff is financially helping the patients with their own money and such situations even KSACS is unable to help due to the formalities and procedures.
- Issue Identity cards to all staff members and volunteers of service centers to ensure uninterrupted entry to hospitals and other institutions whenever situation warrants.
- Exploitation of services- some people having a tendency to exploit the service of volunteers by using the service unnecessarily or repeatedly even if they can manage the situation

- Distance issue – in some cases volunteers wants to travel a long distance (more than 4-6 hours) within the district and there by they could not provide the service on time
- Special care needed to positive pregnant women and to her child till his/her status identified
- There is no proper care to the PLHIVs those who are in jail, migrants in street & labour camps, impaired /violent in some cases
- Keep a copy of all relevant GOs and update the same in service centers. The key functionaries of these centers are to ensure unnecessary delays and issues
- In present situation, staffs (PLHIVs) from various centers are acting as bystanders in hospitals and they could not stay there more than two – three days because of their ill health. So the need of standby/substitute is unavoidable and that will be filled by the TCT
- Absence of proper, timely and correct messages and different messages form different staff on same subject creates problem in field
- Set up a data bank (list of service centers with contact persons and phone numbers, list of TCT members with phone number, etc.) with full details in MCH,CHC,PHC and all service centers of KSACS to assist the patients and ensure the services from all centers within a short time
- Install donation boxes in selected institutions and provide enough publicity for the same. This money may be used as reserve/additional fund to assist the PLHIVs in emergency cases.
- Make a list of centers where donation boxes can be kept
- Is it compulsory to select only a PLHIV as TCT member?
- Financial support to the TCT is essential for the smooth functioning of the team as envisaged

Objectives of TCT

- ❖ To provide care and support to the PLHIVs
- ❖ To support and be a part of services of KSACS
- ❖ To ensure proper & timely treatment and continuity of medicines
- ❖ To ensure special focus to women, children, old aged people, migrants and orphans in home based and hospital based treatment and follow up support.
- ❖ To support PLHIVs for ART and ensure usages of medicines in proper course and adherence.
- ❖ To address stigma and discrimination associated with the epidemic in the case of individual, family and community
- ❖ To provide psycho-social support to the individuals, more particularly to the marginalised women and children affected by the epidemic for positive living

Selection criteria (Finalized with the consensus of participants in workshop, KSACS officials and Dr. Mini Abraham MCH, Trivandrum)

1. Educational qualification - SSLC desirable
2. A person with service mentality, pious and gentle
3. A person with good personal qualities and morale
4. Person ready to serve at any time
5. PLHIVs and if negative people are ready to work should incorporate to reduce social stigma and showcase the case as an exposure to others
6. Person should have contacts, good relations and ability to build rapport
7. Communication skills
8. Should not hesitate to disclose HIV status
9. It is better to be a member of PLHIV network (having field experience)
10. Should be healthy
11. Person should have already revealed his/her status at home and in community.

Selection process of TCT members

- ✚ Notification and short listing by the district network without any bias and adhering to the selection criteria
- ✚ Final selection is made only in consultation with KSACS
- ✚ 10 - 15 candidates should be selected from each district. The selected candidate needs to work initially three months on probation.
- ✚ After the conditional selection, the candidate shall work with the existing volunteers/staff members in district centers and get on the job training. They shall be monitored closely during this period.
- ✚ Gender balance should be ensured (possibly 40:60-F:M)
- ✚ While fixing the number of TCT members, special consideration may be given to the districts having ART centers and wide area
- ✚ Final list may include the waiting list and select 10 candidates according to the selection rank. These wait-listed candidates may be used to fill the drop outs/substitutes or for the up-scaling process in future.

Support group (SG)

It is better to form a support group (people with and without HIV) in panchayat/taluk/district levels to assist and help in care and support activities. Voluntary people from govt. departments, NGOs, NSS, religious forums and organizations, youth clubs, SHGs, etc. can be the members in this group. Moreover, convergence of govt. line departments and other stakeholders could be an added advantage to this support group to streamline and strengthen the activities.

Expectation of the TCT members from KSACS

a). Financial support to TCT members

Financial support is very essential for the smooth functioning of the TCT as envisaged by KSACS. It is proposed (suggestions evolved from the workshop and individual interaction with officials) that the service of TCT members can be

rendered as and when required on a daily basis during the first year with following allowances.

Daily allowance including food - Rs.200/-

Travel allowance - actual on the basis of claim

They are also expecting some financial support for insurance, communication facility, office stationary and a revolving fund for incidental expenses.

b). Official Identity Card

To avoid delays and formalities and for the smooth entry of the team members in hospitals, service centers and govt. offices, they are expecting an official ID card from KSACS to all members of TCT and even for other functionaries.

c). Training, Exposures and hand-holding support

Training need assessment completed in the workshop in a participatory method and detailed module is also included. Moreover they requested to conduct a few exposure visits to similar projects if any, within or outside the state.

Roles & responsibilities of TCT members

- Support and extend the service of KSACS as a member of TCT
- Provide care and support to the PLHIVs in hospitals and homes
- Support PLHIVs for ART and ensure usages of medicines in proper course and adherence.
- Ensure proper & timely treatment and continuity of medicines
- Provide special focus to women, children, old aged people, migrants and orphans in home based and hospital based treatment and follow up support.
- Address stigma and discrimination associated with the epidemic in the case of individual, family and community
- Provide psycho-social support to the individuals, more particularly to the marginalised women and children affected by the epidemic for positive living

- Provide proper counseling and advices for motivation and for better living
- Documentation and reporting
- Related IEC and awareness creation
- Legal support
- Referral support
- Care centre service
- Post death family counselling

Anticipatory challenges of TCT

- ✓ Address and reduce stigma and discrimination associated with the epidemic in the case of individual, family and community
- ✓ Livelihood support to affected people
- ✓ Care and support to orphans, migrants especially children after the death of parents
- ✓ Death cases from other states and no relatives to receive the body
- ✓ IDU and mentally impaired cases,
- ✓ Vehicle for the transportation of patients
- ✓ Police station issues during the death of migrants/orphans
- ✓ Support from hospital staff
- ✓ Costly medicine, CT scan, MRI scan etc.
- ✓ Blood demand – rare group, time of govt. blood banks, availability and supply of donors
- ✓ Financial issues
- ✓ Mental depression and health issues
- ✓ Pregnancy cases
- ✓ Lack of committed members
- ✓ Lack of information, updating of information, networking and advocacy
- ✓ Lack of training
- ✓ Distance and extensive travel in wide areas to attended the cases
- ✓ Behavioral clash between caretaker and PLHIVs
- ✓ Absence of second line ART

- ✓ Care and support to PLHIVs in sinking stage
- ✓ Role clarity among the service centers and staff

Training to Treatment Care Team

Training is the only way to capacitate the team members in this sector. According to the participants of the workshop, we have to provide minimum two trainings in the beginning stage to familiarize and capacitate the members. Induction training should be organized to introduce the project, institutional arrangements, experience sharing and discuss the training need. This may be organized as a two-day programme in regional (three regions- north, central and south) level for 50- 60 participants. Then the second level training should be followed immediately with special focus on skill and knowledge up-gradation.

TRAINING MODULE FOR TREATMENT CARE TEAM

- ✚ Basic Information of HIV/AIDS
- ✚ Opportunistic infections (OIs)
- ✚ Prevention /precautions
- ✚ Anti Retroviral Therapy (ART)
- ✚ Timing of treatment and adherence
- ✚ Side effects
- ✚ Social stigma
- ✚ Positive living
- ✚ Peer education
- ✚ Paediatric HIV care
- ✚ Service centres in Kerala
- ✚ Communication and counselling skill
- ✚ Advocacy
- ✚ Conflict management
- ✚ Leadership

Basic Information of HIV/AIDS

- a). What is HIV/AIDS?
- b). Precautions/prevention methods
- c). How HIV is affecting the immunity of human body?
- d). Methods/routes of spreading
- e). Other related issues

Opportunistic infections

- a). What is opportunistic infections?
- b). How to prevent opportunistic infections?
- c). Type of infections
- d). Symptoms of opportunistic infections

Preventions

- a). Precautions in general
- b). In-house precautions

Anti Retroviral Treatment (ART)

- a). ART against HIV
- b). Objectives of ART
- c). When & how to start ART?
- d). Challenges with ART
- e). Dos and Don'ts in ART
- f). ART resistance

Timing of treatment and adherence

- a). What is meant by timing and adherence?
- b). Importance of proper timing and adherence in ART
- c). Symptoms of violation
- d). Challenges to adherence
- e). Strategy to overcome the challenges and remedy
- f). Adherence counselling
- g). Objectives of adherence counselling

Side effects

- a). Side effects of medicine
- b). Side effects of ART medicines
- c). Precaution and remedy of side effects

Social stigma

- a). What is social stigma?
- b). Social stigma and ART
- c). Influence/importance of social awareness to reduce stigma
- d). Counselling

Positive living

- a). Support activities for positive living
- b). Role of food habits in positive living
- c). Mental, behavioural and cultural thoughts related to positive living

Peer Education

- a). Who is a peer?
- b). What is peer education?
- c). Peer educator
- d). Qualities of peer educator
- e). Responsibilities of a peer educator

Paediatric HIV care

- a). Children's psychology
- b). Counselling
- c). Paediatric treatment and care

Service Centres in Kerala

- a). Details of service centres and their services
- b). Government orders and publications
- c). Procedures to acquire the services
- d). Appealing authority to settle the issues if any

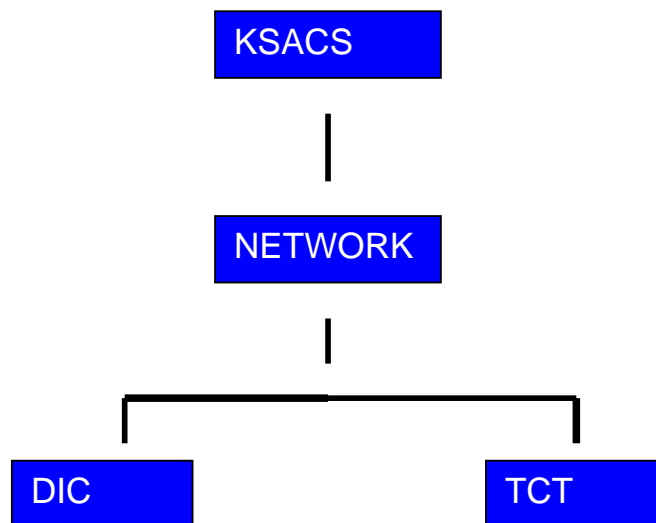
HOME BASED CARE AND TREATMENT

- a). What is home based care?

- b). Features/components of home based care
- c). Objectives of home based care
- d). Role of family in home based care and support
- e). Who is a best caretaker in home based care?
- f). Basic knowledge of home based care
- g). Ability of a caretaker
- h). Role and responsibility of a caretaker
- i). How to tackle the issues related to an abnormal patient?
- j). Follow up care and support

For the preparation of training module, there was a detailed discussion in workshop on existing module prepared by INDIAN NETWORK FOR PEOPLE LIVING WITH HIV/AIDS. All most all the chapters discussed in detail and incorporate same and added some more subjects as per the training need of the participants.

Institutional frame



District level support group should be formed with the participation of all stakeholders and support departments and agencies to enrich the function of TCT.

Conclusion

In short, TCT will be a good initiative from KSACS to support the PLHIVs those who are in miserable condition without any help from families and relatives. This forum is also giving an opportunity for the new PLHIVs to come forward and developing capacity to provide care and support to the PLHIVs isolated from the mainstream. Moreover, this will help to formulate a group of people with volunteerism and concern to others in care and support activities.

Annexure -1

CONSULTATION WORKSHOP ON DEVELOPMENT OF TREATMENT CARE TEAM

Date: 14/01/10

Venue: Regional Telecom Training Centre, Kaimanam, Trivandrum

Participants

	Name	Designation	Contact No;
1.	Sheela Sebastian	DIC- Counselor, Thrissur	9349182352
2.	Bindhu P.B	President, KPWN+, Ernakulam	9746030460
3.	Shalini Joby	Member, KPWN+, Ernakulam	9745972764
4.	Ramesh A	Coordinator, DIC, Palakkad	9744883336
5.	Manikandan	General Secretary, ENP+, Ernakulam	9349201290
6.	Joseph Mathew	President, CPK+, Ernakulam	9947186871
7.	K.Sasikumar	President, KTDNP+	9539523615
8.	Kunhikrishnana K	Exe: Member, CPK+	9495871315
9.	Suresh M	Counselor, DIC, Trivandrum	9995267794
10.	Bharatran P	Counselor, DIC, Wayanad	9895133863
11.	Bindhu A.K	Counselor, DIC, Malappuram	9847452812
13.	Nisha. K	Positive Speaker, Kannur	9746410711
14.	Soyikutty M.M	Counselor, DIC, Idukki	9495864668
15.	Alice George	President, PNP+, Pathanamthitta	9349967026
16.	Jayasree M.G	Counselor, DIC, Alappuzha	9961289453
17.	Cicilet J	Member, NNP+, Trivandrum	9847424852
18.	Ashok.K.Nair	President, NNP+, Trivandrum	9847174912
19.	Thushara. K	Member, KNP+, Kollam	9656644503

Annexure II

Consultation Workshop on Development of Treatment Care Team

Date: 14/01/10

Venue: Regional Telecom Training Centre, Kaimanam

AGENDA

DAY – 1

Time	Topics	Methodology	Facilitated by
9.30	Registration		
10-10.45	Welcome, self Introduction and inauguration		Dr. Velayudhan (APD,KSACS) Shri. S. Ajaikumar, (JD, IEC, KSACS)
10.45- 11.45	Experience sharing & Present scenario	Discussion	Shri. C. Rajeevan, (Consultant)
11.50- 12.30	Criteria for selection of TCT members	Group work	Shri. C. Rajeevan, (Consultant)
12.30-1.30	Expectation of TCT members from KSACS	Group work & presentation	Participants
1.30-2.30	LUNCH BREAK		
2.30-3.30	Roles & Responsibilities of TCT members	Group work & presentation	Participants
3.30 – 4.15	Anticipated challenges	Discussion	Participants
5.30 - 6.30	Problem tree analysis	Group work	Shri. C. Rajeevan, Consultant