Int. Journal of Management and Development Studies 5(2): 19-25 (2016)
ISSN (Online): 2320-0685. ISSN (Print): 2321-1423
Impact Factor: 0.715

Moulding Socially Excluded Women to Be Future Leaders through Income Generation Programmes- 4 case studies on HIV/AIDS Infected and Affected Women in Kerala

Velumani. K[1] and Joy V. K[2]

Introduction

The HIV/AIDS epidemic has been regarded as a major health concern all over the world since the late 1980s. Soon after the emergence of the AIDS epidemic, it became evident that HIV was much more than just a disease. Unlike any other disease, HIV not only touches the lives of those infected, but it also impacts the lives of virtually everyone on earth. One would be hard pressed to find any group not affected by the HIV epidemic in some way. It is clearly one of the most important public health issues.

The World Health Organization in 2013 has estimated that over 35 million globally are living with this deadly disease. The WHO also estimated that there were around 1.2 million deaths, 2 million new infections and over 39 million people living with HIV by the end of the year 2014. The HIV epidemic in India is the third largest in the world. The HIV prevalence in India was estimated at 0.3% in 2013. This number looks small, but considering India's high population, this means that around 2.1 million people are living with HIV. In the same year, 130,000 people were estimated by UNAIDS to have died from AIDS-related illnesses. But, in general, the HIV epidemic in India is diminishing, with a 19% reduction in new HIV infections, and a 38% decrease in AIDS-related deaths between 2005 and 2013.

HIV is found in the blood and the sexual fluids (Semen/Vaginal Fluid) of an infected person, and in the breast milk of an infected woman. HIV transmission occurs when a sufficient quantity of these fluids get into someone else's bloodstream.

There are various ways a person can become infected with HIV:

- **Unprotected sexual intercourse** with an infected person: Sexual intercourse without a condom carries the risk of HIV infection.
- **Contact with an infected person's blood:** If sufficient blood from somebody who has HIV enters someone else's body, then HIV can be passed on in the blood.
- **Injecting drugs:** HIV can be passed on when injecting equipment that has been used by an infected person is then used by someone else.
- **From mother to child:** HIV can be transmitted from an infected woman to her baby during pregnancy, delivery and breast feeding.

HIV/AIDS Stigma

HIV/AIDS, more than being just a medical condition, is also an acute emotional, social and economic problem, the gravity of which has not yet been fully understood. It is an emotional

[1] Professor & Director, Centre for Women Studies, Gandhigram Rural Institute.
[2] Research Scholar, Gandhigram Rural Institute.
Corresponding author: Velumani. K can be contacted at: obed_data@yahoo.in
Any remaining errors or omissions rest solely with the author(s) of this paper

problem as the infected person and the family members become compelled to live in the shadow of death. Isolation in the family, ridicule and decision from friends and relations, and setbacks in personal and professional life etc. have driven many infected person to suicide.

AIDS-related stigma and discrimination refers to prejudice, negative attitudes, abuse and maltreatment directed at people living with HIV and AIDS. The consequences of stigma and discrimination are wide-ranging: being shunned by family, peers and the wider community, poor treatment in healthcare and education settings, an erosion of rights, psychological damage, and a negative effect on the success of HIV testing and treatment.

AIDS stigma and discrimination exist worldwide, although they manifest themselves differently across countries, communities, religious groups and individuals. They occur alongside other forms of stigma and discrimination, such as racism, stigma based on physical appearance, homophobia or misogyny and can be directed towards those involved in what are considered socially unacceptable activities such as prostitution or drug use.

In India, as elsewhere, HIV/AIDS is often seen as "someone else's problem' – as something that affects people living on the outer borders of the society, whose lifestyles are considered depraved. Even as it moves into the general population, the HIV epidemic is still misunderstood among the Indian public. People living with HIV have faced violent attacks, been rejected by families, spouses and communities, been refused medical treatment, and even, in some reported cases, denied the last rites before they die (AVERT, 2015).

In a 2002 study by the International Labour Organization (ILO) on HIV related discrimination in India, 70% of HIV positive respondents claimed to have faced discrimination in one form or another. Discrimination was reported to be highest within the family context (33%), followed by health care settings (32%), neighbours (18%), and the community (9%).Approximately 6% reported discrimination at workplace. Research by International Centre for Research on Women (ICRW, 2005) found the possible consequences of HIV-related stigma to be

- Loss of Income/Livelihood
- Loss of Marriage & Childbearing options
- Poor care within the health sector
- Withdrawal of care-giving in the home
- Loss of hope & feelings of worthlessness
- Loss of reputation

Stigma not only makes it more difficult for people trying to come to terms with HIV and manage their illness on a personal level, but it also interferes with attempts to fight the HIV and AIDS epidemic as a whole. On a national level, the stigma associated with HIV can deter governments from taking fast, effective action against the epidemic, whilst on a personal level it can make individuals reluctant to access HIV testing, treatment and care

In 2008, UN Secretary-General Ban Ki Moon stated that 'Stigma remains the single most important barrier to public action. It is a main reason why too many people are afraid to see a doctor to determine whether they have the disease, or to seek treatment if so. It helps make AIDS the silent killer, because people fear the social disgrace of speaking about it, or taking easily available precautions. Stigma is a chief reason why the AIDS epidemic continues to devastate societies around the world'.

A far reaching and deep-rooted consequence of the stigma due to HIV/AIDS is the resulting phenomenon of social exclusion.

Social exclusion is a complex and multi-dimensional process. It involves the lack or denial of resources, rights, goods and services, and the inability to participate in the normal relationships and activities, available to the majority of people in a society, whether in economic, social, cultural or political arenas. It affects both the quality of life of individuals and the equity and cohesion of society as a whole (Levitas et al, 9).

The outcome of social exclusion is that affected individuals or communities are prevented from participating fully in the economic, social, and political life of the society in which they live.

Women and HIV/AIDS

Women with HIV or AIDS may be treated very differently from men in some societies where they are economically, culturally and socially disadvantaged. They are sometimes mistakenly perceived to be the main transmitters of sexually transmitted diseases (STDs). Men are more likely than women to be 'excused' for the behaviour that resulted in their infection.

HIV/AIDS is the leading cause of death among women of reproductive age. The percentage of women living with HIV and AIDS varies significantly between different regions of the world. At the end of 2009 it was estimated that out of the 33.3 million adults worldwide living with HIV/AIDS, slightly more than half are women (UNAIDS) . The AIDS epidemic has had a unique impact on women, which has been exacerbated by their role within society and their biological vulnerability to HIV infection. Generally women are at a greater risk of heterosexual transmission of HIV. Biologically women are twice more likely to become infected with HIV through unprotected heterosexual intercourse than men.

Women frequently carrying a double burden of generating income outside the home and for care giving as well as maintaining family land (Loewenson and Whiteside, 1997). In this regard, women are responsible for caring for sick members of the household, for childcare, as well as being heavily involved in generating money and supplying food for their households through agricultural production. Further, the burden of caring for people living with HIV/AIDS and for orphans falls largely on women.

In Kerala, the state which is widely considered to be the most literate in India, the moral weight associated with HIV/AIDS stigma appears to supersede concerns of infection from the disease itself, other illness and other perceived causes of infection.

The belief that immoral behaviour is the major cause of HIV infection is the critical factor that fuels HIV/AIDS stigma in Kerala. Moral judgments are often based on behaviours commonly associated with HIV/AIDS such as commercial sex, drug use, or as some participants pointed out, due to the conservative norms that prohibited the discussion of sex and sexuality with Kerala society. Women are labelled as promiscuous, as prostitutes or as disobedient to religious values, and are often considered as the spreading agent of HIV/AIDS.

Social exclusion at the individual level results in an individual's exclusion from meaningful participation in society. Thus, women who are either infected or affected by HIV/AIDS are not welcome for social and community gatherings such as marriages, or festivals. Whenever they venture out to the public for shopping, or going to work, they are discreetly avoided, or even gossiped against. Added to this is the society’s label that she is reaping just dues of her actions. Moreover, some men take advantage of the woman’s need for money, and try to take advantage of her. This, coupled together with failing health due to sickness, or the effort involved in taking care of an infected relative, often leave women unable to go for work.

The expense involved in medication, and the need to repay past debts incurred by the husband often leaves such women in dire straits, and with no option but to turn to prostitution.

It is in such a situation that income generation programmes come in handy. Having an occupation gives the feeling that there is something worth living for, and helps alleviate feelings of depression and suicidal tendencies. In addition to this, IGPs are useful to bring in a small income sufficient to meet day to day needs, and also has the promise of reaping greater benefits with proper skill and dedication.

Income Generation Programmes and Leadership

IGP- Income generation programmes are activities implemented with the intention to improve the income of families affected with HIV/AIDS. They include various trades/types like tailoring, goat rearing, agriculture, cattle rearing, small scale business like petty shop, tea shop, cloth trade, etc.

These IGPs aim at the following:

- Women empowerment through self-employment
- Regular income
- Increase in monthly income of individual as well as their family
- Improve the quality of life

Through increased participation, and consistent engagement, it was found that women benefitted greatly from this IGPs, insofar as they were able to overcome the social stigma and discrimination meted out to them, though the process of self-employment, thus gaining self-respect and acceptance, in addition to a regular monthly income. Moreover, they have stepped forward to become active leaders of women's self-help groups, thereby transforming themselves from outcasts to local leaders.

It is seen that women who are identified as HIV/AIDS Infected and Affected face numerous stigma and are socially excluded. In the context of this paper- moulding these women to be future leaders means to enable them to attain commonly defined leadership traits such as Determination and drive, which include traits such as initiative, energy, assertiveness, perseverance; Cognitive capacity including intelligence, analytical and verbal ability, behavioral flexibility, and good judgment; Self-confidence-- high self-esteem, assertiveness, emotional stability, and self-assurance.

It can be seen that the women possessed these leadership qualities as put down by Field Marshall Viscount Slim, and they used it to overcome social exclusion. Income Generation Programme helped them to mould and use these qualities. Due to constraints of space and time, these case studies are only brief narratives.

Case Study 1

Sujatha hails from Muthalamada in Palakkad district of Kerala. She was infected with HIV/AIDS through her husband, a driver. He passed away in 2009, leaving behind a 10 year old son, a 63 year old mother and a 32 year wife who was also infected. The cost of treatment for her husband, and then for herself was too much for them to bear, leaving them with heavy debts. When her husband, the sole breadwinner of the family died, she had to rise up from her misfortune, and take up the reins of her family. She was shunned by her neighbours and friends for having HIV/AIDS.

She realized that weeping about her condition would not help. Her first step to leadership was to exhibit courage and responsibility that comes with courage. She stepped out from the

confines of the society and approached Kuriakose Elias Service Society- an NGO offering services for those affected by HIV/AIDS. They offered her guidance and startup loans to begin a small Income Generation Programme. Her courage was not only moral, but her physical courage too is one that needs commendation. In spite of a body weakened by lack of immunity, she was determined to work. This is also an example of the determination and will power that leaders strongly need. A circumstance of poverty, debt, sickness and exclusion was one that would force a person of lesser will and determination to commit suicide, as is so common in Kerala.

Her judgement is also a prime example of leadership. She weighed her capabilities against her needs, and decided that Cow and Poultry Rearing were the best options she had. Her good judgement is reinforced by the fact that she was aware of how much money would be generated through this programme, how much money would be spent on expenses, and how much could be saved. She had total assets of Rs. 5000, and debts amounting to Rs 35,000. The cost of treatment for herself was Rs. 500, and that of her mother was Rs 200, in addition to expenses required to pay for daily needs like food, and for her son's education. She was also flexible enough to learn a new profession at a difficult stage in life. Her Knowledge was kept up-to-date by her increased interaction with counsellors of the IGP, who gave her proper guidance and advice.

The result was that she paid back her debt of Rs. 35,000, bought a 3.5 cent piece of land, and constructed a house for her family solely through Cow Rearing. Her hardwork and determination to succeed, plus the financial stability she has built has brought on acceptance and admiration in her locality. They no longer see her as a 'promiscuous woman who got HIV/AIDS through a bad life', but as a role model.

Her leadership was not confined within her family. She confidently stepped out into the society, and moreover, used her free time to her other similarly affected women to come out of their shells. At present, she is the Secretary of Sneha Kripa, a women empowerment society.

Case Study 2

Mini comes from Nenmara in Palakkad district of Kerala. She was infected with HIV/AIDS through her husband. But when he came to know about this condition, they got separated, with him blaming her for not being faithful and of having given him this disease. The shock of this disease, combined with her husband's accusation of infidelity and ultimate breakdown of their family, and the burden of caring for her aged mother, 75 years old, made her depressed, and without hope. She moved to her brother's house, but again, the knowledge that she had to depend on other's kindness to live made her seek out alternatives to succeed.

The first step that she took was one of desperate courage. Fed up with having to depend on the patronizing attitude of the society, she wanted to know how she could use the skills she already had to better use. Consequently, she decided to use her judgment to leave the rolled-gold shop where she was currently working, and to use her tailoring skills to start out on her own. This judgment was one of calculated risk, since her job at the rolled-gold shop offered her a steady, though small income. This is also proof of her flexibility, since she had to learn a new skill.

Her next step was one of will and determination. She set a target of stitching at least 60 shirts per month, with expected income of Rs 20,000. Even though she was suffering from HIV/AIDS, and working long hours would be tiring, she held fast to her goal of achieving her target.

Her tailoring shop, interaction with people, and increased income gave her confidence to step out and start helping other women. She donned the role of President of a Society named, *Karunyadeepam*, which helps around 100 HIV/AIDS infected and affected women to face life head-on.

Case Study 3

Prema hails from Pallassena, Palakkad. She was infected with HIV/AIDS through her husband, a driver. With a 19 year old daughter who was pursuing her undergraduate degree, and a 16 year old son who was studying in class 11, in addition to her aged parents who were living with her, Mini had no time to spend in depression and disappointment.

Having a grown up daughter and a teenage son who were aware of their mother's HIV/AIDS condition was difficult. Knowing about her condition would affect future marriage prospects for her daughter.

But her courage in stepping out and taking the role of the leader of her family was immense. She risked mockery. She knew that the burden of her family rested on her shoulders. At first she began working as a coolie, a daily wage labourer, even though her body was weak with disease. She enrolled in the Income Generation Programme to learn Goat Rearing. Learning a new trade in the middle years of life is tough, but this speaks about her determination and flexibility.

Prema started to apply the knowledge she gained though classes on goat rearing to practical use. She bought goats for Rs. 15,000, and went to work. In four years she repaid her debt of Rs. 2 Lakhs, successfully had her daughter married at a good wedding, paid for her son's higher education and had a thriving business.

She began to take interest in the upliftment of other women too. She took up the role of the executive cum treasurer of the society, *Snehakripa*. She also started to work with the Panchayath members for the upliftment of other women in the locality.

Case Study4

Omana comes from Mundur, Palakkad. She was infected with HIV/AIDS from her husband in 2005. He died in 2011. The cost of treatment for both herself and her husband drained their finances. As a widow and mother and patient she had to struggle a lot to repay her debts, take care of her children's' education, and take care of her ailing father who was 88 years old.

Her desperate situation gave her courage. The period from 2005 to 2011- from when she was diagnosed with HIV/AIDS to the death of her husband was the training time to develop her courage and determination. The burden of her family was now on her shoulders. She stepped forward bravely to face it.

Six years of suffering from HIV/AIDS did not daunt her. In spite of her weakness and ill health, she took up Goat Rearing. She was able to repay her debts of Rs. 5 lakh, and also pay for her sons' education, and take care of her aged father.

She had a small income from Candle Making. She was flexible enough to learn the new skill of goat rearing to supplement her income. She bought goats for Rs. 18,000, and started with monthly savings of Rs 1000.

After rebuilding her family's future, she stepped out to help rebuild other families who were affected with HIV/AIDS. She became a volunteer of *Swapnam Palakkad*, a society which fights for the rights of PLHIV's and downtrodden, and actively helps other women to face life.

Conclusion

These examples are just to show that leaders are common men and women who possess the qualities of Courage, Will Power and Determination, Judgment, Flexibility and Knowledge. The pathetic state from which these four women rose to become local leaders can inspire ordinary people to believe that nothing is impossible. Everyone is a leader. It only remains for circumstances to bring out true leaders. Not every famous sport person or politician is a leader, but leaders are those people who can inspire others.

References

"Fact Sheet: Global Statistics." UNAIDS. UNAIDS. 2014. Web. 23 Nov 2015.

"HIV/AIDS: Data and Statistics." WHO. World Health Organization. N.d. Web. 23 Nov 2015.

"UNAIDS Report on the Global AIDS Epidemic 2010." UNAIDS Global Report 2010. UNAIDS. Web. 02 Dec 2015.

Ki-Moon, Ban. "The Stigma Factor; Biggest Hurdle to Combat HIV/AIDS." The Washington Times (Washington, DC). 6 Aug. 2008. Web. 26 Nov 2015.

Levitas, R., Pantazis, C., Fahmy, E., Gordon, D., Lloyd, E. and Patsios, D. *The Multi-dimensional Analysis of Social Exclusion*, London, Department for Communities and Local Government (DCLG). 2007. Print.

Loewenson,R and Whiteside, A. *Social and Economic Issues of HIV/AIDS in Southern Africa* Harare, Southern Africa AIDS Information Dissemination Service (SAfAIDS), 1997

Ogden, Jessica, and Laura Nyblade. ICRW/ Common at Its Core: HIV-Related Stigma Across Contexts. Rep. International Center for Research on Women, 2005. Web. 26 Nov 2015.