Empowerment of Women Living with HIV/AIDS in Association with Self-Help Group – A study in Uttar Dinajpur district of West Bengal

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Abstract:

Over the years, there has been growing evidence of continuous narrowing gender gap in new HIV infections. The relationship between women's empowerment and contracting HIV infections has been accepted worldwide. It may be primarily due to poor status of women, lack of control over sexuality and poor reproductive and sexual rights among women. In India Self-Help Groups (SHGs) or 'Support Group' is conceived as a strategy to bring together women from socially under privileged section of the society and empower them with information and opportunities for economic securities., empowering People living with HIV(PLHA) and in reduction the risk & vulnerability to STI/HIV. Integrated intervention approaches are proving to be effective when financially sustainable platforms such as microfinance are coupled with non-financial services, such as non-formal education, health linkages, and health services. HIV disproportionately affects women because of their unequal cultural, social and economic status in society. This paper studies the role of SHG or support group as structural intervention strategies in empowering PLHA in addition to improving the key HIV program outcomes, including, but not limited to, awareness, access to HIV/STI testing, treatment services and condom usage. The likelihood of utilizing HIV services including, knowledge on HIV/AIDS and its mode of transmission (94%), accessed drop-in Centre (97%), heard about joint health camps (26%), Received counselling on STI, HIV, condom use and safe sex practices from different sources (94%) and heard of ART (85%) were higher among PLHA associated with SHG in comparison to PLHA not associated with SHG. With their indispensable and influential role, the SHGs have proved to be a blessing in the lives of the PLHA of Uttar Dinajpur. It has been manifested that when a single woman fails to fight, the whole group will stand and fight for her.

Keywords: PLHA, SHGs, Women Movement

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1. INTRODUCTION

Women Empowerment basically refers to the creation of an environment where women can make independent decisions on their personal development which leads them to have equal rights in community, society and workplaces[3]. Women in India remained within the four walls of their household where they totally depended on their counterparts for a long time. After extensive struggle women has been delivered the property rights, voting rights, equality in civil rights before the law in matters of marriage and employment[4].According to Human Development Report in 2015, India ranks 130th out of 188 countries on gender inequality index and 108th out of 145 countries on gender gap index according to World Economic Forum in 2015[5],[6].

Women not only are kept aloof from economic opportunities but are denied of access to health care services in many parts of the country. The vulnerability of women can be attributed to a socio-economic and cultural context of India. Women are always susceptible and, therefore, lack awareness in various fields including health which has resulted in the growth of women suffering from HIV. According to India HIV estimations 2015, National adult (15–49 years) HIV prevalence is estimated at 0.26% (0.22%–0.32%) in 2015[7]. Further, the prevalence in 2015 among males is estimated at 0.30% and among females is estimated at 0.22% in comparison to 2007 which estimated 0.40 among males and 0.26 among females. There is a clear decline in the infections nationally but the gender gap is found narrowing in new HIV infections. Data also reveals that women continue to account for more than 40% of people living with HIV infection in the country[8]. Current literature indicates that economic insecurity of women and their dependence on men increase their vulnerability to HIV by limiting their agency to negotiate the conditions for safer sex.

Self-Help Groups (SHGs) in India, (wherever also known as 'Support Group') is conceived as a strategy to bring together women from socially under privileged section of the society and empower them with information and opportunities for economic securities. SHGs comprise of members who share the same local context, life situation or crisis. Members provide emotional support to one another, learn new ways to cope, discover strategies for improving the well-being of their children, and overall help other members while helping themselves. SHG members who share common shame and stigma can come together, without judging, or to provide an "instant identity" and community; combat together. Through participation, they can enhance their social skills and promote their social rehabilitation. Over a period, this strategy has proved to be successful, and HIV program has leveraged SHG, for reaching out to the women in general population and this has been extended to[9] People Living with HIV/AIDS (PLHAs) for ensuring favourable HIV program outcomes.

In developing countries, the studies emphasize the importance of SHGs in empowering People living with HIV (PLHA) and in reduction the risk & vulnerability to STI/HIV [10].The additional benefit is that such group can play an important role in addressing HIV prevention

[3] Chamar V (2015) Short Essay on Gender Inequality. Social Issues in India.

[4] Mondal P. Essay on Women Empowerment in India. Young Article Library.

[5] http://hdr.undp.org/en/composite/GII

[6] http://reports.weforum.org/global-gender-gap-report-2015

[7] India HIV Estimations. Technical Report 2015. NACO and NIMS.

[8] http://health.economictimes.indiatimes.com/

[9] Kerrigan, D.L., Fonner, V.A., Stromdahl, S. and Kennedy, C.E. (2013) Community Empowerment among Female Sex Workers Is An Effective HIV Prevention Intervention: A Systematic Review of the Peer-Reviewed Evidence from Low-and Middle-Income Countries. AIDS and Behavior , 17, 1926-1940.

[10] Yadav, D., Ramanathan, S., Goswami, P., Ramakrishnan, L., Saggurti, N., Sen, S., et al .(2013) Role of Community Group Exposure in Reducing Sexually Transmitted Infection- Related Risk among Female Sex Workers in India.

behaviours such as safe sex practices, HIV status disclosure and condom use to decrease the spread of the disease. Literature suggests that developing countries may continue to establish similar kind of groups as one of the structural intervention approaches to combat HIV/AIDS. Integrated intervention approaches are proving to be effective when financially sustainable platforms such as microfinance are coupled with non-financial services, such as non-formal education, health linkages, and health services. Literature on the role of SHGs in generating awareness and exposure to HIV/AIDS prevention interventions among PLHA in developing country like India is limited, with focus on community mobilization, social capital and social support[11].

This paper analyses the role of SHG or support group as a structural intervention strategies in empowering PLHA in addition to improving the key HIV program outcomes, including, but not limited to, awareness, access to HIV/STI testing, treatment services and condom usage.

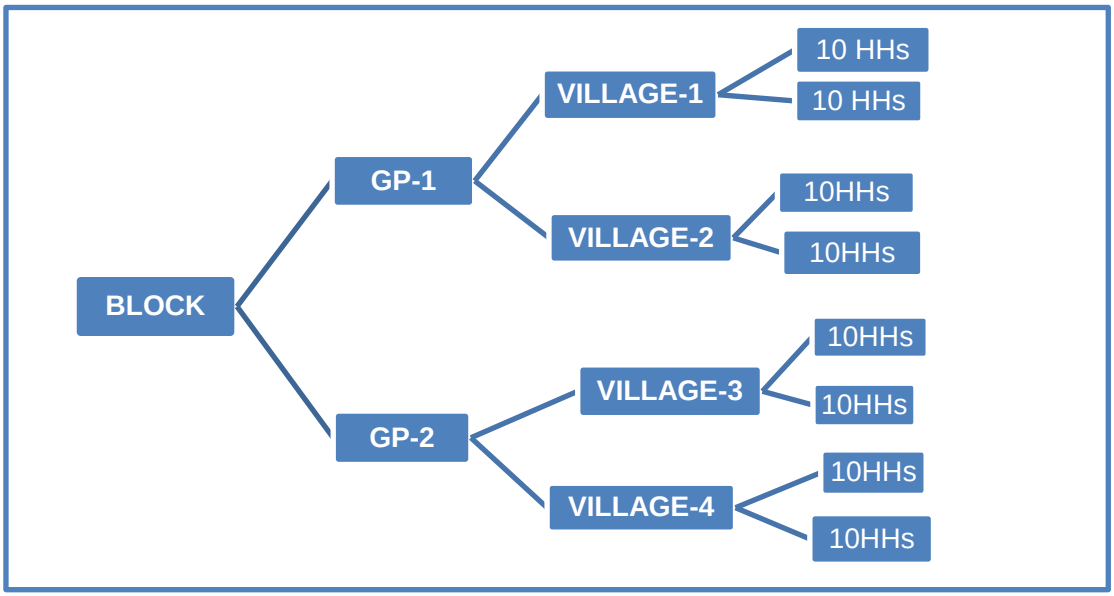
2. METHODOLOGY

Research design:

The study is exploratory and descriptive in nature through use of qualitative in depth techniques, in which vulnerability of PLHIVs and their experiences in coping with such vulnerabilities in association with SHG or Support groups are analysed.

Study location and Participants:

West Bengal is a low prevalence state but some districts have reported higher prevalence and therefore it is designated as 'A' category district. On the basis of data available to support the above statement, *Uttar Dinajpur* district among 'A' category districts is more vulnerable to HIV. High levels of migration, Extreme Poverty, poor social status of women to low literacy levels, trafficking, huge number of child labour, and unawareness of the community on health related issues, make the district vulnerable to HIV/AIDS.



[11] Kalichman, S., Rompa, D. and Cage, M. (2005) Group Intervention to Reduce HIV Transmission Risk Behavior among Persons Living With HIV/AIDS.

A total number of 80 households were randomly selected, out of which 40were associated with SHGs and another 40 were non - associated with SHGs. The total sufferers among these selected households were 256. Out of which Male and Female population was 55 and 69 respectively (all are infected).The suffered population also includes children's among which Boys were 69 (infected-53) And girl were 63(infected-51).

Data Collection Tools:

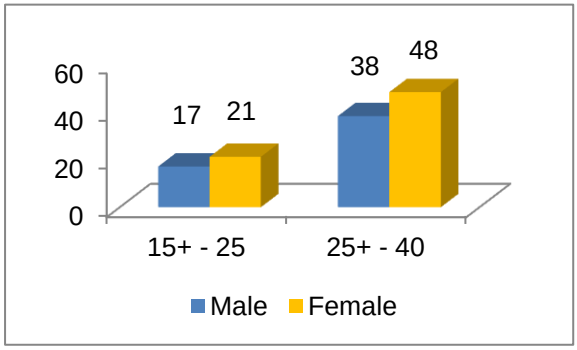
Both quantitative and qualitative data was collected for the study. The data was collected through primary sources using a semi structured interview schedule with key informants and focus group discussion guide with PLHIVs.

Experiences of the PLHA associated with SHG and not associated with SHG.

- Relevance and advantages/disadvantages of the association;
- Benefits of the association with SHG and satisfaction/dissatisfaction with the same;
- HIV Sensitive Social Protection;
- Facilitating factors and barriers in while associate with SHG;
- Strategy of mainstreaming.

3. Discussion:

➢ Socio-Economic Conditions of Selected Households:



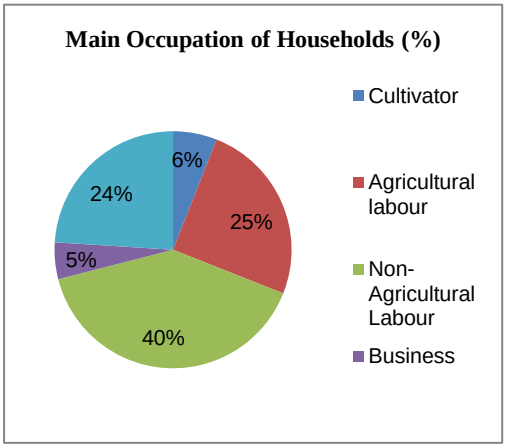
The age group of sufferers mainly belong to working population both for male and female. The main earner of the households was infected with the HIV virus. The study states that the female population was higher than male in surveyed area because most of the male member of HHs was expired due to this virus.

Mainly Unprotected Sexual Intercourse was responsible for HIV transmission both for male and female in the study area. Table 1 reflects other mode of transmission of the virus.

Table-1: Mode of Transmission of HIV Virus

Mode of Transmission	Male	Female	Children
Unprotected Sexual Intercourse	41	59	0
Use of non-sterile syringes & Needles	8	6	0
Untested Blood Transfusion	6	4	6
From HIV+ Mother to child	0	0	98

Source: primary data



Most of the male members migrated out to other places in search of better earning. Reason behind that was lack of job opportunity in the district for unskilled labour. The left behind women of that migrated out male population sometime work as Female sex worker locally to earn extra money due to isolation from in-laws house, support from neighbours and also for some economical sustenance. As a result they are more exposed to the virus and thus became more vulnerable.

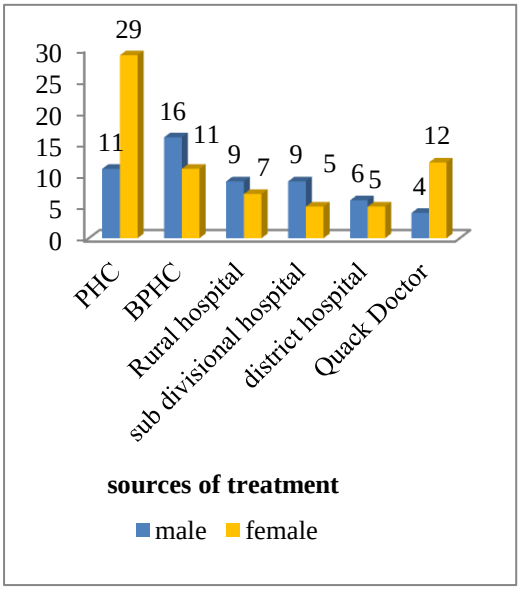
Source: Primary data

- ***Women's Vulnerability to HIV/AIDS in Uttar Dinajpur:***

> *'The voice of women, particularly poor women, will never be heard unless and until they are empowered financially and their capacities increased to a level where they can be able to make informed choices based on high quality skills and knowledge.'*- Mary Mathenge, General Manager, National Cooperative Housing Union, Kenya.[12]

HIV disproportionately affects women and adolescent girls because of their unequal cultural, social and economic status in society.

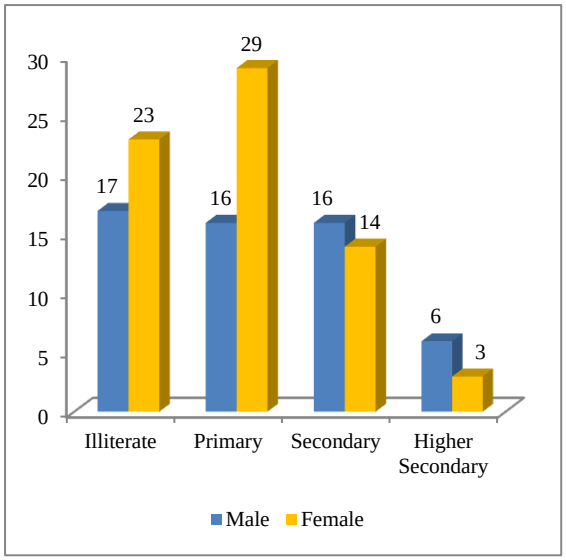
- **Lack of access to healthcare services**



Women face significant barriers to accessing healthcare services. Female are less accessible to higher tier of health system. These barriers occur at the individual, interpersonal, community and societal levels. Barriers take many forms including denial of access to services that only women require, discrimination from service providers and poor quality services. Various factors can act as barriers to women adhering to ART including a lack of accurate information about the use of ARVs. Misunderstandings about treatment have been linked to poor adherence and loss to follow-up, increasing the chances of drug resistance and treatment failure.

[12] Mary Mathenge, presentation, The Health, Gender and HIV/AIDS: cooperative Cares Seminar, ICA Oslo, August 2003, http://www.coop.org/gender/seminars/2003-oslo-nachu.pdf

- **Lack of access to education and information**



Lower literacy levels among women limit access to HIV/AIDS information. Poorer and less-educated women may be less knowledgeable about risks and therefore less able to adopt HIV risk-reducing behaviours. Many women have poor understanding of their own bodies, mechanisms of HIV/STD transmission and their level of risk in unprotected sex. Women hear about HIV/STD and infrequently have little or incomplete information about transmission. Poverty is an overarching factor that increases vulnerability to, and the impact of, HIV. The poorest women may have little choice but to adopt behaviours that put them at risk of infection, including transactional and intergenerational sex, earlier marriage, and relationships that expose them to violence and abuse.

Table 2 depicts the symptoms which the sufferers could identify before they came to know about the infection by which they get infected. Most of the male population were able to identify the symptoms as compared to female population. Female have poor understanding about their health conditions as they found the symptoms as normal illness and thus ignored the suffering.

Table-2: Health condition of sufferers

Major illness	**Male**	**Female**
Recurring fever	47	42
Body rash	38	35
Sore throat	38	22
Severe headaches	42	47
Persistent diarrhoea	47	53
Rapid weight loss	29	38
Fatigue	47	42
Vomiting	42	45
Vaginal Infection	-	42

3.2 *Role of SHGs as coping mechanism to various vulnerabilities of the women infected by HIV:*

Self-help groups (SHGs) not only play a hastening role in the life of women infected by HIV in Uttar Dinajpur but also have a role in their economic development. The self-help groups have achieved fair success in reducing women's vulnerability in all streams be it in reducing poverty, to induce education or to socially uplift their position. The HIV

infected women who face many problems coped with problems and empowered themselves by getting involved with self-help groups.

The SHGs have moulded the lives of these women for their beneficence. They have empowered the women from within by creating conditions to facilitate the real development. SHGs have been capacitated enough to make the women capable of addressing their vulnerability towards HIV/AIDS and protecting themselves from any form of harassment. SHGs are also working on enhancing women's awareness to STI and HIV/AIDS related issues with the active support of Peer Educators and Out Reached Workers of on-going projects run by local NGO's. Focus group discussions (FGDs) with SHG members have encouraged the community to visit the clinics for their STI/HIV related problems. This has facilitated early diagnosis and treatment of STI/HIV. SHGs have also capacitated women for seeking treatment for themselves and their children and have also developed linkages with the health care providers at these clinics and encourage their members to visit the clinics for the utilization of available services. The infected women are now able to address their vulnerability to HIV/AIDS and have started protecting themselves. Self-help groups are emerging as a positive approach to promoting women's empowerment, allowing he infected women to raise their voices against HIV, stigma and discrimination and violence.

The SHGs have made a significant change in the mind-set of these women, simply by empowering them and making them understand their vulnerability to STI/HIV. The women impart the knowledge of various STIs and HIV/AIDS to their husband and also sometimes ask them to abstain from sex in their work places or to use condoms when they are engaged in sex with female sex workers. Promoting more open dialogue and communications between spouses can also empower women and lead to more equitable conjugal relationships and engaging in less risky sexual behaviours.

SHGs are being considered as a community based resource for dealing with various community based issues and conflicts, especially those relating to women. SHGs also have impacted their social position and reduced the social harassments which used to occur daily in their life. Among the infected women, the cases of torture by in-laws, harassment by neighbours and others have been reduced significantly, and women's capacity to deal with their problems has increased manifold. The left behind women used to face severe opposition and restriction from family and society and were not allowed to go to the market or any other places, as their husbands were working elsewhere and not staying with them.

SHGs have enhanced their participation in decision making and also their mobility to the market, health facilities, and other nearby areas. The stigma associated with the mobility of infected women has been eliminated. They now interact freely with anybody meeting them and do not accept the norms to cover the faces in front of strangers and visitors.

The SHGs have also helped these infected women in financial crisis. Several women beneficiaries reported that with the active support of SHGs, they are able to take loans or arrange money from other sources with a minimum rate of interest.

Previously, the local administration did not address the problems of infected women and often they were deprived of governmental facilities since there was no spousal support or isolated from family. But after becoming members of SHGs, they are now conscious of their rights and are capable of negotiating their rights with local elected bodies and government officials. Another area where SHGs have contributed is to curtail the number

of marriages of minor girls, which has been a major cause of women's vulnerabilities to trafficking, sexual exploitation, and HIV/AIDS infections. They have made the women understand the risks that are associated with early marriage.

Part of SHGs success among the infected women has been possible through establishing linkages with existing public and/or private service providers to strengthen the referral system for them.

Following table presents the result of different indicators of program exposure and awareness among PLHA associated with SHG and not associated with SHG. The PLHA associated with SHG were significantly having higher knowledge on modes of HIV transmission, higher percentage of them have accessed Drop-in-Centre (DIC), and high percentage of them found to be aware about Joint Health Camp (JHC) and Anti- retroviral Therapy (ART).

Table 3: Responses of Households associated and non – Associated with SHGs

Services for PLHA	Associated with Self-help group (no. of HHs)	Non – associated with Non self-help group (No. of HHs)
Knowledge on HIV/AIDS and its mode of Transmission	36	22
Knowledge on modes of prevention of HIV/AIDS	34	19
Contacted by outreach worker to provide STI/HIV/AIDS information	32	20
Received condom from NGO	39	29
Accessed drop in centre	34	24
Knowledge about HIV testing Centre	40	23
Received counselling from a NGO/ICTC on STI, HIV, condom use and safe sex practices	35	23
Accessed NGO Clinic/ doctor for routine medical check-up and counselling for STIs	27	17
Heard about Joint Health Camp (JHC)	26	13
Have you accessed any services from JHC in last 12 months	25	13
Have you heard of ART	30	17
Insist on Condom Use	30	19

Source: Primary data

PLHA associated with SHGs had increasingly heard about health camps, accessed DIC, and heard of Anti-Retroviral Therapy (ART) in significant numbers. While indicators, like knowledge on modes of transmission, received condom, contact by outreach worker and received counselling showing programmatic difference between PLHA associated with SHGs and not associated, but found statistically insignificant. This difference could be due to the long existence of HIV prevention program in Uttar Dinajpur, which was able to reach across the spectrum of PLHA, but information on services like ART has not reached due to limited focus of HIV prevention interventions. Hence, it is suggested, CBOs or NGOs working in Uttar Dinajpur should strengthen providing information on HIV treatment services, irrespective of their association with SHGs.

4. CONCLUSION AND RECOMMENDATION

In a nutshell, it can be said PLHAs vulnerability to STI/HIV has reduced significantly due to increased knowledge, capacity building and negotiating skills for condom use. Existing interventions in the area have been focusing on health-seeking behaviour in a larger context rather than HIV/AIDS services, especially among PLHA and also providing essential services to PLHIV. That is why women's participation in the program and association with SHGs has increased significantly and has been visible during interaction with the impact population.

From reducing the PLHAs vulnerability to looking after their financial crisis, from helping them to exercise their rights in local administrative bodies to imparting knowledge of HIV/AIDS vulnerability to their husbands, SHGs have achieved a fair success. The women are now not any more 'Left Behind' in their lives. They have proceeded towards an empowered and enlightened future leaving behind all vulnerabilities. Their development is not superficial and has occurred from within. The SHGs have nurtured their lives and gave freedom to the women infected by HIV.

However, SHGs have to work for and form groups addressed more effectively by adopting a dual approach of sending them to ICTC and also linking services for them. Openly talk about their doubts, fears and problems and discuss with spouse, doctors, ANM or ICTC counsellor show the new light of hope to the infected. With their indispensable and influential role, the SHGs have proved to be a blessing in the lives of the PLHA of Uttar Dinajpur. It has been manifested that when a single woman fails to fight, the whole group will stand and fight for her.

PLHA get the primary support from their local support group in a form of SHG. But following are the recommendation which help them to mould their life in near future:

- By directly helping meet the needs of members with HIV/AIDS and their families;
- By using their experience and community involvement to increase awareness on HIV/AIDS;
- Formation of ***'Support Groups'*** including local PRI members, local school teachers, local clubs, CBOs, health workers and any other influential person of local area to provide moral as well social support to the infected in order to remove stigma and discrimination from the local community and also help them to survive in the society and make them able to lead a normal life like others.

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