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Livelihood Options and Social Stigma of PLWHA in Andhra Pradesh, Tamilnadu and Maharashtra

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Abstracts: *PLWHAs need support systems, which provide opportunities for livelihoods in view of their decreased physical strength, community attitudes, family non-support and inadequate health infrastructure. A livelihood framework pursues multiple approaches and goals and hence one should adopt a multi-dimensional approach. The proposed framework must have the capability to address the complexity of the situation and at the same time it should be feasible under local conditions. The livelihood framework described here is a three dimensional intervention strategy, rather simple and straight forward, namely developing human capital, creating access to physical capital and wider social acceptance of those affected with HIV. Many other components having a bearing on the livelihood function could be brought under these three heads. For example financial and social capital could be considered as a part of the physical capital and social acceptance respectively. Since, nearly 60 percent of those affected with HIV/AIDS probably live in the villages, it has serious adverse implications on the rural economy. Poverty, migration and limited access to health care are among the major factors render rural India more susceptible to the spread of this virus. The most vulnerable people in the rural area are the migrant workers. Migration often becomes inevitable as many rural households compelled to depend upon off-farm sources of income in nearby areas particularly during the lean agricultural seasons. Such migratory phenomenon opens up channel of flow of the infectious diseases. Providing appropriate livelihood opportunities in the rural areas for those affected with HIV/AIDS is one of the major challenges faced today. The present paper is an outcome of a study conducted in three states namely Andhra Pradesh, Tamilnadu and Maharashtra. It brings the type discrimination PLWHAs and people supporting livelihood initiatives taken by the selected NGOs in the study region.*

Introduction

PLWHAs need support systems, which provide opportunities for livelihoods in view of their decreased physical strength, community attitudes, family non-support and inadequate health infrastructure. A livelihood framework pursues multiple approaches and goals and hence one should adopt a multi-dimensional approach. The proposed framework must have the capability to address the complexity of the situation and at the same time it should be feasible under local conditions. The livelihood framework described here is a three dimensional intervention strategy, rather simple and straight forward, namely developing human capital, creating access to physical capital and wider social acceptance of those affected with HIV. Many other components having a

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bearing on the livelihood function could be brought under these three heads. For example financial and social capital could be considered as a part of the physical capital and social acceptance respectively.

Since, nearly 60 percent of those affected with HIV/AIDS probably live in the villages, it has serious adverse implications on the rural economy. Poverty, migration and limited access to health care are among the major factors render rural India more susceptible to the spread of this virus. The most vulnerable people in the rural area are the migrant workers. Migration often becomes inevitable as many rural households compelled to depend upon off-farm sources of income in nearby areas particularly during the lean agricultural seasons. Such migratory phenomenon opens up channel of flow of the infectious diseases. More importantly the mobile people have limited access to health services and consequently the prevention means becomes very little. Also the rural population is at a further disadvantage as they have little access to appropriate information about the nature of the disease and its consequences. Providing appropriate livelihood opportunities in the rural areas for those affected with HIV/AIDS is one of the major challenges faced today.

Discrimination on HIV/AIDS Patients and Their Families in the Study Region

With increase in number of HIV infections, people's attitude and behaviour towards the infected persons have been changing over a period of time, resulting in to increased social discrimination against the infected persons as well as other family members of the households. The observations on discriminations against HIV/AIDS are under

Discrimination at Family Level

As the health condition of the diseased was deteriorating over a period of time, both medical and physical assistance had been required. The physical assistance from the household members for a longer period lead to fear of possible infection among other family members and hence resulted in the discrimination against the persons living with HIV/AIDS even by their spouses and other family members.

It had been observed that in some households separate room, bed and eating utensils had been arranged for the persons living with HIV/AIDS. It was also observed that in few households, the women proposed for divorce from their husbands, infected with HIV/AIDS and in some cases they get separated from their husband also. In some cases, it has also been found that some women have shifted their place of residence along with their children within the village, however a few such women were shifted to their parents.

Discrimination at Societal Level

The HIV/AIDS infected persons were reported to often face the adverse comments of the villagers. The infected persons had to face the social boycott by their co-workers at their work places due to the perception prevailing in the society that HIV/AIDS occurred only because of multiple heterosexual relationships.

As most of the infected persons were the cultivators and have to work along with other workers, their co-workers used to pass comment in filthy languages. In some cases, it has also been reported that the villagers did not allow the infected persons and their family members to participate in social activities at village and community level viz; marriages, other ritual and cultural programmes. Politically strong and rich HIV cases are not getting much discrimination from the society as compare with the ordinary affected people. The discrimination at the health

care centres was often reported by other patients both to the infected persons and to their family members.

Discrimination in Marriage
It was observed that the impact of HIV/AIDS on marriage for girls was profound and significant. No one is coming forward to marry the girls of the HIV/AIDS households, including close relatives and friends of those particular households, due to fear of infection. However, in case of gents there is no much problem for marriage.

Discrimination against the Family Members
In many households it has observed that the infection of one of the household member led to the discrimination against all the household members even if they were not infected with HIV. The discrimination against the elderly persons also exists in the society due to HIV/AIDS. The discrimination due to HIV/AIDS death to a woman both in the family and in the community is revealing the extent of discrimination how it led to a lower status of the dependents in the family.

Discrimination Out of Hostility
The discrimination due to HIV/AIDS is leading to unfriendliness among some families. The close friendly ties are became slacken and disappearing over the period of time and the future of the children are become question. The death of a couple due to HIV/AIDS is resulted into the insecurity among the elderly members in both houses.

Discrimination by Parents
The discrimination made by the parents towards died persons is also visible in some areas. In a household the parents of died person denied to give interview first. In that household only two elderly members mother and father of died person are there and they were not at all interested to give the information about their son. The aged man said "Though my son died we are not feeling bad because he died due to AIDS, the dirty disease, because of that fellow we lost our prestige and reputation among our relatives and society. Let that fellow died no need to talk about him now. It is good that he died and now we are peaceful and we are feeling shame as his parents". This old man is also thinking that AIDS is the infection occurred only through the multiple heterosexual relations in which risk behaviour his son was involved.

Discrimination against Children
Another woman of aged 55 years narrated her experience as "my son married a prostitute, all the people used to pass comments and treated him as worthless. Because of his deed, we did not allow him to stay in the house and we felt that our prestige and social status of the house has gone down and we forced them to stay in other house. He was a driver and died two years before and after that other people started commenting our grandson and questioning in regards to his birth. But now we the aged people are not getting any support from any body in the village. Now the child is with us and we are providing him the education and other support, because no body is helping forward to help that poor boy as he born to a prostitute and his father died due to HIV/AIDS. We are treating the boy as our grandson. Some neighbours and other children are commenting the boy unnecessarily.

Discrimination against Females

The discrimination against a woman in rural area leads the women into a state of psychological depression. The unnecessary verbal abuse from the relatives, friends and from villagers was found common. By facing all these type of verbal abuses sometimes leads a strong psychological depression of the women and sometimes it results into commit suicide.

NGOs and Their Activities for PLWHA in the Study Regions

It is now serious issues to consider in protecting the affected people through appropriate rehabilitation measures in sustainable manner. It is true that in study regions of Andhra Pradesh, Tamilnadu and Maharashtra, all the selected NGOs and CBOs have initiated livelihood strategies to strengthen the economic conditions of poor PLWHAs family. But, those are temporary arrangements for taking care of subsistence of the families. Some of the important initiatives are

- HIV and AIDS people were organized into groups to share their personal feelings and coping strategies at the village level.
- Some of the groups were registered under society registration act to work and fight for their social and economical rights.
- Positive networks were created at cluster level; district level and state level, majority of the positive members were joined in this network. These organizations are taking activities like counseling, motivating for health care and support, also tries to unite people with marriage of mutual understanding. They are also working in protection of PLWHAs from social evils prevailing in the society.

Action for Integrated Rural and Tribal Development Social Service Society (AIRTDS)

Andhra Pradesh

Informal Foster Care of orphans and vulnerable children by placing them in an unrelated family in the neighborhood is a community initiative led by AIRTDS, Andhra Pradesh, India. An effective community based foster care not only absorbs the orphans in the locality but also encourages the community to widen the support base for foster case.

Blended Approaches

This approach involves placing the vulnerable children in hostels to avail themselves of basic amenities such as food, clothing and shelter in a residential surrounding and also extending educational support wherever available. Secondly, it permits the children to experience and enjoy a family environment by visiting their single parent or relatives (either uncles or grannies) periodically or whenever possible. Within the VMM network, St. Paul's Trust is implementing this approach. These institutions are hostel providing residential care:

- The aim of these hostels is to give the triple dimension of the teacher, the taught and the parent (wardens, matrons in place of the parents) and to promote and level up the children's education on par with other children
- The hostels function for 10-12 months in a year and even further in the summer for implementing various vocational schemes.
- There is uniform time schedule for all these hostels for the day to day program of academic routine and there is uniform menu for all the boarders. The boarders are also provided with facilities like soaps, hair oil, text books, note books, bedding material, trunk boxes plates and glasses etc. free of cost.

At the time of admission at the hostels and at the beginning of every year, the family members pay a very nominal amount for registration of the children and their continuance.

The children can stay at the hostel still the completion of their secondary school. They stay 10 months of an academic year at the hostel, and during holidays (i.e) for 2 months, children spend with their parents/relatives. These arrangements continue till the end of the children's high school education (i.e) 10 years. If a child joins in the first class, it can continue till 10^{th} class (i.e) 10 years.

Granny Approach

With an increasing HIV prevalence rate, the current challenge for India is to look into the possible caregivers for the children of PLHA and orphans. Currently grandmothers are seen to be playing a primary care giving role for these children. The emotional bond between the grannies and their grandchildren make them largely mutually dependent and supportive. Vasavya Mahila Mandali (VMM), Vijayawada has supported grannies to provide care for vulnerable children. However, due to age factors, the grannies experience difficulties in caring the children such as the children not listening to them, overburden of domestic work due to the children, and no system to help them to ventilate their feelings and sharing their emotions.

VMM has supported them whenever possible with income generation and educational support to their grand children's schools fees, uniforms, books and notebooks. Needy children are also provided with nutritional supplements and periodic health checks. As a model to support these grannies, VMM has initiated grannies club to help these grandparents ventilate their feelings and emotions with fellow members. Their problems appear small when they listen to others' experiences. One granny is consoling the other; the peer based emotional support generates a positive attitude among grannies to intensify their care to their grandchildren.

Extended Family Approach

Extended families are the families who are either paternal or maternal uncle families to the child. Sometimes they may be distant relatives to the child but residing in the neighborhood. They take care of the child or the single parent along with the child or children when they become orphaned due to the death of the father or both parents. They become natural guardians and provide primary care. Under the current program, extended families are provided support with income generating activities to improve the living conditions of the extended family, to provide supplementary nutrition, referrals, and medicines and follow up and to help the children of PLHA/child orphans to continue their education. Though care by extended family is very common, the family is in need of specific support to provide quality care. The extended families are widely supported by two partners: SHADOWS, Chirala and Mahila Mandali, Chirala.

Foster Care Approach

Informal foster care is placing orphan children under care in unrelated families in the same neighborhood. It provides a continuity of care in a family and community setting and provides a natural, personal and loving environment in which the children can develop. AIRTDS is implementing this approach in Tenali, Guntur district, Andhra Pradesh and currently has 20 orphans in 10 foster families.

A child orphan is defined under the program as those children aged 3-15 years who have lost either of their parents or both and the relatives do not have capacity / willingness to take care of children. The children are identified through other PLHA and their family members. The

children are also identified through regular field visits by the AIRTDS staff. The selection is done through three stages of consultations. First is the Consultation at the AIRTDS with PLHA families and potential foster families. At the community level, local HIV positive network members, women groups and community leaders are consulted; At the foster family, all eligible members are consulted. Based on a review of these consultations and concurrence with board members the AIRTDS project director finalizes the selection of the foster mother.

Foster mothers are selected by AIRTDS who are older mothers who have been settled for a long time in the locality and who have demonstrated a passion for service and interest in devoting their time to looking after the orphan children. They are also trained in caring for the orphans.

The essential services provided under the foster care program are:

- Distribution of groceries / provisions worth Rs. 500/-. per child /month
- Health referrals of children for treatment of sickness and for HIV test in case of prolonged illness.
- Support for Education – School uniform, books, school fees
- Psychosocial support for children and foster parents and this counseling is done by AIRTDS staff.
- Nutrition – education on nutrition food and demonstration for preparing least cost locally prep arable nutritious food.
- Training on child care, emergency care and child rights etc.

Human Action for Rural Development (HARD), Andhra Pradesh

Since 1990, hard has organized various training programmes and awareness building programmes for the communities. The following table indicates some of the activities. In the process HARD identified 48 HIV positives that are willing to take up livelihood options.36 cases are supported by hard in the following mode:

S. No	Name of the unit	No. Of units	Unit cost (in Rs)	Net income per day
1	Diary units	15	5000	40
2	Pan shops	5	3000 to 8000	50
3	Tea shop	3	5000 to 7500	40
4	Vegetable shop	5	2000 to 2500	25
5	Iron scrap	2	3500	50
6	Provision shop	3	5000	50
7	Cool drink shop	1	7500	65

Astha Health Counseling & Help Line Center (Maharastra)

Astha Health Counseling & Help Line Center has been promoted to support the People Living with HIV/AIDS (PLHA) with grant assistance from Avert Society, Mumbai since June 2003. The income generation activities are also promoted to provide self-employment to the PLHA and HIV affected people.

The achievement of the Home Based Care Project (Center) is stated below

Sl. No.	Details of Achievement / work done	Nos.
1	No. of PLHA reached	591
2	No. of HIV infected & affected children reached	131
3	Nos. of PLHA whom Referral services provided	776
4	Counseling Sessions conducted at the Center	678
5	Counseling Sessions conducted at the field villages	2028
6	No. of Home Visits paid by Astha Staff (ORWs & others)	2326
7	No. of PLHA benefited through Vocational Training & jobs	26
8	No. of Support Groups Promoted	05
9	No. of PLHA Self Help Groups Promoted	05
10	No. of Awareness Programs attended	61
11	No. of Capacity Building Programs for PLHA conducted	11
12	No. of PLHA study tours / picnics conducted	03
13	No. of PLHA marriages organized	02
14	No. of children admitted to schools & free hostels	05
15	No. of PLHA NGOs Registered	01
16	No. of PLHA benefited through Government Schemes	41

Yerala Project Society (YPS) Maharastra

Yerla project society is a reputed NGO, working in Sangali district of Maharshtra. It has been implementing many appreciable strategies and programmes for the welfare of the downtrodden community in the district. It also works with special programmes for HIV/AIDS affected people in the region. In collaboration with AVERT society, an establishment of Maharashtra Government for special purpose on implementing and coordinating programmes of HIV/AIDS in Maharashtra, implementing good number of programmes. Along with many campaign, care and support programmes it implements many programmes on income generation for PLWHAs families. Livelihood activities of YPS are given under .

Supply of Goat Units

Majority of the rural families are having small holdings of rain-fed land, they have adequate basic skills of maintaining animal husbandry and having adequate grazing land. YPS has given two parent goats of male and female as a seed asset to start the goat unit on free at the initial stage. The beneficiaries were also given financial assistance of Rs. 1000 to Rs. 2000 as loan without interest to each family. After two years, the beneficiaries have to give back young male and female goats back to YPS, this in turn for supply to another family. They also conducted training camps on scientific rearing of animals.

Same as like of goat unit, YPS also gives one buffalo to poor HIV family as livelihood activity either amount worth of buffalo or the animal has to be given back to the society.

Supply of Poultry Units

The same strategy as above activity also as a rotational supply of income generating activity. In this, first each family has given 50 birds to raise poultry unit. The matured birds would taken by the society for its marketing. The amount of birds cost supplied by the YPS will be deducted on every batch of selling of grown birds.

Sub-Soil Irrigation Development

In order to increase the income of the poor dry land farmers in their service regions YPS has developed and trained the farmers in sub-soil irrigation based cultivation practices. The area which getting low rainfall and command areas were given attention. Even though, it is common for all farmers, focus was given on HIV/AIDS affected families. Through this scientific irrigation project, the farmers are able to do cultivation of cash crops, short and long duration crops with available less water. Water harvesting structures were also advocated to adopt and built.

Formation of SHG and income generating Activities

SHG formation is a massive strategy of women development and empowerment under YPS activities. It formed general SHGs and encouraged to include HIV positive women as members. The SHGs were trained and built capacity on trade based skills to start group or individual production and service based activities. Majority of the trained women were started economic ventures like candle making, medicinal products making, washing powder making, grocery shop, textile shop, vegetable vending, etc. women are earning comparatively good income to run their family.

Employing in Small Scale Industry

As a new intervention, it started a small assembling and manufacturing of choke used in tube lights. Around 25 young HIV positive women were trained in assemble and manufacturing of the chokes. They are paid on piece rate, based on the performance they earn good income. The product is supplied to entire Maharashtra and Goa states.

Livelihood Strategies Implemented by NGOs in Tamil Nadu

The following NGOs are working for the PLWHA in Tamil Nadu

- Women Organisation for Rural Development (WORD), Erode
- Women Organisation for Rural Development (WORD), Namakkal
- Human Mirror Trust (HMT), Namakal
- Rural Education and Development Society (REDS) Namakkal

1. One SHG manufactures the sanitary products like phenol, brooms, brushes and cleaning clothes. These products are selling in the open market and to the NGOs and also the hospitals through District health mechanism.
2. Some people were helped financially to start individual economic activities like tailoring, spices powder manufacturing, candle making, vermicelli preparation, magi production, soap making, agar bathi (incense sticks), perfume making and selling.
3. Group activity on nutritious powder preparation and sale.
4. Tailoring and embroidery teaching.
5. Agri-oriented activities like rearing of goats and buffaloes, etc

Conclusion

Continuous support system considering vulnerability of the affected people is need of the hour. Health support system, nutritional supplement and regular flow of income and prevention and rehabilitation measures are important areas of concentration for the government or any other functional agencies working with the HIV/AIDS affected people.

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