ROLE OF COMMUNITY CARE CENTER IN PROVIDING SUPPORT SERVICES TO PEOPLE LIVING WITH HIV/AIDS (PLHIV): A CASE OF DELHI

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INTRODUCTION

People living with HIV/AIDS (PLHA) require a range of HIV services including care, treatment and support depending on the progression and stage of the HIV infection. The progression of the infection and consequent weakening of the immune system will result in PLHA being vulnerable to various opportunistic infections. The PLHA will require care and treatment for opportunistic infections (OI) and some of these illnesses may require in-patient care in a hospital or other centres that provide this facility.

Under the National AIDS Control Programme Phase- II, 122 Community Care Centres (CCC) were set up to provide treatment for minor OIs and provide psychosocial support through sustained counselling. CCC was intended to function as a bridge between hospital and home care. Hence, CCC was envisaged as stand-alone short-stay homes for PLHA. These were not linked to other activities of the programme. The introduction of Antiretroviral Therapy (ART) has brought about a change in the role to be played by the CCC. The CCC needs to be transformed from a stand-alone short-stay home to playing a critical role in enabling PLHA to access ART as well as providing monitoring, follow-up, counselling support to those who are initiated on ART, positive prevention, drug adherence, nutrition counselling etc. The monitoring of PLHA who do not require ART yet (Pre-ART care) will also be a critical function that needs to be carried out by CCC.

Under NACP III, it is proposed to set up 350 CCC over the period 2007-12. PLHA networks, NGO and other civil society organizations need to promote setting up of CCC to strengthen community care and support programmes. The CCC will be established on priority, in districts which have high levels of HIV prevalence and high PLHA load and will be linked to the nearest ART centre.

Start of Community Care Center (CCC) is a revolutionary thought to provide support services to PLHIV. CCCs are doing tremendous job to provide quality services within the prescribed budget. Community Care Centers (CCC) plays a critical role in providing treatment, care and
support to people living with HIV/AIDS (PLHIV). CCCs are linked with ART Centers and ensure that PLHIV are provided (a) counseling for ARV treatment preparedness and drug adherence, nutrition and prevention (b) treatment of Opportunistic Infections (c) referral and outreach services for follow up and (d) social support services. These Centers are mandated to seek better community and family response towards PLHIV through family counseling. For better treatment outcome, the centers provide families of PLHIV counseling on the patient’s nutritional needs, treatment adherence and psychological support. The CCCs were run and managed by local NGOs.

With linkages and referrals to ICTCs, DOTS, PPTCTs, and ART centers and other treatment services and interventions, CCC serves as a vital link in providing holistic support to PLHA with district hospitals and provides referral service to PLHA when needed.

**ACCORDING TO NATIONAL AIDS CONTROL PROGRAMME (NACP) III GUIDELINE, THE CONCEPT OF CCC FOLLOWS AS**

Short stay home. Advocating actively against stigma, discrimination and denial, Actively linked with ARTC, Linked with many other Government schemes and programs, Centre with basic aim to recover, recuperate and reintegrate PLHIV back into active life. Similarly, A CCC is envisaged as a home away from home, provides the following services to PLHIV:

- PLHIV receives counselling on a wide range of issues including drug adherence, positive prevention, nutrition etc.
- PLHIV initiated on ART would be oriented on the ART drugs, the dosages, importance of drug adherence, common side effects of the medications and adverse drug reactions which need immediate medical attention.
- PLHIV could come for regular health checkups as well as for management of minor opportunistic infections.
- Newly diagnosed PLHIV could receive support and come to terms with their diagnosis.
- Psychosocial, nutritional and educational support would be extended to PLHIV along with services of orphanages, destitute homes, vocational trainings, rehabilitation centres, legal support etc. These would be provided through strong linkages with governmental schemes and various organisations working in their respective districts.
SERVICE DELIVERY MODEL OF COMMUNITY CARE CENTER

(Fig: 1)


PLHA is being provided holistic care at the CCCs. Besides CCCs, PLHA are also getting services from linked centers has shown fig:1. This is only possible due to the team has committed personnel, having a comprehensive understanding of the problem, availability of support services. Functions of CCC can be largely categorized as medical, psychological, social and outreach.

OBJECTIVES

The objectives of this paper as follows;

1. To explore the nature of services provides to the PLHIV/ AIDS.

2. To study the satisfaction level of the beneficiaries (PLHIV) towards CCCs’ services.
METHODOLOGY

A rapid assessment was carried out to collect the perception of the people living with HIV/ AIDS with respect to the Community Care Center and their level of satisfaction with the services of CCCs. With the help of Delhi Network for Positive People (DNP+), 50 beneficiaries (25 male and 25 female) of different age group were interviewed. Snow Ball sampling technique is used to select the beneficiaries to collect data. The numbers of interviewees were given below;

RESULTS AND DISCUSSION

Overall, the PLHIV expressed satisfaction with the services of CCC. The only problem, the number of CCCs in Delhi are only four where the numbers of ART centers are nine and only four Community Care Centers in 7 districts. The table below shows the perception on the status of services, gathered from the beneficiaries who had come to avail the services at the CCCs. The table shows that the community was satisfied with the services and has rated them above average on almost all indicators. As far as medicine dose is concerned, 20 per cent of the beneficiaries reported to receive medicines for 3 or less than three days. Above 65 percent reported about more that 5 days of medicines. That means, some patients are coming immediately to CCCs whenever they feel the sight symptoms of OIs. Mostly such kind of people are diagnosed by the doctors of CCCs immediately and relieved after 2/3 days of treatment. But those patients are newly registered for ART, the ART centers send them to CCCs for 5 days observation of OIs and such patients are advised to receive treatment for five days.

Patients also appreciated the treatment and behavior of doctors of CCCs. 80 percent of beneficiaries stated that the treatment of doctor was very good. Patients also appreciated the behaviour of the other stffs (coordinator, nurses, counselors, helper etc. of the CCCs). A woman stated, Doctor is our God. Immediately, he starts to listen our problem and diagnosis accordingly. He advises us very softly what to do and how to keep our health healthy. The nurse sister sits whole night with me when I was admitted in CCCs. The counselor sister also very soft in nature and told me to take meal and medicine in time.

The most important service of the CCCs is counseling to patients. More over patients were satisfied with counseling. They stated that the counselor provides the tips on nutrition, positive prevention, drug adherence/ positive health seeking behavior, side effects of drug and health management. But some patients expressed dissatisfaction on some areas of counseling i.e. psychological support, spirituality, yoga & meditation, which areas plays more important for a PLHIV. One beneficiary states that, Yoga and meditation plays important role for increasing immunity, concentration power and body stamina etc. Similarly, psychological support to a PLHIV is more important because a PLHIV is more affected by his/ her psychological states of mind. Half of our life collapsed due to lack of moral support from our home. Most of patients ran away from their own village and home due to stigmatization and lastly him/her self fight with the critics given by the society. This entire situation creates psychologically disturbance in the life of PLHIV.

Cent percent of beneficiaries expressed their views that the CCCs are more relevant for PLHIV for their treatment. One beneficiary states that in Delhi as per ART centers there are less
numbers of CCCs where as it should opposite in number. Most of the patients are affected by OIs due to very low immunity. PLHIV are also affected by seasonal diseases very quickly. Our health system of rural areas, semi urban areas are not accepting yet now to provide health facilities to a PLHIV. So that a special set-up like CCC is more important in rural and semi urban for the treatment special treatment and care with facilities. Due to only four CCCs are in Delhi most of the patients are not preferring to visit centers do to far distance from their colonies, apartments, villages or residence and facing lots of problems.

One important service was found not available in CCCs i.e. the basic diagnostic tests which are more important in such centers. One of the beneficiary expressed her views that many times we are sent by the CCCs to ICTC or private clinic for any kind of urine or blood test. In these cases, patients face financially problems.

**TABLE: 1 BENEFICIARY’S PERCEPTION ON THE STATUS OF THE SERVICES BY CCC**

<table>
<thead>
<tr>
<th>Total patients interviewed</th>
<th>Yes</th>
<th>Percentage (%)</th>
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<tbody>
<tr>
<td>N</td>
<td>50</td>
<td>100</td>
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**Treatment by Doctor was**

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<tr>
<td>Very Good</td>
<td>40</td>
<td>80</td>
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<tr>
<td>Good</td>
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**Availed diagnostic service/s**

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**Received the report of the test**

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**Received medicine timely**

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<td>50</td>
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**Knowledge about the side effects given by doctor**

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<tr>
<td></td>
<td>37</td>
<td>74</td>
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**Medicines provided for**

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<tr>
<td>&lt;=3 Days</td>
<td>17</td>
<td>20</td>
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<td></td>
<td>33</td>
<td>66</td>
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**Received counseling on**

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<tbody>
<tr>
<td>Nutrition</td>
<td>33</td>
<td>66</td>
</tr>
<tr>
<td>Psychological Support</td>
<td>18</td>
<td>36</td>
</tr>
</tbody>
</table>
Positive prevention 42  84
Drug Adherence/ positive health seeking behaviour 35  70
Counselling on spirituality 12  24
Received Yoga & Meditation Instruction 2  4
Counselling on side effects of drugs and health management 44  88
On Health and Hygiene 43  86

<table>
<thead>
<tr>
<th>Cleanliness of the CCC (Scale of 0-10)</th>
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<tr>
<td>Good (More than 7)</td>
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<tr>
<th>Overall Perception</th>
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<tr>
<td>CCC is relevant</td>
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<tr>
<td>Satisfied with Service CCC and will continue to use its services</td>
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<tr>
<td>Have recommended about CCC to its up gradation in infrastructure including more beds, some important diagnostic tests and trend professional on Science of living and Art (SOLA)</td>
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ROLE OF CCC IN REDUCING HIV + PREVENTION/ ‘POSITIVE PREVENTION’

However, there has been an increased domestic and international awareness in recent years that HIV prevention efforts need to address not only risk reduction among HIV-uninfected individuals but also the adoption of preventive measures by HIV-positive individuals.

One positive person is involved in each case of HIV transmission. A change in the risk behavior of a PLWHA will have a much bigger effect on the spread of HIV than an equivalent change in the behavior of a HIV-negative person. (King-Spooner, 1999)

In addition to developing more efficient approaches to prevention, as antiretroviral therapy becomes more widely available in India, it is increasingly important to direct intervention efforts toward PLHA. More individuals with HIV are living longer, feeling better, and enjoying a renewed interest in life. These very important improvements in the health and well-being of PLHA bring new challenges, including the challenge of negotiating safer sex behavior as an HIV-infected individual.
Convincing arguments based on research from the United States, Kenya, and Uganda have recently been made for consideration of prevention activities with HIV-infected individuals (commonly referred to as "Positive Prevention" or more recently as "Positive Health, Dignity and Prevention"). Moreover, directing prevention efforts toward individuals who are aware of their HIV-infected status is a cornerstone of the advancing HIV Prevention Initiative, for which four core strategies have been identified:

1. Make HIV testing a routine part of medical care whenever and wherever patients go for care.
2. Use new models for diagnosing HIV infections, outside traditional medical settings.
3. Prevent new infections by working with people diagnosed with HIV and their partners (when serodiscordant couples are involved).
4. Continue to decrease mother-to-child-transmission.

Community Care Center is also plays important role in positive prevention. The CCCs are providing counseling on positive prevention and its positive measures how to protect him/her self the partner from the viral load. The perception of PLHIV on the role of positive prevention shows in table.no.1 above that 84 percent of the PLHIV expressed their opinion that they learn about the positive prevention from CCCs during counseling session and its measures to maintain healthy mind and mind.

QUALITY SERVICES AND CLIENT SATISFACTION

The term ‘quality’ itself has been defined as fundamentally rational. 'Quality is the ongoing process of building and sustaining relationships by assessing, anticipating, and fulfilling stated and implied needs. Similarly, in terms of CCC the health services were provided to the HIV/ AIDS patients in limited time and resources is quality in nature. The services are provided by CCC is free of cost and accessible in nature. So that the HIV/ AIDS affected people were satisfied with the services of CCC. One of the beneficiary expressed his views on the services that,

“...This center is more important for us. During suffer from opportunistic infections we are coming to this center and getting immediate treatment. In big/ general hospital treatment and care ir very difficult. First stand on queue for one to two hours, When doctor see to patients he/ she tells why you come here, why not to CCCs. Here, only medicines are available but in CCCs there are nutrition, doctor consultation with medicine for OIs are available. One can stay for 5 days in CCCs. There is also availability of counseling and recreational services. So that whenever I face any problem immediately I visit to CCC. Really, the CCC is more important in block and district level for us. (Translated)”

Overall, the patients of CCC expressed satisfaction with the services. On a general level, the services provided by CCC were appreciated by the doctor and Project Coordinator of CCC. The doctor of CCC expressed his views that this programme is very much effective for the HIV/
AIDS patients. Within a small scale budget this programme is cost effective in nature. Monthly, approximately the 45-55 and sometimes up-to 65 patients are getting all kind of services i.e. free diagnose and treatment for opportunist infections, mental health counseling, nutritional support for three times with tea and milk in morning and evening, recreational facilities, referral services, timely monitoring their health status, nursing care, follow-up activities etc. The most important service is provided i.e. familiar environment with full of emotional support which service is more significant for their lives. All staffs of the CCC are well trained and serving full time sincerely with a very low remuneration compare to others in same job profile. The doctor of the CCC is part-time in nature but the CCC is providing emergency services to the patients also. Besides these services, it was found that the CCC makes with NGOs, trusts, charity organizations, private hospitals, government departments and linkage the patients for their welfare.

SUGGESTIONS WITH CONCLUSION

For understanding Care, Support and Treatment of the PLHIV, it is imperative to understand their needs. The needs of the PLHIV are not just medical; they range into the socio–economic and psychological fronts as well. Hence treatment demands a more comprehensive approach that addresses all the needs of the patients in a holistic manner.

MEDICAL NEEDS

- Everywhere (Block & district level) more CCCs should set-up that ART centers to cover all the pre-ART patients and others also in emergency.

- Everywhere the CCCs should up grade in nature of health infrastructure and services/ (Trend professionals, full time MO who is well trend on HIV/ AIDS issues, important diagnostic tests, quick referral linkages with emergency and specialised wards should available at CCC) for accessing treatment of opportunistic infections and specialised treatment if required.

- In rural India HIV/ AIDS test and diagnosis should available at every CHC/ Block hospital/ First Referral Units because rural population will get more advantage to access treatment easily.

- So many time PLWA cases are not going to Community Care Centers for treatment of opportunistic Infections because these centres established at district level or far from their resident. Another major factor is affecting to access CCCs is low economic status of family/ poverty and poor frequency of road transportation, poor road linkages. The own observation of researcher in hilly terrain, desert and plain rural India so many PLWA cases are dying due to inaccessibility of health care services during emergency. So that the Community Care Centers and link ART centers should be extended to block level by which PLWA will get more benefit and definitely such facilities will bring changes their health seeking behaviour, drug adherence and stop positive prevention.

- Palliative care for terminally ill patients
Quality nutritional services should be provided by the government and also monitored timely.

PSYCHOLOGICAL NEEDS

- Stress reduction through psychological & spiritual counselling, yoga & meditation etc.
- Retain self esteem, dignity and respect of others
- Create to develop confidence level and positive emotional stability and enabling future planning among PLWA cases
- Psychological support through counselling

SOCIAL WELFARE NEEDS

- To continue to work, provide vocational training
- Income support through social security etc.
- Shelter/housing, equal access to existing provision
- Care for dependent and orphan children
- Legal assistance and prevention against discrimination should be provided.

REFERENCES

1. NACO (2007). Operational Guideline for Community Care centers, MOH&FW, GoI.
2. NACO (2010). Operational Guideline for Community Care centers & Comprehensive Care and Support Centers, MOH&FW, GoI.