CHAPTER - V

CONCLUSION & RECOMMENDATIONS
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This chapter has been divided into two parts. The first part focuses on conclusion which centered on the overview of the major findings in line with the objectives of this research. The second part focuses on recommendation for effective implementation of HIV/AIDS intervention by using various social work methods.

5.1 Conclusion:

The purpose of the study was to investigate the nature and the impact of stigma and discrimination relating to HIV/AIDS experienced by WLWHA in Darjeeling district of West Bengal. The results of this study effectively identified, described and analyzed the HIV/AIDS knowledge level, its socio-economic impact on infected women and affected households, and the ways in which HIV/AIDS related stigma and discrimination appears in the contexts in which they occur as reported by the WLWHA, themselves.

The socio-economic profile of the respondents of this study indicates that HIV/AIDS is affecting most productive age group of human life. The mean age of the respondents is 33.5 years. Majority (60%) of the respondents are from age group of 26-35 years. The average age the WLWHA, who participated in this study are similar to the previous studies, indicating that women of child-bearing ages have been disproportionately infected and affected. Most of the respondents are married; on the other hand the study also found that 15% respondents are widows, which indicates the serious impact of HIV/AIDS on women in the district.

Further it has been found that majority of the respondents (53%) are from rural area, which indicates the problem of HIV/AIDS is not confined to urban area, it’s spreading fast in the rural or semi urban areas. The result of this study also signifies that majority of the rural women are most vulnerable and victims of HIV/AIDS.

The result of the study further illustrates the poor educational background of the respondents. Majority of the respondents (46%) do not have any formal education, 29% respondents are school drop outs. This may be one of the key reasons for poor knowledge of HIV/AIDS among the respondents.

Lack of education for women as a result of HIV/AIDS diffusion is threatening to their social wellbeing. It prevents women from access to valuable knowledge and
skills that enable them to prosper as independent and empowered citizens. Moreover, limited education increases the chances of women engaging in unprotected sexual activity, risking the possibility of contracting the HIV/AIDS. UNICEF mentioned in a report that education serves as the basic defense against HIV infection. It enables women to have alternative professional options that prevent the risk of contracting AIDS.

The National Behavioural Surveillance Survey, 2006 carried out by NACO, found that the level of awareness about HIV/AIDS is less among the uneducated (45.8%) as compared to educated. As the education level increases the awareness about HIV/AIDS increases, which is because of the fact that illiterate people are less exposed to informative material than educated and the level of understanding of the information increases with education.

This study also found that most of the respondents are self-employed and engaged in non-formal sector; only 17% are in jobs either public or private. The living conditions of the respondents are miserable, 91% of the respondent owns their house but condition of houses are very poor, most of the houses are mud houses with hey roof.

The first objective of the study was to assess HIV/AIDS related knowledge, Attitude, Behaviour and Practices among the respondents. The study reveals that all the respondents are familiar with the basics of HIV/AIDS, ICTC (69%) and health care professional (18%) which are major source of information. The study further illustrated that ICTC (Integrated Counselling and Testing Centre) playing vital role in improving knowledge base on HIV/AIDS among the respondents.

Although majority of the respondent are aware about the main causes of HIV/AIDS but still misconception prevails. Altogether 24% of the respondent believed that mosquito bite and sharing razor can cause HIV/AIDS which is a wrong perception on HIV/AIDS.

The study reveals respondent are aware about the preventive modes of HIV transmissions, 61% of the respondent believed that condom use is the best method to reduce the risk of contracting the HIV virus during sexual intercourse, condom use is an important tool in the fight of spread of HIV/AIDS. According to the Joint United Nations Programme on HIV and AIDS (UNAIDS), knowledge of the effectiveness of
condoms in preventing HIV transmission is high in most countries; however many people still fail to use them consistently especially those who engage in high risk sexual practices. A survey commissioned by the United Nations General Assembly in 2007 in 64 countries, found levels of knowledge related to condoms is average. However, on a differential analysis the level of knowledge in females was lower at 55% compared to the males at 70% (UNAIDS 2008).

This study found that the main motive behind using condom is both to prevent unwanted pregnancy and transmission of HIV (80% respondent). Most of the respondents of this study have pointed out that more conservative traditional attitudes toward gender roles had even perceived barriers of condom use; such an attitude has a negative effect on women’s self-efficacy in protecting themselves from risky and compulsory conditions as majority (58%) of the respondent shared that use of condom depends on willingness of male partners about half of the women are still lacking in negotiating sexual activities with their partner, 68% women are victim of forceful sexual activities by their partner.

This study further found that most of respondents are unable to differentiate between HIV and AIDS, however 92% of the people believe that it create poor body resistance and it is not curable. More than half households are found where more than one member is infected with HIV/AIDS and 24 % are such households where partner deceased due to HIV/AIDS.

The second objective study was to assess the socio-economic impact of the HIV/AIDS on affected households. The economic impact and consequences of HIV/AIDS are costly to most households and communities. During the period of illness, medical costs rise, work and incomes are disrupted, family members specially women are drawn away from work to provide care and in some instances children have to work to supplement household incomes. The economic impact of HIV/AIDS is significant and often dramatic in terms of changes in income, asset and longer term prospects for economic security.

HIV/AIDS and poverty continue to exceed all expectations in the severity and the scale of their impact on the households and countries in general. The study explored that most of the affected household are suffering from acute poverty, 60% households monthly income is less < 5000/-month. The Study found that 80% of the
women from the affected household lose their income amount to Rs.2000 to 5000 per month because of increase workload of care giving.

The illness and the death of infected members resulting in loss of income for the family has been found to put additional burden on women; not only does the demand for women’s labour at home, but also the demand for women’s paid labour to supplement income.

Women members of the affected household are forced to take additional measures like engaging themselves in wage earning activities and petty businesses, children are forced to work, even they are bound to sale or lease the land, sale of valuable goods etc to meet the extra burden.

The third objective of the study was to assess the stigma and discrimination experienced by the HIV/AIDS infected women. HIV-related stigma and discrimination is a global problem. People living with HIV and AIDS face stigma and discrimination in various contexts from within their households, communities, workplaces and health settings.

This study gave voice to WLWA, to shed light on the stigma and discrimination that they experienced after being diagnosed with HIV/AIDS. The stigma attached to HIV/AIDS often leads to discrimination against infected people and their families. Family is one of the major institutions of society, which provides a sense of security to an individual. Ironically in majority of the cases discrimination mainly occurred at the family level towards the WLWA. This study also found that the initial reaction from the family members are denial (24%), shocked (56%) and embarrassing (16%). The negative attitude among the family members are common phenomenon, majority (64%) of the women faced neglect, isolation and avoidance, verbally abuse and tease, deprived from using common amenities even some time treated as untouchable. However, this study found that very few families are supportive and shown positive attitude towards the infected family member.

People’s attitudes and thinking towards women living with HIV/AIDS continue a major community challenge. In some cases, the impact experienced is because of society’s explanations and attitudes towards HIV/AIDS (Madru, 2003). These attitudes, usually negative, are sometimes fuelled by cultural or local beliefs
about the disease and its cause (Parker and Aggleton, 2002; Liddell, Barrett and Bydawell, 2005).

As documented in some studies on HIV/AIDS related stigma and discrimination, PLHA often experience different forms of stigma from kin, friend and community members (UNAIDS, 2000; Ogden and Nyblade, 2005; Duffy, 2005). Majority of the respondents in this present study also reported that they had similar experiences like denial in participation in community events / activities (78%), refused in religious place (58%), discrimination by spouse/relatives (72%), becoming subject for gossip (84%), faced harassment /intimidation (64%) etc.

Stigma and discrimination are the major barrier to care and support services in the context of HIV/AIDS. HIV related discrimination in healthcare remains an issue and is particularly prevalent in some countries. Various perceptions of the attitudes that health care providers have towards PLWHA were reported. Marshall (2002) describes enacted stigma and discrimination as a collective dislike of what is unlike. It is further assumed that enacted stigma is usually deliberate, although people are not always aware that their attitudes and actions are stigmatizing.

This study also reported the occurrence of HIV/AIDS related stigma and discrimination in the district. The WLWHA are denied medical and dental services by medical professionals (26%), denial of reproductive and sexual health services (8%), denial of surgery (2%) etc. They also indicated that some doctors do not physically examine them on visits whereas they examine other patients. These negative behaviours prevent them from wanting to seek help in health care facilities.

Most unfortunate part of the HIV/AIDS epidemic is persecution of children those who are not accountable in any way. HIV related perceived stigma and discrimination against children affected by HIV/AIDS was fairly prevalent in the study area. The gravity of the discrimination is very pitiable like dismissal of children from the school (7%), children are separated with other children (20%), denial to play with other children at playground (26%), denial of basic services like drinking water, toilets and kitchens (47%) etc.

People Living with HIV/AIDS (PLWHA) may suffer from considerable stigmatization in their homes, communities and workplaces when their HIV+ status is known. This may lead to various forms of social and political discrimination/exclusion.
including reduced chances for employment and in some cases dismissal from work. This study also found that the 11% cases job descriptions / responsibilities has been changed and in 17% cases job has been lost by the HIV/AIDS infected / affective households.

HIV transmission-related misconceptions and fear of HIV risk from casual contact, as well as symbolic stigma (value judgments, blame and shame) were found to be associated with endorsement of discriminatory actions against PLHIV (which can be understood as indirect intentions to discriminate against PLHIV). These have serious implications in the context of health care delivery as well as care and support for PLHIV within their own families or communities. This study also found that respondents are discriminated because of people’s fear of getting infection from them, lack of proper knowledge on modes of HIV transmission, people believed that HIV is a shameful infection, it associate with people’s morality.

The HIV/AIDS related stigma and discrimination impacts severe negative consequences on any HIV positive people specially women living with HIV/AIDS. This study found that due to HIV status and fear of discrimination, women keep them away to join any social events, isolate themselves from family and friends, quit their employment, preferred not to get married and most pathetic is thought for committee suicide (72%).

HIV/AIDS is no longer a medical problem, the manner in which the virus is impacting upon society reveals the complex way in which social, economic, cultural, political and legal factors act together to make certain sections of society more vulnerable. The epidemic exposes the method and the impact of marginalisation and disparity in clear terms.

This is also the time to recognise that HIV/AIDS epidemic itself has given rise to denial of human rights to a large number of people specially women suffering from HIV/AIDS. The denial of treatment, denial of access to essential drugs including antiretroviral therapy, discrimination in the health care, educational and employment sectors, women being deprived of their rights and thrown out of their homes etc are the few examples of these violations. Apart from having a serious impact on the lives of people living with HIV, denial of these rights is pushing the epidemic underground. Unless these human rights violations are addressed, there cannot be any creation of an
enabling environment, where people come forward to access health and other services, or even get tested. The result of this study also confirmed the Human Rights violation towards WLWHAs. The study found that 15% respondents reported they are denied to access treatments as because of HIV infection, 3% respondents reported that they faced denial to access the Government Public Distribution system, 68% reported that the confidentiality regarding their HIV status has been broken.

A major challenge that requires frequent debates, the human rights approach would prove to be a long term investment for HIV/AIDS treatment and prevention. There is a need to bring an understanding between the rights of the individual, who is at risk of exposure and condemnation because of stigma and discrimination, and the rights of the rest of the society for the effective development of large scale effective public health programme. A human rights approach lies at the heart of any HIV/AIDS programme that seeks to prevent HIV transmission and supports those already infected. In the long run of the third phase of HIV pandemic centering on the human rights would emphasize on minimizing the erosion of the social, economic, cultural and political impact this pandemic has caused. The human rights approach would also reduce the stigma and discrimination.

HIV/AIDS-related stigma and discrimination is recognised as a major barrier to HIV prevention efforts and hindrance to reducing its impact on individuals and communities. It is clearly concluded that HIV and AIDS are as much about social phenomena as they are about biological and medical concerns. HIV/AIDS is associated with suppression, discrimination, as well as individual’s living with HIV has been rejected by their families and by the community as whole.

Women and men are not dealt with in the same way when they are infected or assume to be affected by HIV/AIDS. There is evidence that women are more likely to be blamed, even when they have been infected by their husbands in what for them have been monogamous relationships. This double standard exacts a terrible toll on women “as mothers, as daughters, as care-givers and as people living with HIV/AIDS”.

5.1.1 Limitation / Challenges of the study.

The shortage of India specific data and literature on stigma & discrimination among WLWHAs is limiting factor for the designand conceptualisation of this
research. Since this research was an exploratory study, the scope of the research was primarily focused on stigma, discrimination, Human Right Violation and socio-economic condition of WLWHAs. In-depth interviews were conducted throughout the district ensured the representation from both the hills and plain area of Darjeeling district. Total 100 responded has been covered which include both category of respondent i.e. HIV/ADS infected and affected women from the area.

Due to the prevailing stigma and discrimination in the society till people hide their HIV status in public. The situation of HIV infected women are more vulnerable and harsh which includes the threat of violence, embarrassment, fear of rejection and stigma and discrimination, partner’s objection to testing, lack of access to financial resources, reliable information, and transportation etc.

Therefore the main challenge for this study was to access the respondent i.e. WLWA. In general terms in our society especially in rural area women are still lagging in terms of their education, social and economic rights. At the initial stage the women were not open up and cooperative. Due to lack of education and the understanding level among the respondent was extremely low, which took huge time to complete the data collection.

Due to time and financial constrain this study does not cover a large sample size; furthermore, the results of this research could also not represent the whole country scenario as the sample size was too small, and the findings would be biased in terms of the different social context, situation, livelihood, and location of the respondents. Despite these impediments, every effort was made to deal with all above issues in order to complete the field research.

5.1.2 Future scope of research.

This study focuses on socio-economic stigma impact, discrimination experience and coping mechanism among women living with HIV/AIDS. As this study was only conducted for academic purpose, it could not capture detailed information of the research and any issues due to scope, sample size, research contents, and others. Therefore, it is recommended to propose future studies, as this study was only conducted with Women living with HIV/AIDSs, not included male PLWHA as well as perspective of general population. Hence, the research results
were more likely to be bias as it reflected only the experience and viewpoint from WLWHAs’ side.

Therefore, there is scope for conducting further studies on perspective from community people side; the proposed study will capture the overall areas of knowledge, attitude and practice in order to find out whether the result is consistent with findings from this study.

Lastly, because this study has limited scope to focus on any solutions to stigma and discrimination for WLWHAs, further studies should focus more on solutions to stigma and discrimination.

5.2 Recommendation:

The study found specific scope for social worker in HIV/AIDS management, the scopes are counseling of women living with HIV infection, conducting crisis intervention, providing case management, educating the general, bridge and high-risk populations to reduce risk for HIV infection, advocating for the needs of HIV/AIDS patients, care and support etc.

Counseling by the professional social worker may help the HIV infected/affected women in understanding their needs, feelings or motivations, so that they can make appropriate decisions for themselves. They should be able to decide for themselves what is best for them regarding the choice services and facilities.

Organizing community level sensitization activities for addressing the stigma and discrimination towards women living with HIV. Protection of PLHA specially women, in many contexts, women and girls often fear stigma and rejection from their families, not only because they stand to lose their social place of belonging, but also because they could lose their shelter, their children, and their ability to survive. The isolation that social rejection brings can lead to low self-esteem, depression, and even thoughts or acts of suicide.

Ensuring women’s participation in building their own health: Women should be motivated to talk and discuss their status openly in an attempt to de-stigmatize the HIV/AIDS and provide support and care for those living with HIV/AIDS. It can increase their knowledge on the particular health problem, taught to be self dependent on their health, and make control over their decision.
The economic impact and consequences of HIV/AIDS are expensive to most households and communities. Therefore income-generating activities need to be developed based on micro-credit, micro enterprises, and rural employment creation and poverty alleviation programmes, particularly to meet the needs of the households infected /affected with HIV/AIDS.

As shown in the study findings, HIV/AIDS appears to intensify the financial condition of the affected households. The affected households are meeting the instant need through short-term survival strategies like sale off or mortgage their valuable assets, borrowing from others/relatives, women engaged themselves in different wage earning activities etc. Hence alternatives will need to be developed urgently to prevent individuals and households resorting to measures which put them at greater risk of financial and food insecurity.

In order to effectively address the economic impact of the epidemic on households, there is need to strengthen inter-sectoral collaboration in the prevention and reducing of the impact of HIV/AIDS. This study strongly recommend interaction and engagement of multi-stakeholders especially involvement of Panchayati Raj Institution /Urban local bodies for mass sensitization and crisis intervention.

Women living with HIV/AIDS need to be better education about their rights as patients and about how to get help to challenge the discrimination and stigmatization they face in health care settings.

When testing pregnant women for HIV, couple testing can be offered; both husband and wife can be tested together after providing proper pre-test counselling. Couple testing may reduce the chances of others blaming women for bringing HIV into the families that often lead to rejection by husbands or parents-in-law.

This study also recommended urgent attention to the gender-biased nature of HIV/AIDS related stigma & discrimination. Efforts should be made to address not only women’s risks of HIV/AIDS infection but their heightened vulnerability to the social stigma and discrimination associated with HIV/AIDS.

The healthcare providers’ awareness of anti-stigma and anti-discrimination rules and regulations also contributes to the reduction of stigma and discrimination. Nevertheless, in this study, though the percentage is not so high but still it prevails. Therefore more sensitization and advocacy is required at health care facilities.
This and other studies (Nyblade et al. 2003) have shown that health care workers perceive themselves to be at high risk of infection because of their continuous exposure to the virus during service delivery. Thus it is crucial to address the concern of health care workers and implement workplace policies that ensure staff safety and respect for health care workers rights. These policies need to ensure the availability of essential supplies (e.g., gloves, post-exposure prophylaxis) for maintaining optimum infection control practices by health care workers at all times to not only protect themselves but also to protect their patients from exposure to infection.

Women living with HIV/AIDS need legal education and access to the justice system to address the violation of their rights in the context of employment and education. Advocacy is required for enforcement of the property rights of women upon divorce and widowhood and support the WLWHA to get their rights and entitlements.

Legal efforts to tackle HIV/AIDS-related stigmatization, discrimination and denial seem doomed to fail in the absence of a supportive legal framework. The recent initiative by the Government of India to enactment of “The Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (Prevention And Control) Act, 2017” is a welcome move but widely dissemination of the act and its provisions are urgently needed.

Social Worker can play a role of watchdog to protect Human Rights of infected people and in implementation of Universal Declarations. In March 2016, UNAIDS and WHO’s Global Health Workforce Alliance launched the Agenda for Zero Discrimination in Healthcare. This works towards a world where everyone, everywhere, is able to receive the healthcare they need with no discrimination, in line with The UN Political Declaration on Ending AIDS. Zero discrimination is also at the heart of the UNAIDS vision, and one of the targets of its Fast-Track response. This focuses on addressing discrimination in healthcare, workplace and education settings.

Involvement of electronic & print media is very essential for highlighting the best practices related to reducing HIV/AIDS related stigma and discrimination. Media can also highlights the community responses and concerns to the policy
makers and in the different international platforms. Media is one of the most powerful tools to take the smallest, poorest and most marginalized voices so that they are heard.

Engaging WLWHA, policymakers and programmers to support the framework and promote its implementation across settings through production of information, education, and communication materials for the framework and engaging and involving the media and community.

Support groups for women living with HIV/AIDS should be offered as a fundamental part of HIV services and should be advocated as an effective and useful intervention. Government should provide financial and technical assistance for establishing and sustaining support groups and policy should incorporate these issues.