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A Report
on
Effectiveness of Treatment Counselling Centres under Access to Care and Treatment Project

An evaluation study conducted by Vivekananda Institute for Leadership Development

Submitted to

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Vivekananda Institute for Leadership Development
(Unit of Swami Vivekananda youth Movement)

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Glossary

ACT	Access to Care and Treatment
ART	Anti-Retroviral Therapy
ARTC	Anti-Retroviral Therapy Centre
CMIS	Computerized Management Information System
DLN	District Level Network of PLHIV
DOTS	Directly Observed Treatment Short Course
GFATM	Global Fund to Fight AIDS, tuberculosis, and Malaria
HIV	Human Immunodeficiency Virus
ICTC	Integrated Counselling and Testing Centre
INP+	Indian Network of People Living with HIV
LFU	Lost to Follow Up
MO	Medical Officer
NACO	National AIDS Control Organisation
NGO	Non-Governmental Organisations
OI	Opportunistic Infections
PFI	Population Foundation of India
PLHIV	People Living with HIV
RCC	Rolling Continuation Channel
RCH	Reproductive and Child health
SACS	State AIDS Control Society
SLN	State Level Network of PLHIV
STI	Sexually Transmitted Infections
SVYM	Swami Vivekananda Youth Movement
TCC	Treatment Counselling Centres
VILD	Vivekananda Institute for Leadership Development

I. EXECUTIVE SUMMARY

1. Introduction

The Global Fund and Population Foundation of India (PFI) have signed a grant agreement on 7th March, 2005 to implement five years program, "Access to Care and Treatment (ACT)" in the six HIV/AIDS high prevalence states of India. This program is a public - private partnership where the National AIDS Control Organization (NACO) provides Antiretroviral Treatment (ART) at the public health facilities. The PFI led NGO/Private sector consortium provides ongoing care and support and follow-up services for people receiving ART under the NACO programme and to the people not on ART. The essential elements of this care and support component include creating and strengthening the networks of people living with HIV, providing comprehensive care and support through psycho-social support, referral, outreach and institutional care.

2. Treatment Counselling Centres

In 2004-05, antiretroviral treatment to both adults and Children was a new intervention to be introduced with the GFATM support. Public-private partnership through partnering with a consortium of NGOs was seen as fundamental to sustaining increased access to treatment and support. It was proposed to have robust mechanisms that would ensure smooth referrals of people eligible for ART, together with psycho-social support and peer counselling through partnerships between public sector providers of ART, PLHIV's, NGOs and the corporate sector.

3. Need for the study

The representatives of NACO during their visits to few TCCs reported that TCCs strategy needs reworking. Coupled with space constraints at ART Centres and increasing default rate, it is said that TCCs better focus on outreach rather than spending time at ART Centre. This differs from what was mentioned in the grant agreement signed by PFI with The Global Fund. PFI conducted a national level TCC consultation meeting. The discussions in the meeting reflected that many of the TCCs were functioning as per the envisaged role although facing difficulty at certain centres due to lack of support from ART Centre with respect to their role. Also, it was found that several ART Centres strongly felt the need for TCCs.

4. Objectives of the study

The objective of the study is to measure the effectiveness of TCCs in promoting the treatment adherence among PLHIVs on ART and linking them with the larger care and support services.
The study was conducted to find an answer for the following questions

- Is the TCC as a strategy in promoting treatment adherence working well? What has been its evidence and value addition?
- What is the scope to scale up TCCs? Is there any adequate evidence?

- What are the alternate strategies of implementation of TCC that can be incorporated in the future program?

5. Methodology

The overall strategy was to take up ARTCs with TCC and compare their physical performance with ARTCs without TCC, to bring out the effectiveness of TCC based on selected output indicators. It was proposed to study the effectiveness of TCCs in six high prevalent states. Four states namely Karnataka, Maharashtra, Manipur, and Nagaland were identified for the study. Tamil Nadu and Andhra Pradesh were not included in the sample area.

The sample size included two TCCs in each of the states of Karnataka, Maharashtra, Manipur, and one TCC in Nagaland. In addition to seven ARTCs with TCC, two ARTCs without TCC, one in Karnataka and one in Manipur, were selected for the study. In each of the ARTC, the Medical Officer, MIS Officer, Counsellors, and 10 PLHIV were interviewed. Similarly, in each of the TCC, the Counsellors, and 10 PLHIVs were interviewed. At the State level the key personnel of State AIDS Control Society as well as Population Foundation of India officials were interviewed. The networks of positive people in each of the Centres at the district level (DLN) were also contacted. Secondary data included information from the Monthly Registers at ARTC and TCC for the period 2007-08 and April – September 2008.

6. Limitations

Due to logistics reasons the study could not be carried out in the States of Tamil Nadu, and Andhra Pradesh. ART Centres without TCC also could not be covered. The data availability in some of the ART Centres, and TCC were not adequately available. Study team also encountered problems in obtaining complete cooperation of the ARTC staff and access to some of the secondary data due to non availability of official instructions from NACO and respective SACS.

7. Major Findings of the Study

The Treatment Counselling Centre is expected to play an important role in providing antiretroviral treatment adherence counselling to people living with HIV / AIDS on a sustained basis. The performance of the treatment counselling centre is divided into five aspects based on the role it has to play in complementary with ART Centres.

7.1 Treatment Counselling Centres: A Resource Hub on ART for PLHIVs

The treatment counselling centre is a place where complete information related to HIV / AIDS is expected to be available in addition to counselling. If the complete information is not available at the treatment counselling centre, the counsellor would refer them to another agency where the same would be made available to the client. Thus the study has attempted to analyse the capacity of the counsellors by their years of experience, training obtained, and knowledge on HIV / AIDS.

In addition we have compared the type of services offered by ARTC and TCC and the infrastructure available at both places to offer the services.

7.1.1 YEARS OF EXPERIENCE: The number of years of experience is taken as a proxy for their capacity to carry out good counselling. Comparing the experience of the counsellors across the four types, about 9% of TCC counsellors having more than 10 year experience and 1/3rd of them have about 04 to 70 years experience as compared to about 90 percent of ARTC counsellors having only 01 to 03 years experience. This shows that experience as a proxy, the capacity of TCC counsellors is comparatively higher than the ARTC counsellors.

7.1.2 TRAINING OBTAINED BY COUNSELLORS: The capacity of counsellors is also gauged by the trainings obtained by them in the field of HIV / AIDS. *Table 2* shows that TCC counsellors better trained with refresher / advanced training in HIV / AIDS and also on topics related to HIV / AIDS as compared to the ARTC counsellors. The topics in which the training was obtained by the counsellors have been categorized as basic, refresher and others. Thus 26 responses to basic training refer to all 22 persons having received basic training and four have received more than once. Similarly 11 ARTC counsellors have received basic training and seven have received more than once. Counsellors have taken training four times, on issues other than basic, and refresher courses also.

7.1.3 COUNSELLORS KNOWLEDGE ON HIV: Topics were discussed with the counsellors by the investigators on various aspects of the subjects and rated them as excellent, good, satisfactory, and poor depending on their responses. As per the survey, the knowledge on Basics of HIV / AIDS is very good across all the four categories of counsellors. However, in Opportunistic Infections, Basic Investigations, and side effects of ART, the TCC counsellors are better compared to ARTC and DLN counsellors.

7.1.4 TYPE OF COUNSELLING CONDUCTED BY COUNSELLORS PERSONALLY: The four categories of counsellors have revealed the types of counselling done by them personally to PLHIV clients. Apart from regualar ART counseling done by all categories of counselors, TCC counselors are additionally doing psychosocial, positive living, nutrition and hygeine counselling more intensively.

7.1.5 SERVICES RENDERED BY ART CENTRES AND TC CENTRES: The type of services rendered by TCC includes mainly counselling for adherence to ART and behavioural change in PLHIV for positive living that are obtained by sizable proportion of the clients. Linkages to other related institutions, home visits, OI management, and nutrition related services also done by TCC counsellors. In ARTC, counselling for adherence of ART, and supply of Condoms are the two main services rendered.

7.1.6 INFRASTRUCTURE IN ARTC & TCC: By and large the ARTC have better infrastructure in terms of rooms for all activities including administration, waiting hall, and counselling as compared to the TCC (see, Table 6). Despite this the space given for each of the activities is questionable, as the investigators who visited the ARTC and TCC centres informed of the lack of space to carry out the counselling activity peacefully.

7.2 Share the client load of ART center with respect to counselling. Counsels PLHIV's and their family on treatment education, treatment adherence and positive life after infection.

The treatment counselling centres are expected to share the load of PLHIV clients at the ART centres for counselling, referrals and linkages. To analyse the effectiveness of load sharing the secondary data was collected from both ARTC and TCC in seven sample centres. Availability of data at both ARTC and TCC was a major limitation in analyzing the data to obtain any conclusive results. However, given the limitation the analysis of the data on total registrations, average number of follow ups made per day, number of cases on ART and not on ART, and average number of clients per day for the time period April 2007 to September 2008 has been made.

7.2.1 PLHIVs REGISTERED: The total registrations were more than 4000 clients in one of seven samples ART centres and more than 2000 clients in one ART centre. In four of the seven ART Centres the registration was less than 500 clients. The TCC data shows that in four of the seven sample centres the total registration was less than 500 clients. Hence it may be inferred that the TCCs have shared the load of ARTC to an extent of about 25 percent to over 50 percent of total clients.

7.2.2 NUMBER OF FOLLOW UP PER DAY: The average number of follow up per day in both ARTC and TCC sample centres varies from less than five clients to about 100 per day. The average figures show a similar trend for both ARTC and TCC, for both time periods. This shows that the load sharing by the TCC is evident.

7.2.3 NUMBER OF ELIGIBLE CASES FOR TREATMENT BUT NOT STARTED: If TCCs are effective the number of cases yet to start ART would low or nil. From Table 9 it is observed that the number of eligible cases for ART but not yet started is by and large low with less than five and less than 10 in one centre each. The low values shows that the effectiveness of follow up by the TCC.

7.2.4 NUMBER OF PLHIVs ON ART: The number of PLHIVs in ARTC varies from less than 50 to over 1000 clients during the reference period. Similarly the number of PLHIVs in TCC varies from about 50 to 500 clients which accounts for over 25 to 50 percent of clients in ARTCs. This also proves that TCC accomplishes the task of load sharing with the ARTCs.

7.2.5 NUMBER OF PLHIVs NOT ON ART: There are significant proportions of PLHIV clients who are not on ART as compared to the numbers who are on ART. These numbers vary from less than 100 clients to over 1000 clients during the reference period. The number of clients visiting TCC accounts for about 50 percent of total client load in ARTC.

7.2.6 AVERAGE NUMBER OF CLIENTS: The average number of clients per day visiting ARTC is shown to vary from less than 10 to about 50 in about 45 percent of ARTC and over 100 clients per day in 14 percent ARTC. The average number of clients visiting TCC per day is shown to vary from less than to about 25 per day in 45 percent of sample and over 100 clients in about 30 percent. This data summarises the above described points and substantiates the fact that TCC has a supplement role to play.

7.3 Nature of Counselling by Counsellors

TCC has a vital role in counselling the PLHIV clients on aspects related to ART adherence, and the side effects of the treatment. Building confidence in the clients, give a positive outlook to life is a great challenge to the counsellors. This task is carried out well by the counsellors in TCC. This is verified by looking into the number of sessions taken by the counsellors, issues covered and topics dealt in counselling sessions, and the number of sittings per client before starting ART.

7.3.1 TOTAL NUMBER OF SESSIONS PER YEAR: The number of sessions is shown to vary from less than 25 to over 500 during the reference period. The number of sessions conducted by TCC counsellors in family counselling and one to one counselling is more than satisfactory.

7.3.2 NUMBER OF SITTINGS PER PATIENT IN PRE-ART PHASE: The number of sittings or sessions by the counsellor before initiating ART for the PLHIV client reflects on the concern of the counsellors for the clients. It was found that about 55 percent of the clients had pre-ART counselling. Out of the total response, majority of the clients has less than six sittings.

7.3.3 TYPES OF TOPICS COVERED BY COUNSELLOR: The topics covered in pre-ART have a range of issues from information on ART, physical and psychological effects of the treatment, and other supports. Comparing the topics covered by ARTC and TCC counsellors, the range of topics covered by TCC counsellors is much more.

7.4 Link PLHIVs to District Level Networks (which are established and strengthen in the ACT program) for care and support services and adherence monitoring.

The PLHIV visiting the ARTC and TCC for treatment and counselling are linked to various other agencies for further counselling or providing some value added services. As per the structure the

ARTC counsellors prepare a list of referral cases and hand it over to the TCC counsellors once a month. The follow up is normally made by the TCC counsellors and the district level network members. Linking and referring the PLHIVs is one of the value added services of TCC counsellors.

7.4.1 LINKGES MADE BY COUNSELLORS: Among the ARTC counsellors, their referrals are mainly to community care centre, ICTC, DLN, and NGOs. However, the TCC counsellors have a greater reach to other Institutions such as government Institutions, lawyers, DOTS, de-addiction centres, and rehabilitation centres.

7.4.2 RELATIONSHIP OF COUNSELLORS WITH OTHER INSTITUTIONS: The opinion of the counsellors regarding their working relationship with other Institutions in order to obtain their services for PLHIVs has been analysed. The linkages made by the counsellors are also reflected in the relationship with institution. TCC counsellors have better relationship with district level network of positive people, community care centre, private doctors, and government institutions, as compared to ARTC counsellors.

7.4.3 ADVOCACY BY COUNSELLORS: Advocacy is an important activity to improve relations with different agencies and provide better services to PLHIVs. We identified agencies that deal with the general public and provide certain services. DLN counsellors who have maximum contacts at the operational level is reflected in their response as shown in the Table. TCC and ART counsellors are also observed to be advocating about HIV / AIDS to some of the agencies.

7.4.4 DOCUMENTS MAINTAINED BY COUNSELLORS: Maintaining documents is an important task to be carried out by the counsellors. There are mainly 10 types of documents to be maintained by the counsellors. As per the response, the data reveals that TCC counsellors maintain more number of documents as compared to DLN and ARTC counsellors.

7.5 Trace defaulters through DLNs.

Defaulters to be traced and made to revive ART are important and challenging tasks of TCC counsellors. The TCC counsellors utilize the services of district level network to complete the task. Two issues concerning lost to follow up cases have been analysed here. One is the number of cases, and the methods used to trace the defaulters.

7.5.1 TRACING DEFAULTERS: ARTC and TCC counsellors as well as DLN counsellors trace PLHIVs defaulting in ART adherence. Sending information through postal cards, and NGOs are two main sources of tracing the defaulters (see, Table 20). Reaching through telephone and out-reach workers are also options adopted in addition to the home visits. The ARTC counsellors are also indirectly involving in tracing of the cases. TCC and DLN

counsellors play predominant role in tracing the defaulters with the support of their wide spread network.

7.5.2 NUMBER OF LFU CASES: The number of lost to follow up cases in ART centres varies from less than 10 persons to over 250 during the reference period. In four of the six sample ART centres, the number of LFU cases is more than 75 persons. However according to the TCC data, five of the seven centres have less than 25 cases of LFU. Only in two centres the number of LFU cases is in the range of 76 to 125 persons. We infer that the TCC are able to manage the LFU cases better than the ARTC.

8. Performance of ART Centre and TCC

8.1 OPINION OF PLHIVs ABOUT COUNSELLING: Response by the PLHIV in ARTC on time provided to the clients, their waiting time and privacy available received was good. On the socio-economic linkage and confidence building the response was not so positive.

8.2 OPINION OF PLHIVs ON COUNSELLORS AT ARTC: Similarly the PLHIVs at ARTC response on the counsellors were positive with respect to their comfortability with the counsellor and ensure on treatment adherence accounting for 34 % and 44 % of total. On aspects of socio-economic linkage, accessibility, and life style issues, the response was not so whelming i.e about 08 to 20 percent.

8.3 OPINION OF PLHIVs ON TCC SERVICES FOR ART ADHERENCE: Adherence is vital in the efforts of antiretroviral treatment to PLHIVs. It was attempted to look into how significant was TCCs role in Adherence of the treatment by getting the opinion of the PLHIVs on certain indicators that relate to ART Adherence. The PLHIVs have expressed good opinion for the services in pre-ART counselling side effect counselling, and ART registration. Their opinion has been good for peer counselling, and linkages to DLN also. The opinion on their linkages for socio-economic support has been comparatively poor.

8.4 PLHIVs SATISFACTION LEVEL ON COUNSELLORS IN ARTC AND TCC: Here a comparison is made between the counsellors in ARTC and TCC based on the opinion given by PLHIVs using certain indicators of their work performance. Comparatively the TCC counsellors have been giving more time to the clients; the waiting time is also less. In terms of privacy, the opinion is similar. However, in other indicators namely building confidence, behavioural change, comfortability levels, and facilities for other socio-economic linkages, life style issues, accessibility, and ensuring treatment adherence the satisfaction level of PLHIVs of TCC counsellors' is very high.

9 Conclusion and Suggestions

The treatment counselling centres have been effective in improving and maintaining treatment adherence by the PLHIVs. Quality counselling in terms of time and information is the strength of the TCC counsellors. The effectiveness of the TCC is well acknowledged at the ARTC both by the Medical Officer as well the Counsellors. According to ARTC, TCC Counsellors have been taking much of the client load thus able to give more time to each of the counselling sessions. The effectiveness of TCC is highlighted by the fact that the Counsellors are able to reduce the LFU, defaulters by their tracing mechanisms and their link with DLN. The socio-economic linkages which are being provided by the TCC counsellors is bringing comprehensiveness to the service delivery mechanism to the PLHIV without just being restricted to mere Medicare.

10 Policy Implications

TCC as a strategy in promoting treatment adherence

By and large, we can find that TCC as a strategy is promoting treatment adherence, peer counselling strategy is working really very well, clients feel more comfortable talking to peers rather than non-peers. Peer support is very much needed for ART center, TCC has provided that, that itself as is great advantage of having TCC within the ART Centre.

What is the value addition of TCC

The case load of each ARTC is very high and it is difficult to provide required amount of time for every client to counsel all issues an ideal time for counselling per counselling is 30 minutes. The data of ARTC shows that the time provided for counselling per client is less than five minutes. The clients in ART Centre require help and support, but ART centre cannot provide them as they concentrate on ART Medicine which is their prime responsibility. Here, TCC is adding value by providing peer counselling, referral, linkages services, adherence counselling, follow up etc.

11 Recommendations:

- Information on Counselling time provided to each PLHIV client needs to be maintained in the counselling register maintained by the counsellors
- Capacity building program especially on issues of opportunistic infections, HIV Co- infections, and Paediatric counselling is necessary for TCC counsellors
- A Good service delivery mechanism can be provided for PLHIV using TCC. The existing gaps in the present service delivery process can be filled. The IPPCC (Integrated Positive Prevention and Care Centre) model which is being implemented in Karnataka to provide added services like providing 'free of cost'

drugs to opportunistic infections and STIs, Nutritional Supplement and psychosocial support can be easily provided using TCC. Surely TCC can serve as a readymade platform to replicate the model of IPPCC in other states as TCC are administratively attached to DLNs.

- There is a strong need to give importance to the capacity building activities for the TCC Counsellors. Their knowledge and skills needs honing which is assessed as per their needs.
- Developing a monitoring mechanism is an important requirement for the TCCs. The suggested monitoring structure is cited below which can be considered and adopted suitably.