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Community based rehabilitation services to HIV Victim – Case studies

Dr. S Radhakrishnan and S Yesu Suresh Raj

Abstract

The present study entitled, Community based rehabilitation services to HIV victims - development perspectives, was undertaken. The researcher started his work with defining rehabilitation that it is intended to create an environment favorable for the person living with any disability or disease. To understand more about the context of HIV/AIDS, and the rehabilitation of HIV victims through CBR approach the researcher has reviewed a number of literatures to find out the dimension of the problem taken by different researchers and the methodology adopted by team in testing their hypotheses.

Keywords: rehabilitation services, HIV, CBR, Millennium Development Goals

Introduction

The seriousness of HIV/AIDS could be understood when nearly 187 United Nations Member states and 23 international organizations came together to establish the sixth goal – Combating HIV/AIDS and other diseases as one of its eight Millennium Development Goals (MDG). Because HIV/AIDS had already become one of the major killer diseases of humankind. As per the UNAIDS/World Health Organizations (2007) statistics that over the past 25 years, nearly 25 million people have died of AIDS.

The present study entitled, Community based rehabilitation services to HIV victims - development perspectives, was undertaken. The researcher started his work with defining rehabilitation that it is intended to create an environment favorable for the person living with any disability or disease. To understand more about the context of HIV/AIDS, and the rehabilitation of HIV victims through CBR approach the researcher has reviewed a number of literatures to find out the dimension of the problem taken by different researchers and the methodology adopted by team in testing their hypotheses.

Objectives

This study is mainly aimed to find out the community based rehabilitation services for the betterment of HIV/AIDS victims in Dindigul District.

- To understand the socio-economic conditions of the HIV/AIDS victims.
- To analyze the community based rehabilitation services implemented by the Government and Non-government organizations.
- To analyze the relationship between the Communities based rehabilitation measures and socio-economic factors with reference to age, income, dependents, educational qualification, marital status and area of domicile.
- To provide suggestions for improving appropriate rehabilitation services to the people living with HIV/AIDS.

Research Methodology

This study involved descriptive design and collected the primary and secondary sources of data through interview schedule, case studies and focus group discussion. The investigator selected 300 respondents by simple random method from Dindigul, Palani, Athoor, Kodaikkanal, Oddanchatram, Vedsandur, Natham, and Nilakkottai unions in Dindigul district. This study analyzed the greater impacts of CBR approach on individual HIV victims who received services like counseling, capacity building program, exposure, linkage with govt. welfare schemes, health and education institutions, networking with local CBOs and

district level positive network etc. More over this study also brought out recommendations for better delivery of CBR services to HIV victims and the areas to be improved by the family members and engaging the community for a more fruitful partnership.

Case studies are research that focus on and gather in depth information about a specific person, group, community or event. They have numerous advantages and disadvantages. But do they actually have an important place in research.

Advantages

- a) Good source of ideas about behavior
- b) Good opportunity for innovation
- c) Good method to study rare phenomena
- d) Good method to challenge theoretical assumptions
- e) Good alternative or complement to the group focus of psychology

Disadvantages

- (i) Hard to draw definite cause-effect conclusions
- (ii) Hard to generalize from a single case
- (iii) Possible biases in data collection and interpretation (since single person gathers and analyzes the information)

Case Study No.1

Name and her background

Smt. Ananthi (name changed) aged 39 is a widow hailing from Gandhinagar at Batlagundu in the Dindigul district. She has two children. Her daughter namely Janani is in 10th standard and son Hari Krishnan is in 9th standard. Her husband was a lorry driver, used to move from one place to another and so had the habit of returning home in long gap.

The issue

Once returned home, her husband was suffering from high fever and severe diarrhea. Ananthi took him immediately to a nearby private doctor but no improvement in the treatment. As per the advice of the doctor, she took her husband to the govt. hospital in Madurai, located about 40 km distance from Batlagundu. Blood test was conducted for her husband as well as to herself. It was found that both of them were HIV positive.

Her husband accused Ananthi that she only spreaded the disease to him. He scolded her in ugly words and suspected her fidelity. Ananthi tolerated all the ill-treatment but for her children. She looked after her husband well and within a short period of one month her husband died. It seemed that the in-laws and the family members waited for the death of the husband of Ananthi. Immediately after the death, they abused Ananthi and chased her away from the home. Ananthi and her children becomes orphan. No one came to support them.

Ananthi's health was also frequently affected by diseases. She would able to engage as domestic servant in some houses and earned only a meager amount. She could not be able to meet both ends. She could not be able to repay the loan and the interest she availed to meet the medical expenses of her husband. With the ration commodities she feed her children and lost hope in her life. In the meantime the owner of the house Ananthi hired was poisoned by the neighbors and he compelled her to vacate his house.

NGO's Intervention

It was in the context of that Ananthi became orphan and excludes by the neighborhood community, the field staff of NGO came to know her pathetic condition. They met Ananthi and counseled her and explained the services available in the CBR project being implemented NGO. Ananthi was not in faith about her future. Hence she refused to the advice of the project staff. But after considering the scope of her children she joined with NGO and availed the services under CBR project of NGO.

The process of transformation in the life of Ananthi

Ananthi witnessed the care and welfare availed by other PLHAs, moved with them, interacted with them and slowly gained a positive mind. Her self confidence was strengthened and she learned to look after herself during suffering from many opportunistic illnesses through medicinal plants. Further she underwent orientation training in Income generation programmes and determined to redo her earlier skill of tailoring. She had a refresher cum special training in tailoring and got a tailoring machine also. Ananthi earns now-a-days around Rs.100-150/- per day and able to pay house rent in time, look after her children's health and education to some extent.

Her association with the NGO helped her to empower with information on the various government's welfare programme to poor and marginalized sections. She applied and succeeded in availing Rs.1000/- widow's pension. She was involved in the SHG at the behest of NGO and save money properly. She was able to credit assistance of Rs.25,000/- from SHG and her saving of Rs.15,000/- totally with Rs.40,000/-. She got a house for lease.

The impact

Due to proper treatment, she availed from the govt. hospital and the other comprehensive support and care services under CBR project, her health is improved and confidence on the future is strengthened further her stress is reduced. Having understanding the seriousness on the disease, she takes care to avoid activities which contribute towards the spreading of HIV to others. In spite of her illness, suffering from HIV positive, her relatives/ friends visited at her house and participated in the celebration of her daughter's puberty ceremony. Her family members helped her in many odd activities at her home without any fear or stigma.

The community extends its acceptance to her. They encouraged Ananthi to move freely to all other members and take her along with them for work. Many families came forward to support her children for their health and educational needs. Ananthi refers "The important point to share that the community treats me and my children as fellow human beings".

Her expectations for the successful implementation of CBR project

- PLHA needs support to have treatment as in-patients.
- Monitoring and counselling in taking ART/TB tablets properly and having food adequately.
- Help them to get more rest by reducing their work burden. Motivate them to develop self –confidence.
- The period of repayment to credit extended by SHG could be extended.
- Give preference to PLHA when selecting beneficiaries for housing scheme in state/central government.

- Exempt PLHA from paying water & land tax.
- Organize more training to them.
- Increase the monetary support for IGP/ House repair to Rs.20,000/-.
- Create proper awareness on the places/procedures available for treating HIV/AIDS.
- Tablets for treating TB/ HIV could be at one place for the convenient of PLHA.
- More number of hospital/dispensaries for getting treatment of PLHA.
- Enhance the provision amount of PLHA from Rs.1000/- to Rs.2000/-.
- Provide free bus pass to move around freely.
- Provide free house pattas for them.
- Distribute 35 kg free rice in the PDS shop.
- Extent credit assistance for the livelihood of PLHAs from banks without demanding security.

Case study No. 2

Name and her background

Smt. Chitra (name changed) aged 35, living at Chatthirapatti hamlet at Agaram Panchayat in Vedasanthur block of Dindigul district. Her first husband was a construction worker. She was also a worker in the construction industry. After the death of her husband due to HIV she was married to another person. Now Chitra has two female children, one from her first husband namely Kaleswari studying in 5th std and the second girl namely Anjalai studying in 1st std whom she got after her remarriage.

The issues

Chitra informed that within two years after her marriage, her husband suffered frequently from fever and cough. She took him to govt. hospital located at Dindigul for treatment. Her husband's blood test confirmed that he was HIV positive. She did not reveal the truth to anybody due to social stigma and continued the treatment in govt. hospital at Madurai. After a week they returned home. Her husband felt ashamed and committed suicide. The parent's of Chitra took her and her daughters to their own village as the in-laws did not come forward to support her.

The parents had doubt over the scope of spreading of HIV to their daughter and granddaughter. It was confirmed that Chitra and her daughter Kaliswari were suffering from HIV. As Chitra had to look after her 2 year old daughter and herself she could not go for any work. In that circumstance her parent arranged, second marriage to Chitra. As she continued her treatment, she gave birth to a second child who was in good health. Her second husband looked after them well. But he had the habit of taking money and left them frequently. Her hope about her life was diminished.

At that stage the field staff of NGO met Chitra and consoled her. The staff explained the services available under CBR project and advised Chitra to join with NGO. Since she joined with NGO in the year 2012, the life of Chitra is in good shape, she reported.

Care and support services of NGO

Chitra remarked that the counseling given in by NGO and activities for building her capacity brought a good change in her life, Chitra added. She gained knowledge and practice on kitchen gardening plantation of medicinal plants and preparation of nutritionally rich food items with less cost by which she was able to improve her health.

The credit assistance given by NGO for the livelihood of Chitra to rear a milch animal helped her a lot. She earned regularly and looked after her family well. One of her daughter's educational supports was met by NGO which was a remarkable. Her daughter was provided with counselling, all educational supports and recreation, picnics and exposures to various places empowered them in their in social and academic activities besides brought happy and joyful to the minds of children.

Chitra was able to construct her own house from her saving and a loan from NGO she availed. Her second husband after receiving counseling and guidance improved his vision happily involved and mingled with her family. Witnessing a happy life Chitra, her brother voluntarily visited her home and helped her in many ways.

The impact

"I could also live, in the hope I gained," Chitra shared. Because of her vigil, her second husband is not affected by HIV.

- Having included in financial services/benefits.
- Availed much assistance eligible to my daughter from the government.
- NGO arranged tie-up with other stakeholders from whom expenditure for their children's highest studies, present educational expenditures could be addressed successfully.
- Many trainings and capacity building activities given to her and her children helped them to become part and partial of the community life.

Her expectation

The services of the government have to be given to all eligible HIV persons.

- Treatment has to be done at Dindigul not to Madurai Govt. hospital.
- Providing for treatment free of cost
- 35 kg free rice to all HIV people.
- Education loan to the ward of PLHAs for their higher studies.
- CBR must be extended to at least for next 3 years including for all children in each PLHA family.

Case Study No. 3

Name and her background

Smt. Vijayalakshmi (name changed) aged 35 hails from Malliampatti of Nilakottai block in Dindigul district. She lives with her husband, a cloth vendor and four children; two sons and two daughters. Her husband visited various places to sell cloths and so once or two time only returned to home in a year. In year 2011 he returned to home at the time of Deepavali celebration. Vijayalakshmi told that it was a happy day but the happiness end very soon as he was suffering from various ill-ness and the doctor informed after testing his blood that he was HIV positive.

The issues

Vijayalakshmi shared that her husband was not able to bear the impact of the HIV, had a stroke and lost the mobility of his hand and legs. Relatives of her husband showed aversion to her and her sons and daughters and avoided them. In public places especially at public taps her children were treated as out-casted persons. Vijayalakshmi recollected that "fearing over the future of my family I made attempt to

commit suicide more than two times' always under stress and nervous", she added.

The NGO intervention

Vijayalakshmi informed that she earned a very little money from agriculture manual labour and NREGP work. And so unable to look after the family expenditure, used to get loan from known persons. She actually struggled every day, she added. She further shared that she was fortunate as she came to know the service of NGO and so joined with the organization. Vijayalakshmi acknowledged that from NGO she received love and support along with many material and other assistances. The most remarkable change in her life Vijayalakshmi told that she wished to live a long life, with her children and husband, thanks to NGO.

The impact

- Her children are continuing their education.
- She joined in self help group and has regular savings.
- Even she served as the leader of her SHG.
- She is able to mingle with community as community members invite her for various function and celebrations.
- Regularly follow the treatment so as she could save her and could look after her children properly.
- Have healthy food – nutrition vegetables, greens.
- The community has the positive mindset and come forward to respect the HIV affected persons right to live in the society.

Her expectation

- The change in the mindset of family/ close relatives has to be changed a lot.
- More support/ care is needed when the HIV affected person are very sick.
- Educational support in very much needed to the children of HIV affected persons.
- There are many children who need assistance under CBR care.
- Monetary assistance under IGP and house repair in CBR has to be increased.
- More training/ capacity building have to be planned.
- Vocational training to adolescent girls.

Case study No. 4

Her Name and family background

Smt. Pandiammal (name changed) lives in Chinnamuthampatti, of Vadamadurai block in Dindigul district. She is a widow. She has two girl children. Her husband expired five years ago due to HIV.

The issue

Pandiammal's husband was a mason. She informed that her husband returned to home once in a week. Once he suffers severely from vomiting and diarrhea besides high fever. She took him to a private hospital and got treatment for a week. And then as per the advice of the doctor she took her husband to the Dindigul government hospital. At that time she was conceived for her second daughter. She also suffered from fever and so the doctor tested her blood. The result was that herself and her husband suffered from HIV positive beside her first child also.

Pandiammal informed that she felt depressed as her husband cheated her and her children and she left him, went to her parent's home. Her husband died after two days from that incident, she added. Considering the fate of her two children, she returned to her in-laws house. But she had to face a new danger. Her cousin-brother compelled her yield to the pleasure of his ugly wish and advanced her to sexually exploit. Unable to bear the torture of her cousin brother, she decided to commit suicide and pleaded her brother to look after her son. But her cousin sister is wife her brother scolded her and let all in her family commit suicide. She was in broken stage – to live or to die.

NGO intervention

Pandiammal informed that it was the right time that she comes to know the services of NGO and availed the comprehensive services under CBR project. She further told that through various trainings like self care training, home based training, IGP training, preparation of cost effective nutritious food etc empowered her and brought a confidence to live. She felt that she was not in safe due to the condition of her house. She shared her concern during the SHG meeting and so she was given money to undertake necessary repair at her house. Now she was able to repair her house and felt better safety. The educational and other supports given to her daughters made a good impact. They sustain their education, their level of CD4 is improved; and they had a dream of having higher education after schooling.

The impact

The children of Pandiammal are in safe environment. Gained confidence that she would able to afford higher education to her daughters.

- Social status of Pandiammal is improved.
- In spite of HIV positive, Pandiammal has satisfaction in her life. She came out from despair and hopelessness.
- She became creditworthy and availed loan from various sources and rear about 10 goats for her livelihood.
- Relatives/ friends are visiting her home.

Her expectation

More awareness to the community in general and to the family member specially on the issues of HIV positive persons.

- Due to attention in the health of PLHA when they suffered from illness. Give encouragement for their social mingling.
- Organize family counselling.
- Training and financial assistance for their self employment.
- The CBR has to be for 5 years duration
- Monetary assistance to procure provisions and follow up treatment, every month.
- Guidance/ support for the higher education of their children.
- Allocate more money for house repair.
- Awareness building about the schemes and programmes related to the welfare and economic development.
- Advocacy for better local resource mobilization.
- Ensure to avail all necessary basic civic documents.
- Help to get employment to young widows.

Case study No. 5

Her background

Smt. Vimala (name changed) lives at Sittur of Authoor union in Dindigul district. She and her husband are agricultural laborers. They have two female children. Their elder daughter is in college and the younger one studying in 12th std. They are HIV positive persons. Earlier they did not know about the disease which affected them. Later they were told that in Kerala an effective treatment is available to HIV positive persons but the cost of treatment as around 1 lakh. She decided to take that treatment at any cost. She sold out available jewels and vessels besides mobilized money from money lenders and spent the amount for treatment in Kerala.

The issues

Vimala told that through they belong to cast Hindu community, they were not able to get recognition from the so called untouchable – SC community. They were not allowed to fetch water from the public tap. Even she was denied to join in the NREGP activities. Considering their fate, Vimala and her husband decided to end their life. They planned to undergo a four programme so as they could take their daughters and proposed to end their life including the life of their daughters. But as circumstances were not helpful to execute their plan, they returned back to Sittur.

NGO intervention

“At that time of losing hope in our future the staff from NGO met me and spend two days consequently and counseled me for developing constructive thoughts, the significance of tolerating all happenings at one’s life”, Vimala stated. She remarked that her association with NGO brought a new change in their life. She empowered herself through various training she undergone and become capable to carryout self-care, home care and establishing linkages with other support group and organizations like Jeevan Jothi, Arulagam improved her CD4 level. She learnt the details of do’s and don’ts in managing herself from spreading of HIV. She compelled her husband to use condom during sexual intercourse but her husband refused to and so her health status was deteriorated. She felt very bad and took corrective measure in that respect with the guidance of field staff of NGO.

The impact

Her health status is improved and she was able to take food and good digestion.

- The occurrence of opportunistic illness is reduced
- CD4 estimation is increased
- Availing of Anthayctya Anna Yojana benefit- free rice of 35 kg from the PDS shop.
- Joined in the Prime Minister Selvamahal Thittam Yojana and save monthly Rs.200/- in the Bank
- Having a deposit of Rs.10,000/-
- Availed Aadhar card
- Undergo monthly check up regularly
- Able to engage in wage earning activities as her health is improved a lot.
- Her daughters interested in education is improved and they pursue their higher education
- Friends and relatives restored their relationship with Vimala and her family

- At public places their rights to fetch water from public taps has been protected.
- Local resource mobilization activities, every common man get knowledge on the issue of HIV positive.
- Avoided the support and other assistance from various stakeholders by establishing rapport with them.
- Became a member in the village education committee
- Availed Rs.10000/- cash assistance from NGO and made use her saving, Vimala purchased a milch animal and earn a considerable amount daily.

Her expectation

The higher education to their children has to be ensured.

- Need a food allowance of Rs.300/- pm when for every HIV positive person suffered from opportunistic diseases.
- Need monthly pension.
- Need special scholarship to the wards of HIV positive person for their higher education.

Case study No.6

Background

Smt. Nivetha (name changed) aged 35 lives at Lion’s Street in Dindigul town. She is a tailor and her husband is an auto driver. They have two sons but one son died due to illness. The second son is studying in 6th std. at Holy Mariannai Higher Secondary School. They live in a rented house.

The issues

During 2004 the husband of Nivetha suffered from severe fever and head ache frequently. She took him for treatment, the doctor advices to take him to the government hospital in Madurai. She took him to Madurai Govt. hospital and after testing his blood the doctor reported that he was infected by HIV. Further the doctor advices Nivetha also to undergo medical checkup and blood test. She too underwent to checkup and it was informed that she too was infected by HIV.

Nivetha informed that after knowing the fact that both she and her husband were suffering from HIV, she lost hope in future. She did not want to live but for the sake of her sons, she decided to live in the world. In the meantime her husband was affected by TB also. And the TB was spreaded to her son also. Unable to bear the severity of the disease her son died. Nivetha told that, “I got angry with my husband as he was the culprit for all the happenings. And so I decided to leave him immediately”. Her family members consoled her that she had to live for the sake of her only son. She lost her hope and decided to commit suicide. She told that she did not have courage to kill her son. Further she feared over the stigma and ill-treatment meted out to her by society and relatives if the truth is revealed to them. Thus she was leading her life in the midst of fear and stress.

The intervention of SSH

The project worker of SSH met Nivetha and counseled her to build her self confidence as she could improve her health, increase the lives span if she is to empower with knowledge and practice in managing herself and her family. The various trainings she received from SSH helped her to gain confidence and she reorganized her tailoring vocation with the financial support extended by SSH.

Under CBR project her son’s education is continued his health is improved his life scoping skill is also improved,

Nivetha told. She appreciated that the activities under Alternative Learning Centre (ALC) were very much useful to the children in their curricular and extra-curricular activities, personality development and social citizenship. The tour/picnic, periodical meetings, cultural training and sports and games organized by SSH helped a lot to her son, she added.

The neighborhood families came forward and recognize the rights of PLHAs. They extend loan and invite Nivetha during the celebrations in their homes and community. The SHGs permits her to become a member and distributed loan to Nivetha without charging any interest.

Her expectation

- Help and assistance to ensure higher education of her son.
- Training for IGP and credit support to commence self employment activities.
- Better counselling.
- In employment opportunity at govt. department, preference to the educated persons living with HIV.
- Providing skill upgradation to serve peer educators.

Case study No.7

Her background

Smt. Kalyani (name changed) lived with her husband at Dharmathupatti in Authoor block of Dindigul district. Her age is 32 and her occupation is washing clothes. Her husband died a years back due to HIV. She lives with her only one son, who is in 10th standard.

The issues

Kalyani informed that she came to know that she too is infected by HIV. For the past six years she is in treatment, properly taking ART tablets. Earlier she lost hope as the loan she availed from friends/relatives to meet the medical expenditure and funeral expenses of her husband, she added. Before the death of her husband, Kalyani lived with her husband at Mylapore a small hamlet near Dharmathupatti. After the death of her husband, the wife of her husband's brother came to know that she was also infected by HIV and so scolded her ugly and sent her out from the family. She told that as no other way, I went to my parent's home. They live in a small house. My father proposed marriage to my younger brother my husband and so felt unhappy over my stay with them. "Even her parents did not come forward to give asylum to Kalyani. Any how they showed a small hut near their house and asked Kalyani to live in that hut which was in very dilapidate condition. Kalyani informed that the hut shown to her was not a safe place and felt very sad over her pitiable situation.

SSH intervention

Kalyani told that when she was in that depressive condition, the field staff of SSH met her. Their soft approach touched the heart of her and she ventilated her all feelings freely to the staff, she informed. The staff consoled her and guided her to join in the support group. Associating with the support group and involving in its activities provided opportunities to Kalyani in understanding the life of many families like that of Kalyani. She along with other members of the group attended self care trainings, ART adherence training and IGP training etc organized by SSH. She understood the importance of taking ART tablets without

any break and eating nutritiously rich meal properly. She shared her regret of living in an unsafe hut. The group recommended SSH to give Rs.10000/- to do necessary repair at her hut. Now she is in improved condition and also became a safe place, she added. Now Kalyani became a member of Ayyanar self help group and learnt the out of thrift and saving.

From the training on home care given by SSH, Kalyani learnt the knowledge of preparation of medicine to treat successfully the issue of white discharge from her sexual organ.

The impact

Kalyani told that she regained herself respect and now-a-days many of her relatives and family members shaded down their discrimination and treat her well. She became the leader of the joint liability group under NABARD micro credit assistance programme and she leads the group in a successful manner, she claimed.

Her expectation

- More awareness to the family / relatives of HIV persons.
- Community should not feel sympathy but render help to HIV affected person and their family members.
- CBR / any other intervention activities of the government / non-government organizations have to be a long term one instead of short period.
- More information has to be provided on the socio-welfare assistance of the governments (federal and state).
- Government must consider giving special care to HIV affected persons when they are affected by TB.
- Local bodies have to give preference to them in allocating welfare schemes and other benefits.

Case study No.8

The background

Smt. Vasanthi (name changed) aged 43 is living at Mettupatti village near Dindigul town. She works in a firm which produces plastic based color ink. She and her husband are HIV positive persons. They have three daughters. One of their daughters was married off. The next one is working in a textile mill as she could not able to continue her education due to their poverty. The third daughter is going to complete her 12th standard.

The issues

Vasanthi told that her husband is a drunkard and always quarreled with her and disturbed the studies of her third daughter. Unable to bear his beating and forcer, she and her daughter regret themselves and proposed to commit suicide. Moreover her husband did not give any money he earned. She lost her hope in her future as she could not find any way to arrange marriage for their daughters. The question of how to settle their life successfully was always thronged in her mind, she told.

Vasanthi, under treatment for the past five and half years, struggles hard to manage the family. Due to pressure she lost her peace of mind and became ir-regular in taking ART tablets, she added.

SSH intervention

At that crucial time, SSH field staff met Vasanthi and explained the scope and opportunities available under CBR project of NGO. She told that for the past five years she regularly visits NGO, attends all training programmes and availed assistances for continuing the education of her daughter. Otherwise she could be a dropout and become a child labour, she remarked.

Impact

- Vasanthi determines to send her daughter to higher studies – college or professional courses.
- Her interest in life is strengthened and so she and her husband adhere properly the advice of doctors, take ART medicines and take proper food.
- Vasanthi decided to do necessary repair so as her family status would be improved.
- Her relatives and friends treat the family of Vasanthi respectfully.
- Vasanthi gains recognition in her community and she became a member in the Bharathi women's federation.
- She actively attends gramasabha meetings and courageously appeals to the Panchayat President to intervene seriously for the course of poor and marginalized sections.
- Her income in improved as she availed monetary support for goat rearing.

Her expectation

- Proper awareness has to be built to the family members and close relations of HIV affected persons.
- Vasanthi expected proper counselling to her husband so as he could come away from the drinking habit and contribute his earning to the family.
- More monetary support to strengthen their livelihood.
- Preference in allotting house Indira Awas Yojana/Green House scheme to HIV affected families.
- Special scholarship to sons/daughters of HIV affected persons.

Case study No. 9

The background

Smt. Preethi (name changed) aged 42 lives with her husband at Margampatti in Sanarpatti union of Dindigul district. Preethi engages herself in the activity of tamarind process and earns Rs.90/- per day. Her husband is doing ironing of washed clothes. They have 3 daughters and one son. All of their children except her son are in school and the son is a small child attending balwadi.

The issues

Preethi informed that when she conceived her third child, she went to hospital to treat her illness which occurred suddenly. She further told that in the result of her blood test, it was found that she was HIV positive. Her husband also underwent to blood test and he was also HIV positive. And as per the advice of the doctor, blood test was conducted to their daughters and came to know that her second daughter was HIV positive. The villages came to know that all the members in the family of Preethi are suffering from HIV/AIDS they refused to give rent for her house. She told that she suffered a lot in the struggle to lead a simple life.

SSH intervention

After her association with SSH, with the guidance of field staff, Preethi's hope is returned through counselling. The tour arranged by NGO was a joyful experience. Preethi said that being in poverty. Families of HIV affected persons could not able to afford to meet expenses on tours and picnic. But she and her daughters were so happy and enjoyed the days, thanks to NGO, she shared.

Preethi informed that she gained leadership through her involvement in Bharathi Women's Federation and had confidence to deal with any issues. She told that she determined to conduct blood test to bride groom before giving marriage to her daughter. She remarked that she understood the concepts like women reservation, gender justice, empowerment of adolescent girls etc and tried to practice / apply in her family also. She acknowledged that there was a positive change in the mindset of community. She is moving freely with everyone.

Her expectation

- Preethi told that her family is a big one. Hence she needs more support for health care & nutritious meals.
- Needs further support to continue the education of her daughter.
- Not only one child in the targeted family but the next children also have to be included under CBR.
- The NGO has to complicate the travel expenditure spent to purchase ART tablets etc.
- Government has to provide special scholarship to girls studying in school/college.
- ART tablets have to be distributed for a period of one month instead of two weeks.

Case No. 10

Background

Smt. Karuppayee (name changed) aged 45 is living at Sirunayakkanpatti village in Nilakkottai union of Dindigul district. Her husband died due to illness. Now she lives in a rented house. Her two daughters are studying in government higher secondary school; first daughter in 12th standard and the second one at 6th standard. Karuppayee is a laborer in Agriculture sector. She earns Rs.60/- per day and with that meager income she suffers a lot in running her family.

The issue

Since 2006, after her husband expired, Karuppayee became ill very often. Her blood was tested at the government hospital and the doctor informed her that she was suffering from HIV/AIDS. She was broken herself and learning the truth, the villagers refused to spare house to her. She was discriminated when she went to public tap. Many families stopped their social relationship with her. She informed that she was under pressure due to the unexpected development and broken herself.

SSH intervention

With the guidance of staff of NGO, Karuppayee was enrolled in CBR programme. She told that the training on self care, home care, IGP, SHG leadership etc brought a change in her life. She become a vendor of clothes and improved her earning. She was happy in self employment than wage employment as she got more time to take rest. Through group activities organized by NGO, Karuppayee has more friends and empowered with many information on

government schemes and programmes. Her knowledge on ART, CD4 etc is improved and she becomes more conscious in managing her health issues. She actively participated in various programmes on international events like AIDS's day, Women's day, Food day organized by NGO. She organized kitchen garden and had the practice of taking balance diet. She gave proper attention to the educational development of her children. Now she is able to get a house for rent. The nearby families show respect and freely move with her and her family members.

Her expectation

- Information empowerment to the family members of HIV positive persons so as their cooperation and concern to the HIV affected would be improved.
- The children of these families need sponsorship support to continue their education.
- Reservation to HIV positive persons in local body's election.
- Plan should be drafted at village level to strengthen the livelihood activities of HIV affected person / family.
- Vocational education to their children.
- Amount for house repair had to be increased.
- The quantity of educational materials supplied under CBR has to be enhanced.

Focus group discussion

The focus group discussion is a rapid assessment, semi-structured data gathering method in which a purposively selected set of participants gather to discuss issues and concerns based on a list of key themes drawn up by the researcher / facilitator (Kumar 1987).

With help of the guide line focus Group discussion was conducted in networking center with four different groups. These four groups were invited from Dindigul Taluk, Natham Taluk, Vedasandur Taluk and Palani Taluk with help of networking of people living with HIV/AIDS, Dindigul. These four FGD was conducted at networking centre, Dindigul. The participants were from Dindigul Taluk was 17, from Natham Taluk was 15, from Vedasandur Taluk was 15 and from Palani Taluk was 12. Both genders were participated in the FGD. Approximately the duration was 90 minutes to 120 minutes. Mostly the respondents were participated in the FGD without any hesitation and provided their support to collect information as much possible.

Findings of case studies and focus group discussion

- People Living with HIV / AIDS support to have treatment as in-patients. Monitoring and counselling in taking ART/TB tablets properly and having food adequately. Help them to get more rest by reducing their work burden.
- The period of repayment to credit extended by SHG could be extended. Give preference to PLHA when selecting beneficiaries for housing scheme in state/central government.
- Exempt PLHA from paying water & land tax. Organize more training to them. Increase the monetary support for IGP/ House repair to Rs.20,000/-. Create proper awareness on the places/procedures available for treating HIV/AIDS. Tablets for treating TB/ HIV could be at one place for the convenient of PLHA. More

number of hospital/dispensaries for getting treatment of PLHA.

- Enhance the provision amount of PLHA from Rs.1,000/- to Rs.2,000/-. Provide free bus pass to move around freely. Provide free house pattas for them. Distribute 35 kg free rice in the PDS shop. Extent credit assistance for the livelihood of PLHAs from banks without demanding security.
- Information empowerment to the family members of HIV positive persons so as their cooperation and concern to the HIV affected would be improved. The children of these families need sponsorship support to continue their education. Reservation to HIV positive persons in local bodies' election.
- Plan should be drafted at village level to strengthen the livelihood activities of HIV affected person / family. Vocational education to their children. Amount for house repair had to be increased. The quantity of educational materials supplied under CBR has to be enhanced.
- The NGO has to complicate the travel expenditure spent to purchase ART tablets etc. Government has to provide special scholarship to girls studying in school/college. ART tablets have to be distributed for a period of one month instead of two weeks.

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