Chapter 5

Findings and Suggestions

Based on the analysis and interpretations the findings were categorized as follows: the personal and demographic profile of the respondents, source of HIV infection and the infection history, specific problems and needs of the HIV infected, the various intervention strategies adopted by NGOs and GOs and social capital created through the interventions of GOs and NGOs for the respondents. Meaningful suggestions which were generated from the analysis and interpretation are also included in this chapter.

5.1. Major Findings

Personal and Demographic Profile

More than half (61.7 percentage) of the respondents are in the age group 35-50 years. The respondents with high school education are 44.7 percentage. Only a few (6.7 percentage) went for higher education. For a state, proud of its high literacy rate in general and higher education levels among its women in specific, not even half of the respondents have moved forward for higher education. Awareness generation is easier among the educated.

Though a fine number of the respondents (48.3 percentage, i.e., 46.7 percentage married and 1.6 percentage remarried) are in a secure family atmosphere of matrimony, the majority who are not (51.7 percentage, i.e., 43.7 percentage widows, 4.3 percentage separated, 2 percentage divorced, 1.7 percentage unmarried), present an alarming statistics of single poor women in a vulnerable state of insecurity.

The majority (80.7 percentage) of the respondents reside in rural areas. Both the districts taken for study have majority of rural population which is evident in the findings. The residents of rural India are simple folks unperturbed by the changing modern ways and concepts. As tradition has it, they follow the same routes their forefathers had set such as giving little importance to higher education especially for

girls, early marriages and encouraging early motherhood where the traditional breadwinners would be the men folk. This makes the women in the risk of being exposed to various causative factors of HIV infection. Sixty two percent live in their own homes. But the condition of these houses reflects the state of poverty they are drowned in. For those without a spouse, the threat of being exploited or neglected is also a constant fear, even in the safety of their own homes. Most of the respondents (70.3 percentage) are from nuclear families.

Coolie work, especially in the construction sector based on daily wages has been the occupation of a moderate number of the respondents before (51.3 percentage) and after (60.3 percentage) the HIV infection. An important finding is the drastic reduction of the husband's earnings after the infection (from 39.6 percentage to 20.6 percentage) and the provisions received from the other family members have progressed (from 1.3 percentage to 7.6 percentage), irrespective of the stigma. Before HIV infection, 66 percentage of the respondents were in the lower range of income (Rs.500- Rs.4700) which has increased to 83.3 percentage after HIV infection. This clearly states that the income of the respondents drops significantly due to HIV infections, as they have to spend considerable amount of money for treatment. However, it has to be highlighted that the negative impact on income is balanced by social work interventions as the respondents are able to maintain an average range of income (Rs.4700- Rs.6800), as it is increased from 44.3 percentage to 45.3 percentage. The sources of income have varied with the circumstance. Where, once the source of income was a healthy husband, now both the infected spouses take turns to shoulder the financial burden of the family. The group which earned below Rs.4700 are the ones who readily approach support systems such as the NGOs and GOs during their financial crisis and hence their economic status is maintained or bettered. The reluctance and hesitation of those who earned higher earlier, to seek help even from trustworthy support systems along with the incapacity to continue work have pulled them down from the economic ladder.

Source of HIV Infection and Infection History

Majority of the respondents (88.3 percentage) received infection through their husbands. They have become victims to HIV due to someone else's fault. Having multiple partners for either of the spouse and unsafe sexual practices put themselves and their entire family at risk of infection not just to HIV but also to other STDs as well. Only a meagre number (1.6 percentage and 2.6 percentage) of respondents have tracked their infection source to their parents and from HIV infected blood transfusions respectively. The findings support the general trend of HIV infection in India, which is mainly through heterosexual relations.

Half (51.3 percentage) of the respondents have completed more than 7 years after HIV detection. A considerable number of the respondents (58.3 percentage) went for HIV testing because of prolonged illness. However, it has to be noted that since HIV infection takes a long period to be symptomatic, other than those who take tests during pregnancy, very few go for voluntary HIV testing. Most of them got identified when they were tested for prolonged diseases which are basically opportunistic infections. Since testing is recommended by the physician they are consulting, 53 percentage of the respondents are informed about their HIV infection by the doctor. A good proportion of the respondents (69.7 percentage) prefer government health services. 70 percentage approach Government hospitals to do their primary testing since they have appropriate facilities and is non-chargeable, making them the most opted destination for HIV testing among the general community. Sixty percent of the respondents are denied medical care or get delayed care because of their HIV status. Majority of the respondents (75.7 percentage) do not receive the same quality of care provided to other patients.

Specific Problems and Needs

A moderate number of the respondents (66 percentage) confided in their husbands before they were HIV infected. This trend decreased after HIV detection (33.3 percentage), and parents (35 percentage) and others (21.7 percentage) became

the major confidantes to the respondents. When comparing the relationship and communication patterns of the respondents before and after detection, in all cases, z value is found to be significant indicating that there exists significant difference in the perception about relationship and communication pattern before and after HIV infection. Mean scores decreased after HIV infection which is an indication of reduction in relationship and communication by the respondents.

Some of the respondents rate their sexual life as 'somewhat satisfactory' before (51.4 percentage) and after (59.33 percentage) getting HIV infected. Testing the correlation of respondent's sexual satisfaction before and after HIV detection, using standard deviation, a significant improvement was found. (Mean score was improved from – 1.73 to 2.4 out of 3, the t –value is 12.205, and p – value- 0.000). This betterment in the marital quality with regard to sexual satisfaction after the HIV infection could be due to a deeper level of marital interaction and sharing, generated from the social support interventions.

A good number of the respondents (91.6 percentage) have their legal husbands as their only sexual partner. Most of them (88.3 percentage) receive HIV infection through their husbands and nearly half of them (47.6 percentage) never use condoms while having sex. Some of the respondents (39.9 percentage) though not on a regular basis, use condoms. Decisions related to sexual behaviour and practices may not wholly be in the hands of the respondents. Ignorance and patriarchal familial systems makes women feel they are always the weaker sex, slave to the whims and fancies of the dominating husband. Even if they wish for protected sexual intercourse, many a times they might have to succumb to the decisions of their male counterparts, however wrong or unhealthy it may be. However, fifty three percent of the respondents are still blamed for transmitting the infection to the spouse. They are often labelled as the carrier of HIV not only within the family, but also among the community. Such labelling aggravates when the women are widowed.

Majority (92.6 percentage) of the respondents have no experience of their spouse disclosing their HIV status to others. Generally, when one of the spouses

shares the HIV status of the partner, he or she is equally at risk of being stigmatized. So they keep such secrets to themselves. But in certain cases, to maintain their good name, very few (5.7 percentage) publicises their partners' HIV status.

All the respondents have disclosed their HIV status to an ART centre (treatment centre with doctor, counsellor, pharmacist and nurse), NGO staff and their spouse (in case of married) or parents (in case of unmarried). A considerable number of the respondents (64.7 percentage) have not disclosed their HIV status to any person other than the above mentioned category. Fear is the reason behind non-disclosure for many (58.8 percentage). The intervention strategies of the GOs and NGOs to boost the morale and confidence of the respondents can go a long way in bringing down the discrimination itself when the infected take a stand for themselves. Fear of isolation, discrimination, unemployability, poverty, being denied basic needs and friendship are all reasons that prevent the respondents from disclosing their illness. Their state of hopelessness accompanied by the negative understanding of the illness fuels the fear factor that the society will treat them like outcasts.

Of the fair share (69 percentage) of the respondents who go for a job, 42.7 percentage are able to go on a regular basis. Among the 106 respondents who disclosed HIV status, neglect (65.09 percentage) and job rejection (34.91 percentage) are the most discriminating factors they address. The knowledge that they have been purposefully rejected causes greater strain to their emotional health as well. The reasons for the biased behaviour of one individual at the workplace can start up a series of negative strokes leading to negligence, ignorance and a declining social value of the victim by others who are not completely aware of the reality. Even casual contact such as sharing the drinking glass at the common water point or sitting near an HIV positive, is perceived with the fear of being infected "accidentally". These common misperceptions bring the social strata of the victim even below, straining their emotional stability and in the long run, opting out of such employment opportunities because of the mental agony they faced. Most of the respondents have no other breadwinner in their families and have a number of dependents who have no

one else to turn to. Irregular income arises from irregularity of jobs. The ill health of the respondents, shouldering responsibilities such as being caretakers of other infected, aged or infant staged family members, can weaken them physically and emotionally. This, adding to irregular medications and little external motivation, can exhaust the respondents during the hard toil required from their jobs. They are forced to abandon work options and succumb to the hardships of being an HIV patient. The NGO intervention in the area of social capital enhances social participation and social inclusion of the respondents significantly.

Some of the respondents (23 percentage) never felt a decline in their social status because they disclosed their HIV illness. A high number of the respondents have not faced issues related to their children's marriage (95.6 percentage) or education (94 percentage) because of their HIV status. Marriage is an occasion when the stigma hits hard on the face and when it is the girl who is supposed to get married, things are more complicated. Often the parents hide their HIV status or sometimes the bride or groom alone is informed who keeps it as a secret to themselves. Admission procedures in schools rarely check or need to know the HIV status of the applicant or family members. Often, the HIV infected tends to move away from their native place, especially after their HIV status is known in the locality. This is done merely to protect the future of their children. More than the school authorities and teachers, it is the parents of other children who are sceptical about their wards mingling with HIV infected children.

Fifty three percent of the respondents have an average level of participation in social events, in which family functions are attended (56.3 percentage) often. Family events are those where members notice the presence or absence of each other. Perhaps to prevent rumours and curious eyes, the respondents make it a point to be a part of family events more than other social events. Sixty percent of the respondents take part in religious events at times. Being in a land where religion and faith renders them more emotional healing, taking part in such events uplifts their spiritual health, which in turn boosts the sense of well-being of the respondents. There are

respondents who also attend Kudumbasrees (49 percentage) and PTAs (50.6 percentage) at times so that certain benefits or privileges are not missed.

An excellent share of the respondents (88 percentage) are regular in ART intake. ART intake is the basis of the health status of all PLHIV and making sure that PLHIV take regular ART is a major intervention strategy in the field of HIV care and support. As a result, the number of PLHIV with regular ART intake has increased significantly, resulting in better life span among such groups. There is a significant number of irregular and defaulters in ART intake among which the main reason is that there is a loss of memory among PLHIV, which itself is a side-effect of ART to maintain accurate timings of medicine. There will also be tense situations for PLHIV, when they take medicine in public places which will put them into a potential risk of disclosing their HIV status.

Majority of the respondents (85 percentage) do not have any opportunistic infections. More than half of the respondents (66.3 percentage) very rarely have such an occurrence. Half of the respondents (51.7 percentage) have body weight between 41-50 kilograms. An equal proportion (51.6 percentage) have CD4 count between the range 250-500 cells per µL, i.e. below the norm. Only three percent of the respondents have critical levels of CD4. The majority indicating better health status is due to the regular intake of ART and proper medication motivated by the intervention of GOs and NGOs.

A high majority of the respondents have no practice of using substance (98.7 percentage) and alcohol consumption (93.7 percentage). On a general front, majority of the Indian women do not indulge in substance abuse traditionally. The women respondents in this study too, except for a tiny percentage, have no history of substance abuse. This is a good sign since, substance abusers have serious health hazards and its severity is extensively high with people who are under ART.

A considerable proportion (38.6 percentage) of the respondents face the most hardship in health care and medicine. Medical expenses, treatment and travel

expenses are the prime concerns which trouble the HIV infected. Frequent illness of different family members at different times is a stressful affair, draining energy, funds and time. Housing and maintenance is the next major issue (33.3 percentage) after health care. The inability to maintain one's place of residence can lead to leakages, breakages and other issues requiring manpower and money. Fulfilment of children's education (16 percentage) and other basic needs like food (9 percentage) and clothing (3 percentage) are also difficulties faced by the respondents. The interventions of the support systems provide a great relief to the PLHIV to fulfil their basic needs.

Financial worries are a cause of concern for half of the respondents (51.4 percentage) who are in debt of loans ranging from ten thousands to lakhs. Some of the respondents (31.3 percentage) have taken loans from local banks. Local banks provide easy financial assistance and are often a boon in case of emergencies which may be the reason behind a good percentage of respondents' inclination towards them. However, the banks are strict in the procurement of assets once a person is unable to repay. The PLHIV lose their land, house etc to repay such debts. The respondents are forced to take debts with accumulating interests, which they cannot repay and eventually drain them of all resources especially where income is undependable. Almost half of the respondents (49.3 percentage) have approached NGOs for financial help, though only a handful (1.3 percentage) have taken loans from them.

The major crisis is not the situation of debt or the amount they have to repay. It is whether they can sustain themselves with the debt amount. There is no guarantee that a single loan can actually help the financial crisis of their family. One loan leads to another, either to repay or to meet further expenses. Ultimately, this reaches a point of no return. Such families are crushed financially, emotionally, socially and physically too.

Almost half (47.7 percentage) of the respondents have adopted to selling jewellery to resolve their financial problems. The one asset that the respondent can call their own is utilized for the better good. One of the most traumatic and drastic

changes that result from being an HIV positive person is the plunge into financial crisis. The number of reasons for the same include loss of earnings, premature death of an AIDS affected earning member of the household, reduced physical ability to work because of the infection, loss of work time of the non-infected members due to the caretaking responsibilities for the infected members, and reduced employability due to the stigma associated with the infection. This in turn makes them look out for the best possible sources of availing finances.

Seeking the assistance of service providers such as NGOs is opted by a fair number (49.3 percentage) of respondents, which is a great illustration of social capital generation. Though respondents who sought to sell their jewellery follow closely (47.7), it is a sign of progress that external help is being sought in times of family crisis. Money borrowing is also taken as a solace by many though its after-effects such as timely repayment of interests and huge repayment accumulation can be a future hassle. Respondents have also understood the need to check their unwanted expenses and cut down on matters like clothing and other household expenses. Whilst some of the respondents have sought to reduce expenses on vital issues like food and children's educational expenses, many others have opted to send away their children to better caretakers such as orphanages, relatives and grandparents homes, lest their condition may not affect the lives of their little ones. A few of them resort to sell off other aspects they owned such as land, household and other items of value. The extreme economic conditions have pushed a meagre few to stop the education of their children as well.

These are examples of the desperate measures people jump into during the severe times. It is relevant that the majority seeks help from NGOs. Yet education and knowledge is needed since there are sad sacrifices involving sending children away and stopping their education just because the family is in financial crisis.

Intervention Strategies Adopted by NGOs and GOs

Intervention Strategies that Benefitted the Respondents

The awareness activities of the NGOs and GOs have benefitted the respondents, in which ART related awareness classes (for 71.6 percentage), monthly get-togethers (for 49 percentage) and care takers' awareness programmes (for 27.3 percentage) were more useful. Out of the advocacies and lobbying activities by the NGOs and GOs, some of the respondents (37.3 percentage) have benefitted from the nutritious food kits distributed by LSGs and a reasonable number of respondents (33.6 percentage) have benefitted by Local Action Committees (LACs). Twenty six percent have benefitted from monthly get-togethers and a few (24.3 percentage) have benefitted from networking, advocacies and lobbying activities undertaken by NGOs and GOs.

Among the prevention, care and support activities undertaken by NGOs and GOs, more than half of the respondents (54.3 percentage) have benefitted from the ART pension provided by the Government. Some (36.7 percentage) have benefitted from KESS, and twenty nine percent have benefitted from the Chief Minister's Relief Fund. Other (19.7 percentage) respondents have benefitted from medical support and fifteen percent benefitted from the counselling services provided by NGOs and GOs.

Income Generation Programmes by NGOs and GOs are beneficial to 60 percent of the respondents. Some of the respondents (37.3 percentage) benefitted from the women empowerment classes and 32 percentage benefitted from the awareness classes for women empowerment. A few (18.7 percentage) of them have benefitted from the training sessions on better parenting and 13 percent of the respondents have benefitted from Kudumbasree, which are among the various activities undertaken by NGOs and GOs.

Financial support provided by NGOs and GOs was most beneficial for respondents (38.7 percentage) with children. Others benefit from soft skill development classes (25.6 percentage), vocational training sessions (15.7 percentage)

and personality development classes (10.3 percentage) implemented by the support systems for the children of the respondents.

The majority of the respondents have found the intervention strategies of the NGOs and GOs really beneficial. This connotes that the intervention models adopted by the two sectors are bringing about positive results empowering the HIV infected.

Intervention Strategies Rated by the Respondents

Majority respondents have rated all the activities of GOs and NGOs like awareness programmes, advocacy and lobbying, HIV prevention, care and support, women empowerment, child development and education promotion as good (mean=<3) whereas economic development activities were merely satisfactory (mean= >3).

Intervention Strategies Suggested by the Respondents

A fair number of respondents (23.3 percentage) suggested using media, sessions by HIV positives (17.3 percentage), street plays (11.6 percentage), and educational wall paintings (6.3 percentage) to improve the awareness programmes undertaken by NGOs and GOs. To improvise the quality of advocacy and lobbying activities by NGOs and GOs, the respondents suggested strengthening of SSS (34.7 percentage), collaborating with other NGOs (12 percentage) and the participation of elected members (10.3 percentage).

Many of the respondents (31.6 percentage) have an opinion that modification of Government policies can help in the improvisation of prevention, care and support activities undertaken by NGOs and GOs. Few respondents suggested linkage with various NGOs (16.3 percentage) and to include medical support (5.7 percentage) to improve prevention, care and support activities.

Some of the respondents (27.3 percentage) suggest vocational training to improvise women empowerment activities undertaken by NGOs and GOs. For better results, 25 percent of the respondents suggested increasing IGPs. Twenty two percent

of the respondents suggest implementing loans for the improvisation of economic development activities undertaken by NGOs and GOs and an eighteen percent suggest subsidy for self-employment for better results.

It is a strong implication that the respondents, however poor, illiterate or traditional, have opened up with suggestions and opinions to improvise services for them. In awareness activities, the respondents are aware that more appealing teaching techniques can leave a lasting impression where the message stays vivid, memory retains longer and recollection becomes easier. If the opinion of using media, street plays or pictures has come up from the respondents themselves, it reflects how strongly the respondents feel about being informed in its fullness. Likewise, their interest in having more knowledgeable people involved in addressing their issues such as familiar trustworthy elected members and getting Government policies pro-HIV people is a positive indication. The respondents desire ways to be better earning members of their families and hence have suggested better ways for their economic development and empowerment. Their concern for their children's development is also evident in their positive suggestions for their ward's welfare.

Services Received by the Respondents

High majority of the respondents (85.7 percentage) received ART pensions from Government Organizations. Some of the respondents (45.3 percentage) are receiving loans from microfinance. 43.7 percentage of the respondents have not received any support for house maintenance from both GOs and NGOs. More than half of the respondents (59.7 Percentage) have not received any support for new house construction from both GOs and NGOs.

Some of the respondents are receiving education scholarships from either NGOs (29.7 percentage) or GOs (28.7 percentage) or from both (27.3 percentage) respectively. Majority of the respondents are receiving educational aids from NGOs in the form of uniform support (60.7 percentage), tuition fees (75 percentage), books and stationery support (78.3 percentage), and other education support like travel allowance, private coaching fees (62 percentage) etc. from NGOs. High majority of

the respondents (71 percentage) have received 'better parenting' training from NGOs. Majority of the respondent's children (64 percentage) have received soft skills and study skill trainings from NGOs.

A fair share of the respondents (60.3 percentage) have received job training from NGOs. Sixty six percent of the respondents have received personality development training from NGOs.

Sixty five percent of the respondents are receiving medicine support from GOs and 29.7 percentage are receiving medicine support from both GOs and NGOs. More than half of the respondents (59.3 percentage) are receiving counselling services from both GOs and NGOs whereas 22 percentage are receiving such services only from GOs. Majority of the respondents (62 percentage) are receiving consultation services from GOs and 28.3 percentage are receiving such services from both GOs and NGOs. Majority of the respondents (64 percentage) are receiving hospitalization support from GOs whereas others (26.7 percentage) receive such support from both GOs and NGOs. A majority of the respondents (77.3 percentage) are receiving clinical investigation support from GOs. More than half of the respondents (57.3 percentage) are receiving treatment allowances from NGOs. Some (32.7 percentage) are receiving such support from both GOs and NGOs. Half of the respondents (49.7 percentage) are receiving nutritious food kits from NGOs and 44 percent are receiving such support from both GOs and NGOs.

A good number of the respondents (77 percentage) are invited for social functions. Seventy six percent are willing to get services from Grama panchayat, private or Government centres. More than half (56 percentage) of the respondents are willing to disclose their HIV status to the elected members of the Panchayath. Some of the respondents (43.6 percentage) are not willing to disclose their HIV status to religious leaders. A high majority (89.6 percentage) of the respondents are willing to disclose their HIV status to doctors and several others (84.7 percentage) have the opinion that the community is somewhat aware about HIV/AIDS, though the knowledge is incomplete and have misconceptions. Majority (85.7 percentage) of the

respondents have the opinion that the stigma associated with HIV is somewhat reduced, however much the stigma exists in all spheres of life. More than half (56.7 percentage) of the respondents are willing to create the awareness about HIV, however some (43.3 percentage) are not willing, which clearly depict their fear of getting their HIV status disclosed.

Regarding the changes needed in the society for the good of PLHIV, respondents suggested more social acceptance (26.3 percentage), reduction in discrimination (38 percentage) and social inclusion of PLHIV (3.3 percentage).

There are several areas where the Government has not intervened much and there are areas where NGOs' support is not sufficient. However the combined efforts have made significant impact in improving the living standards of PLHIV, generating social capital and enabling PLHIV to live with dignity without any exclusion from the society.

Social Capital Created through Interventions of GOs and NGOs

Well-being and Social Support System

The association of social capital with the respondent's well-being has been established by using the Pearson's Correlation coefficient. There is low negative correlation between the well-being of the respondents and the extent of its negative effects in children in terms of marriage and study. This relationship is significant at 1 percentage significant level ($r=0.123$, $p=0.034$). Well-being is positively correlated with participation in the social functions. Social participation significantly increases the well-being of the respondents ($r=0.184$, $p=0.001$) at 1 percentage significant level. Social inclusion is the most important variable that contributes to the well-being of the respondents ($r=0214$, $p=0.000$).

Social Support System for Social Inclusion of the Respondents

CBOs are typical systems of social capital which further leads to social inclusion and it is positive that relatively high majority of the respondents (90 percentage) have membership in them. Social inclusion begins with being a part of a community based organization. As for PLHIV, they feel they are wanted, are part of a group and have shown interest in spite of their HIV status.

Lack of interest (83.8 percentage) and the fear of HIV disclosure (16.2 percentage) are the reasons given by respondents who are not members in CBOs. Organizations which focus on social support, empowerment, care, and reduction of stigma and exclusion have helped to promote the inclusion of people with HIV/AIDS, have brought about a change in the lives of their beneficiaries, and have stimulated social unity to counter this epidemic. Hence majority of the respondents (78.3 percentage) having access to supportive system or local committee clearly indicate the presence of a society which is open towards the PLHIV.

Lack of awareness (67.7 percentage) and lack of interest (32.3 percentage) are the predominant reasons for not having a supportive system or Local Committee. A good number (77.7 percentage) of the respondents participate in PLHIV group meetings. Lack of interest (56.7 percentage) is the predominant reason and the fear of HIV disclosure (43.3 percentage) is the other major reason for respondents, for not participating in PLHIV group meetings.

A striking proportion (82 percentage) of the respondents have linkage with sponsors. Lack of interest (66.7 percentage) is the predominant reason and the fear of HIV disclosure (33.3 percentage) is the other reason for those who don't. A good share (77 percentage) of the respondents have linkage with service providers. Lack of interest (69.6 percentage) is the predominant reason and the lack of awareness (30.4 percentage) is the other reason for those who don't.

Rating by the Respondents of Activities Undertaken by NGOs and GOs

The functioning of CBOs has been rated as good by 55 percentage of the respondents. The functioning of local committees has been rated as good by 53.6 percentage of the respondents. Several respondents (47.3 percentage) rated functioning of PLHIV group meetings as good. The functioning of linkages with sponsors (52.3 percentage) as well as the agencies assisting PLHIV as a social support system (54.3 percentage) was rated good by the respondents.

The respondents have rated the activities of all the social support systems on a positive note. This means that the service providing support systems present are actively involved in the betterment of PLHIV and their interventions have a profound effect on the respondents.

Aspects to be Included in Activities Undertaken by NGOs and GOs

Regarding the functioning of CBOs, support from LSG is rated most needed by a fair share (59.3 percentage) of the respondents whereas 34 percentage suggest the approval by the Government. To improvise the functioning of local committees, the respondents suggest linkage with various supportive groups (41 percentage), regular meetings of LAC (37.3 percentage) and enabling local support (21.6 percentage).

To improvise the functioning of group meetings of PLHIV, the respondents suggest active participation of PLHIV (57 percentage), better involvement of elected representatives (20.6 percentage), introducing variety programs (12 percentage) and regular meetings (10.3 percentage). Regarding functioning of linkages with sponsors, the suggestions that came were follow up activities (62.3 percentage) and being introduced to sponsors (37.6 percentage). To improve the activities of the agencies assisting PLHIV, some of the suggestions from the respondents included more provisions for children (44 percentage), collaboration with various agencies (34

percentage), maintaining confidentiality (14.3 percentage) and tax reduction (7.7 percentage).

The respondents are open to a variety of suggestions to improvise the services and activities organized for their welfare. These points need to be acknowledged as citizens with rights even though they happen to be PLHIV. This indicates that they are positive about the support systems standing up for them.

Domain Wise Distribution of Overall Well-being

Among these sub domains of the variable overall well-being, social health scored highest (mean=26.557, SD=±5.16), followed by intellectual health (mean=26.24,SD= ±3.59), emotional health (mean=25.133, SD=±4.936) and spiritual health (mean=25.111, SD=±7.185). This indicates that the stigma and social discrimination, attached to HIV infection normally reduces social health. But contrary to the general assumption, the respondents have the highest score in social health. It indicates that the greatest contribution of the community based organizations was to immune its members from the feeling of social exclusion and to enhance social capital.

Rating of the Social Support Systems, by the Respondents

The respondents rated the social support system variables such as linkages with the service providers (mean=3.41, SD=±1.042), functioning of linkages (mean=3.36, SD=±1.017), effectiveness of the functional linkages (mean=3.35, SD=±1.142), providing increased opportunities and the effectiveness of group meetings (mean= 3.27, SD=±1.173). This grading is out of five and these scores indicate the mean scores are between satisfactory and good. One of the major contributions of the CBOs is to develop linkages and connectedness.

Respondents' Satisfaction over the Services

Respondents' satisfaction over the services provided by the CBOs is positively related to the linkages with the service providers (r=0.171, p=0.000), ensuring the functioning of linkages (r=0.277, p=0.000) and the effectiveness of the functional linkages (r=0.326, p=0.000), providing increased opportunities and maintaining the effectiveness of group meetings (r=0.463, p=0.000). These relationships are significant at 1 percent significant level. It showed that the better the functioning of the CBOs, the higher the satisfaction of the respondents. It also suggests the CBOs need to develop strategies to enhance these social interventions to ensure the well-being of the respondents.

NGO Interventions and Well-being

The NGOs play the role of a facilitator. In the absence of NGOs, the liaison between various resources both formal and informal would be lacking and the individual respondents would not have the access to those. The significant variables that contribute to the respondents' overall satisfaction in life are group meetings (r=0.463, p=0.00), functional linkages (r=0.326, p=0.000), various formal and informal services (r=0.171, p=0.000), and the feeling of overall well-being (r=0.208, p=0.000). These relationships are significant at 1 percent significant level. It shows that the better the functioning of the CBOs, the higher the satisfaction of the respondents. It also suggests that the CBOs need to develop strategies to enhance these social interventions to ensure well-being of the respondents.

Social Capital

One of the four major variables of the study is social capital. The focus of the interventions by GOs and NGOs is to enhance the linkages with various resources available in the society in order to reduce stress and ensure well-being. Most significantly positive relationship is seen between the social capital and various other variables such as linkages with sponsors (r=0.409, p=0.000), strengthening the group interactions and activities (r=0.206, p=0.000), membership in CBOs (r=0.221,

p=0.000) and support systems (r=0.159, p=0.006) developed by GOs and NGOs. All those relationships are significant at 1 percentage significant level. It shows that the greatest contribution of GOs and NGOs is to liaison between various resources and respondents and to link the respondents with the resources. It is a very important pivotal role where GOs and NGOs function as single window system to provide all inclusive services to the respondents to ensure their overall well - being.

Social Inclusion

All the variables related to the social inclusion are visually binned with one standard deviation giving a clear idea that there are 68 percentage of respondents who felt they are poorly to very poorly included and only 32 percentage felt the inclusion. It reflects the need for awareness and to include various other methods of intervention to bring them to mainstream.

Social Inclusion and Overall Well-being

It is assumed that the better social inclusion would contribute to overall well-being of the respondents. The four variables have significant positive relation (r=0.314, p=0.000) where the higher the social inclusion, the better the overall well-being in the respondents.

Participation in Social Events

Social events were divided into formal and informal events. Informal depicts the participation in family functions, local programmes and religious functions. The scores were computed and binned to show that 61 percentage of the respondents often participated in these functions and 37 percentage sometimes participated in such events. Whereas the participation in formal or government related programmes is 88 percentage among the respondents, the frequency of participation is often (39 percentage) or sometimes (49 percentage). Attendance in these programmes and meetings are important for PLHIV to be linked with state sponsored social security net. This is high compared to general population attending these formal programmes.

It is an indication that the involvement of NGOs helped the respondents to be linked to the formal networks. This enhances the social capital, social inclusion and thereby an enhanced well-being of the respondents.

There is a significant group difference between the variables and the one way analysis of variance which showed that it is significant at 5 percentage level in all the four constructs such as overall well-being and social inclusion (F=1.477, p=0.018), social inclusion and membership in CBOs (F=2.313, p=0.005), membership in CBO and linkages with the sponsor (F=37.793, p=0.008) as well as social inclusion and participation in group meetings (F=50.761, p=0.000). This variation suggests that these variables are dependent on each other and this is statistically significant. This is an important piece of information to develop social work interventions for the respondents.

Social Work Interventions and Overall Well-Being

The goal of the entire intervention is to ensure overall well-being of the people with HIV. The significant variables relating to the well-being are social inclusion (r=0.314, p=0.000), participation in formal (Govt. related) programmes (r=0.228, p=0.000), linkage with service providers (r=0.200, p=0.000), linkage with sponsors (r=0.182, p=0.002), participation in group meetings (r=0.122, p=0.035), support of local committees, PLHIV groups (r=0.158, p=0.006) and membership in CBOs (r=0.160, p=0.005). Relationship is significant at 1 percentage significant level. This indicates that in order to ensure overall well-being of the respondents with HIV, they ought to be linked to four variables.

To predict the variables contributing to overall well-being, regression analysis is done. The model shows that most important predictor of overall well-being is the social inclusion and participation in the social functions. The r square value is 0.362, which shows 36.2 percent. This model predicts that if the NGOs and GOs work for the inclusion through enhancing the social capital, the overall well-being also will be

improved. So the future strategies of the agencies should be directed towards enhancing social inclusion of the people affected with HIV/ AIDS.

Findings and Observations from the Interview Conducted among NGOs

Kuriakose Elias Service Society (KESS), People's Service Society Palakkad (PSSP), Rajiv Youth Foundation (RYF), Lions Club and Salvation Army are the major NGOs working in the field of HIV/AIDS in the area of research. One third of the NGOs are involved in prevention activities and target intervention programmes where commercial sex workers, injecting drug users, migrants, MSM (Men who have Sex with Men), and truckers are the focused groups. Condom promotion among target groups and awareness programmes in the general community are the major activities focused by such NGOs. The NGOs working in the area of care and support of PLHIV are focused on providing medical support, travel allowances for medical needs, counselling services, house visits, education support for children, loans for self- employment, formation of supportive groups etc.

The major challenges faced by NGOS are identifying PLHIV, motivating them to access the various schemes and services, getting the support of government organizations and officials, erasing social stigma from the part of the general community etc. Improved awareness among PLHIV about various schemes and services offered by Government and NGOs, better participation in rehabilitation activities by PLHIV, improved quality of life and overall well-being among PLHIV, reduced stigma and discrimination among general community who are more empathized on the needs of PLHIV and willing to help them, higher participation of elected members, politicians and government officials in improving the living conditions of PLHIV and ensuring their fundamental rights are the major results of various interventions initiated by NGOs.

As an impact of the various interventions initiated by GOs and NGOs there are more number of groups and networks for PLHIV which support them and their needs. There is better communication and bonding between PLHIV and also with the

general community they belong to. There are better relationships among PLHIV among their family members and neighbours along with the level of participation of PLHIV in social events which has improved well. PLHIV have better access to the various services and support provided by GOs and NGOs and they have faith and cohesion towards the society they belong to. All these aspects clearly denote that social capital has been generated in the research area and NGOs have played a significant contribution in this process of social inclusion.

5.2. Suggestions

Improvising existing formulas and adapting new ones ensure timely changes for the needy. New initiatives and changes can better the current situation of PLHIV. They have positively responded and favoured some novelty into the current system. A few suggestions for their betterment are noted below.

- A sustainable income generation system is required to bring up the PLHIV and their family members so as not to fall prey to other means of financial indebtedness and if at all they need to take resources to loans, they would be confident to raise the income themselves and pay back completely. Women should be provided vocational trainings or to avail job loans to start any income generating activity. Small scale business like petty shops, cloth trade, lottery, tea shops, animal husbandry, tailoring etc are highly successful income generation activities which can help HIV infected women to stand on their own feet. Low or no interest loans and subsidy for self-employment loans need to be provided for economic development.

- GOs and NGOs should create awareness about the existing facilities, schemes and services for PLHIV. They should train them to access, counsel them to overcome their fear and support them to avail such facilities which they did not, due to their lack of awareness and interest associated with fear and prejudice. Social media can be adequately and wisely used for the prevention

of HIV transmission, to reduce stigma and bring policies and social changes by which PLHIV are socially included as people with rights. Street plays, visuals, videos, educational wall art and other IEC materials can capture anybody's attention and create a lasting impact. Encouraging HIV positives to speak in PLHIV group meetings and confidential venues can touch the lives of the infected much more than others.

- The intervention strategies of the GOs and NGOs to boost the morale and confidence of PLHIV can go a long way in bringing down the discrimination and enabling them to take a stand for themselves. Suggestions from PLHIV may be asked and noted for sustainable change and development on a frequent basis.

- One of the major findings of the research is that majority are not willing to disclose their HIV status to religious leaders which also throws light into the non- receptive attitudes and approaches by the latter. Awareness generation needs to begin with these social leaders of religion, administration or education. A suggestion would be to incorporate awareness generation and exposure during their training phase itself which would create open mindedness and correct knowledge about conditions like HIV/AIDS. Later, they can influence the community, be more involved in social capital generation and be an active service providing system. This principle is applicable to persons of all sectors involved in dealing with HIV related issues including the medical professionals.

- The HIV prevention programmes are focused more on the high risk groups and not among the general community including women. Specific intervention strategies are required to prevent innocent women from becoming victims of this deadly disease. Sex education should be incorporated into the general education system and adolescent girls should be given necessary

information to prevent themselves from HIV like conditions, such as being victims to premarital sexual relations. Special focus should also be given on marriage choices where girls should be cautious of getting into marriages where their spouse are likely to be in the high risk activity.

- Emergency support, support for medical needs, support for children's education, assistance for house maintenance or even construction should be provided by GOs and NGOs and at the same time equip them to earn a regular income through job or income generating activities. Such activities can be done individually or even as groups, just like SHGs.

- PLHIV generally have low self-esteem. They need to overcome this state of mind, get organized, knock on supportive doors and express their needs. The respondents have suggested in the study that they require sessions on positive thinking, personality development and other motivational sessions. NGOs and GOs are capable of boosting the morale of the PLHIV, engaging them in sessions to improvise their emotional health. Re-enforcing their need to be mentally alert and active with a positive presence of mind can help enhance their intellectual health**.** Capacity building programmes and behaviour change initiatives by the support systems can enable them to be stronger.

- Many respondents have forced their children to live apart from them due to their HIV condition. The intervention models should sensitize PLHIV and their families on the importance of staying together with their children, ensuring educational aids along with tuition fees, life lessons, soft skill trainings and every possible provision to ensure children are not a burden to the PLHIV.

- The intervention models developed by NGOs like Local Action Committee (LAC), PLHIV group, networked agencies group and Community Based

Organization (CBO) were found to be highly productive in contributing towards social inclusion and social capital generation. These models can be used in mainstreaming the PLHIV by ensuring community participation in the fullest and in seeking comprehensive approach towards the underlying issues, which makes them highly acceptable.

- Social support systems need to introduce regional CBOs to the PLHIV, collaborate with them to support, include the infected and follow them up to ensure PLHIV are treated well. Some of the respondents' fear has barred them from approaching CBOs. Support systems can motivate and empower them to courageously come forward to be part of CBOs.

- PLHIV need access to supportive system or local committee organizations which focus on social support, empowerment and care. To promote inclusion of people with HIV/AIDS, which has brought about a change in the lives of their beneficiaries and stimulated social unity to counter this epidemic, the reduction of stigma and exclusion, will be helpful.

- NGOs, GOs and other support systems need to identify the major areas where supportive systems and local committees for the welfare of PLHIV are not present. The residents may not be aware or interested in having such systems in place. This formation of region wise new support systems can ensure that PLHIV feel there are groups and people within their locality, to advocate and defend them. At the same time, the general community should also be sensitized and encouraged to bring in such groups for the good of the marginalized.

- NGOs can play a very important role in linking PLHIV with sponsors and in finding resources for them with confidentiality. Functioning of CBOs can be improved by taking support from LSG, obtaining approval by Government

and providing more services. Functioning of local committees can be improved by regular meetings of LAC, linkage with various supportive groups and enabling local support. Availability and accessibility of regional service providers should be made mandatory and GOs and NGOs should inform the society about such provisions in their midst. Functioning of group meetings of PLHIV can be improved by active participation of PLHIV, involvement of elected representatives, introduction of variety programmes and by organising regular meetings. The PLHIV group meetings need to be more innovative and creative to keep them interested and ought to address the elements of fear which might prevent them from future absenteeism. As social capital establishes itself gradually, participation and involvement can multiply manifold. Functioning of linkages with sponsors can be improved by introducing PLHIV to sponsors and assuring follow up actions. Service providers or agencies assisting PLHIV can be improved by collaboration with various agencies, tax reduction, including more provisions for children and assuring confidentiality. SSS need to be strengthened; collaboration with other NGOs and participation of elected members can make life better for PLHIV.

- Social capital generation should be the ultimate aim of interventions by NGOs and GOs. Hence, all activities should be undertaken in those lines to ensure the sustainability of the changes they bring to the society. Policies or a legislative mechanism to ensure that the rights of such people are not denied can ensure that they live with dignity. To bring a comprehensive approach, collaborative efforts from all government machineries, advocacy and lobbying activities should be given higher importance in the intervention strategies. Such attempts should work in both ways like government taking initiatives from the top and making policies to support HIV infected and affected people. On the other hand, NGOs and the community who are involved in philanthropic activities need to take sincere attempts to bring HIV specific needs to the government level and force them to take action. Government

schemes for HIV should be sensitive to the emotions of PLHIV and formulate systems which are free of hassles and can be approached without fear. There should be an enabling environment where the HIV infected are provided with opportunities to live a quality life in a society that empathises their ill condition.

5.3. Conclusion

HIV/AIDS is a multifaceted issue and the researcher has tried to understand the underlying issues in detail, at the same time tried to evaluate the impacts of various interventions of GOs and NGOs in social inclusion of HIV infected women through the generation of social capital. The general conditions of HIV infected people such as their productive age group; their financial constraints, emotional distress, stigma and discrimination etc are also evident in the present study. The study also highlights the involvement of GOs and NGOs through its various interventions which have developed various social supportive systems and structures like networking agencies groups, local action committees, Community Based Organization (CBO) and PLHIV groups which have in turn reduced the stigma and discrimination in the society and made HIV rehabilitation more participative in nature.

The community in general has started accepting the HIV infected as their fellow beings and is willing to take the responsibility of supporting them in their hardships. However, the social stigma still persists even though not expressed openly as before. Environmental modification as well as the attitudinal change of HIV infected/affected people is required to bring some sustainable changes in the existing conditions. The general community has to understand that HIV people are normal and HIV does not spread through casual contacts with an infected person. On the other hand people with HIV/AIDS should understand that the entire community is not against them and there are many people who are ready to help them and consider them as their brothers and sisters. NGOs and GOs play a major role in this attitudinal

change process which further leads to social change. Social inclusion is a deeper concept, even when it is explained in simple terms, has broader dimensions. It is a result of social capital generation process in various realms of the social life of an HIV infected/ affected person, which enable them to access the social support both from the part of GOs and NGOs, maintain their health and work to live with dignity and provide quality life to their family.

HIV/AIDS is no longer considered a very serious issue by the government and the health care fraternity; however the problems faced by HIV infected persons are deep rooted and dynamic in nature. So care and attention with genuine understanding of the issues and the existing situation of HIV infected persons is required from the part of GOs and NGOs and it should be in the priority list of people who need support. The developed social supportive structures which have contributed to social capital generation will sustain only if there is a continuous involvement of GOs and NGOs and people of all sectors should support this process for the social inclusion of the most downtrodden group of the society. Together we can achieve the goal of "Getting to Zero- zero new infection, zero HIV deaths and zero HIV related stigma."