AN EXPLORATORY STUDY OF A 'POSITIVE PEOPLE'S' NETWORK IN ALLAHABAD

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in partial fulfillment of the requirements
for the award of the Degree of

MASTER OF PHILOSOPHY

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This dissertation entitled **'AN EXPLORATORY STUDY OF A 'POSITIVE PEOPLE'S' NETWORK IN ALLAHABAD'** is submitted in partial fulfillment of the requirements for the award of **'Master of Philosophy'** of this University. This dissertation is my original research work and has not been previously submitted for any degree of this or any other University/Institution.

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We recommend this dissertation to be placed before the examiners for evaluation.

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To
My Family

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CONTENTS

LIST OF ABBREVIATIONS

AIDS	:Acquired Immuno Deficiency Syndrome
ANC	:Ante-Natal Case
ART	:Anti Retro Viral Treatment
ARV	:Anti Retro Viral
AWH	:Anganwadi Helper
AWW	:Anganwadi Worker
BLN	:Block Level Network
BSS	:Behavioural Surveillance Survey
CBO	:Community Based Organisations
DIC	:Drop-in-Centre
DLN	:District Level Network
DSD	:Discrimination, Stigma and Denial
FPAI	:Family Planning Association of India
GIPA	:Greater Involvement of People Living with HIV/AIDS
HIV	:Human Immuno Deficiency Virus
IDU	:Injectable Drug Use
HIS	:Internalised HIV Stigma
INP+	:Indian Network of Positive People
NACO	:National AIDS Control Organisation
NGO	:Non government Organisations
OBC	:Other Backward Class
PLWHA	:People Living with HIV/AIDS
PWN+	:Positive Women's Network
SLN	:State Level Network
STD	:Sexually Transmitted Disease
UPNP+	:Uttar Pradesh Network of Positive People
UPSACS	:Uttar Pradesh State AIDS Control Society

CHAPTER ONE

Chapter 1

Introduction

Even two decades after the clinical identification of the Human Immunodeficiency Virus (HIV) that causes AIDS, the health status of infected people challenges humanity. The principal mode of HIV transmission is through unprotected sexual practices, leading to a greater impact among individuals in the productive age group of 15-49 years. As sexual practices are private decisions, it makes control of the epidemic complex, with a high chance of multiple infections in the same household, leading to catastrophic social and economic consequences. Lack of preventive vaccine, absence of curative therapy, long incubation and morbidity period of HIV infection demands heavy expenditure. The prognosis, for people living with HIV & AIDS(PLWHA) has improved in industrialized countries. But in developing countries, where 95 per cent of the HIV-infected people live with limited health provision and widespread privations manifesting as hunger, nutritionally-related disease as well as bouts of other epidemics, the situation is complicated [UNAIDS 2002]. Further, the trajectory of HIV infection is accelerated by unaffordability and inaccessibility of anti-retroviral drugs (ARVs).

India's situation, at present in HIV & AIDS

India, an estimated 5.2 million Indians are living with HIV (NACO, 2004). Although prevalence of HIV infection appears to have stabilized in some states (such as Tamil Nadu, Andhra Pradesh, Karnataka and Maharashtra), it is still increasing in at–risk population groups in several other states. As a result, overall HIV prevalence has continued to rise. State-wide prevalence among pregnant women is still very low in the poor and densely populated northern states of Uttar Pradesh and Bihar. Even relatively minor increases in HIV transmission could translate into huge numbers of people becoming infected in those states, which are home to one quarter of India's entire population.

HIV prevalence of over 1% has been found in pregnant women in four of the industrialized western and southern states of India (specifically Andhra Pradesh, Karnataka, Maharashtra and Tamil Nadu) and in the North-Eastern States of Manipur and Nagaland (NACO, 2004). A significant proportion of new infections is occurring in women who are married and who have been infected by husbands who (either currently or in the past) frequented sex workers. Commercial sex along with injecting drug use, in the cases of Nagaland and Tamil Nadu serves as a major driver of the epidemics in most parts of India. HIV information and awareness among sex workers appears to be low, especially among those working in the streets.

In North-East of India, HIV transmission is concentrated chiefly among drug injectors and their sexual partners, especially in the states of Manipur, Mizoram, and Nagaland. IDU is not limited to the country's northern states. There has been a sharp rise in HIV infections among drug injectors in the southern state of Tamil Nadu, where 39% were HIV-infected in 2003, compared with 25% in 2001 (NACO, 2004).

Relatively little is known about the role of sex between men in India's various epidemics. Few studies that have examined this complex dimension of sexuality in India have found that significant numbers of men do have sex with other men. One study, undertaken among residents of slum areas in Chennai, has found that 6% of men had had sexual intercourse with another man. Almost 7% of the men who had sex with other men were HIV-positive, and more than half of them were married (UNAIDS, 2005).

Arunkumar, Irudaya Rajan, Rakkee Thimothy did a study titled **'HIV Patients: Knowledge and Sexual Behaviour Patterns'** in (2004). This study, carried out on HIV-positive persons, in Kerala showed that despite the increase in awareness of HIV transmission among people, there has not been a resultant change in high-risk behaviour. Thus, even though HIV risk information may be necessary, it is not sufficient by itself to motivate behaviour change. In the absence of curative or preventive therapy, creating public awareness and knowledge of HIV & AIDSis the only cost-effective strategy of primary prevention, especially in developing countries such as India. This study by Thrani was an effort to explore the knowledge about HIV and sexual behaviour pattern of HIV-infected individuals. In India, sexual transmission of HIV is predominant and the study was expected to give valuable insights to prevent further spread of the epidemic.

The sample for the study is drawn from new HIV clients who visited the Thrani centre for crisis control during the project year April 2001 to March 2002. All the participants were informed about the nature and purpose of the study and their verbal consent was obtained. Forty-one individuals were included in the study. The sample was composed of 12 females and 24 males. Average age of the sample is 34.36±7.68 years. An analysis of the socio-demographic pattern of the samples indicates that, 55.6% belonged to the low socio-economic income class, while 44.4% hailed from the middle socio-economic strata; 47.2 % of the sample resided in the suburbs of the city, 27.8 % in rural areas and the rest (25 per cent) in urban areas. Majority of the individuals were Hindu and the rest Muslim and Christians. The pattern of education status revealed that 27.8 per cent of the subjects had only attended primary school, while 50 per cent had studied up to secondary. Only 5.6 per cent had education higher than matriculation. Major portion of the sample consisted of unskilled and semi-skilled workers, while 8.3 per cent are unemployed. Housewives constituted 22.2 per cent of the total sample.

Scanning the knowledge levels of subjects living with HIV it was seen that they have fairly enough knowledge about the spread of AIDS; 58.3 %knew that AIDS can spread through sexual contact; 61.1 %knew AIDS cannot spread through sharing food; 52.8 per cent thought condoms prevent AIDS; 55.6 %knew AIDS spreads through skin-piercing objects; 75 %recognised that AIDS can be transmitted from mother to child and through blood transfusion; 72.2 per cent thought that sharing needles can spread AIDS. 58.3% also thought that shaking hands with others could spread AIDS; 52.8% thought that AIDS could infect one through toilets. 61.1% believed that there is a cure for AIDS. Evidence of high-risk behaviour was seen as majority of the subjects. The data also revealed that 91.6 %of the males had multiple sex partners, while 91.6 %of all females in the study had only one sex partner (their husband).

The evidence from the present study pointed to these facts as most of the women included in the survey had no sexual relations other than with their husbands. High rate of infection among housewives can also be taken as an indicator of the fact that the infection is spreading rapidly to the general population. The study also points to the fact that despite the increase in public awareness of HIV transmission, there has not been a resultant change in HIV & AIDS-related high-risk behaviour. Many of the subjects are sexually active and still maintain multiple sex partners. This underlies the truth that, even though HIV risk information may be necessary, it alone is not sufficient enough to motivate behaviour change. These results have also been documented by other studies and the Behavioural Surveillance Survey (BSS) report, 2001. The baseline survey showed that the level of awareness regarding the transmission of HIV & AIDSin most States of the country was high. Nearly 75% of the respondents had heard of HIV/AIDS and of the common modes of transmission (sexual, blood and needle sharing). However, awareness of the other modes of transmission like mother-to-child transmission and transmission through breast-feeding was not as high. Moreover, the levels of awareness on all these aspects were relatively poor in some states, especially among rural residents and among women. These States include Bihar, Madhya Pradesh, Gujarat and West Bengal.

The level of awareness regarding prevention of HIV & AIDSwas not so high. Overall, around 47% of respondents were aware of the two important methods of prevention i.e. consistent condom use and sexual relationships with faithful and uninfected partners. A significant proportion of the population had myths and misconceptions about the modes of transmission (BSS,2001). These misconceptions often lead to stigma and discriminatory attitudes towards the HIV infected people.

Many studies show that infection with HIV raises a wide spectrum of concerns and fears among infected individuals. Even before symptoms occur, those infected with HIV have concerns about future economic security, sexuality and disease transmission, rejection from family, friends and lovers, and eventual ill health and death. In India, AIDS is perceived as a disease of "others"- of people living on the margins of society, whose lifestyles are considered "perverted" and "sinful". Discrimination, stigmatization, and denial are the expected outcomes of such values, affecting life in families, communities, workplaces, schools, and health care settings. Negative responses and attitudes towards people living with HIV & AIDSare strongly linked to general levels of knowledge about AIDS and HIV and in particular, to the causes of AIDS and routes of HIV transmission. In most societies AIDS is associated with groups whose social and sexual behaviour does not meet public approval. In a study by Ambati, Ambati and Rao(1997), 60% of the respondents believed that, " only gay men, prostitutes, and drug users can get AIDS." Thus in virtually every Indian setting in which HIV positive people interact with other people provides a backdrop for discrimination, stigmatization and denial.

Theoretically, stigma can be defined as the imposition of a special, discrediting and unwanted mark on a person or a specific category of persons in such a way that they are looked at as fundamentally and "shamefully different". The mark is imposed on people who have or are believed to have a distinctive status or a "deviance," as it is called in Sociology.

Stigma: a matter of attitude?

In HIV & AIDS, the essence of stigma is a mental and social reaction closely related to many factors, including culture, personal and social fears, denial, misconceptions and myths about the epidemic.

> *'Stigma has ancient roots. It has been described as a quality that 'significantly discredits' an individual in the eyes of others. It also has important consequences for the way in which individuals come to see themselves. Importantly, stigmatization is a process. The qualities to which stigma adheres (e.g. the colour of the skin, the way someone talks, the things that they do) can be quite arbitrary. Within a particular culture or setting, certain attributes are seized upon and defined by others as discreditable or unworthy. Stigmatization therefore describes a process of*

devaluation rather than a thing'. (A conceptual Framework and basis for action, HIV & AIDSStigma and Discrimination, UNAIDS, 2002.)

According to research (Gilmore & Somerville, 1994) many language metaphors used in HIV & AIDSgive clear indications about the stigma associated with it:

1. AIDS is death (both biological and social)
2. AIDS is punishment (for immoral and sinful behaviour like homosexuality, promiscuity, injecting drug use and commercial sex)
3. AIDS is a crime (HIV infected people are "criminals", guilty of harming or threatening the health and welfare of their "innocent" victims)
4. AIDS happens only to others ("them"), not to me/us ("us"): Dichotomization of the world among the "infected" and the "not infected"(the "dying" and "the living")
5. AIDS is a horror; the infection is seen as an abject, terrorizing invader or demon. Those infected are demonized accordingly

These metaphors appear to be the expression of various perceptions of the epidemic. They lie at the heart of stigma because they provide ideas and things to associate with AIDS. So, if AIDS is associated with death, crime, punishment, horror, etc, it is quite easy for the general, particularly the uninformed public (which makes up the majority), to look at infected people as those who carry death, the dangerous criminals, the sinners and ultimately the incarnation of moral decay in society.

In practical terms, Persons Living with HIV/AIDS (PLWHA) are always bearing the burden of at least one of the perceptions above. And, needless to say, no one of us would like to be associated with death or sin or crime. So, for PLWHA, stigma means to be subjected to those negative attitudes. It means having to stand in front of judging eyes and sustaining their corrosive looks. Such attitudes can be enacted and lead to discrimination. ***Discrimination** is the denial of a right or a privilege a person is normally entitled to, solely on grounds that they are HIV positive.*

Stigma, in case of HIV & AIDS, can be of different forms. ***External stigma*** is stigma oriented toward people living with HIV & AIDSthat comes from sources outside the affected person. The media, family, friends, religious institutions, the workplace, the health care system, and so forth, are all possible sources of external stigma. ***Internalized stigma*** has to do with how people living with HIV & AIDSstigmatize themselves. It is the shame associated with the illness, and the fear of being discriminated against on account of the illness. Internalized stigma comes about when, for example, the images, thoughts, or prejudices that a person has formed about HIV & AIDSand about people living with HIV & AIDSsuddenly become that person's reality upon diagnosis. Suddenly, what was outside that person is now his understanding of himself.

When a person is diagnosed as having HIV, internalized stigma can come in a number of forms, including: an inability to relate to friends, a loss of self-esteem, a fear of approaching people, thinking one does not have the right to connect with negative people or that one does not deserve the things one has, an expectation of rejection on the part of others, personal blame, mistrust of others, negative feelings about sex, reduced productivity, or (on the contrary) overdoing things to prove oneself. Beyond the sometimes devastating effects on a person, internalized stigma also jeopardizes the response to the epidemic. It has a negative effect on the resolve, commitment and personalized perspective of people living with HIV & AIDSto confront issues that impact on programs and interventions (Post conference report, 'Celebrating Our Lives', 10th international conference for PLWHA 2002).

Studies have documented HIV & AIDSrelated discrimination, stigma, and denial (DSD) in contexts such as the family, the community, the health care system, and the workplace. One such study was done by S. Bharat with Peter Aggleton and Paul Tyrer in 2001, titled, **"India: HIV & AIDSrelated Discrimination, Stigma and Denial"**. The study aimed to examine the forms determinants and outcomes of HIV & AIDSrelated discrimination, stigma, and denial in India and to explore their possible social, demographic, and cultural correlates. The specific objectives were to-

1. Examine the forms in which HIV & AIDSrelated DSD is experienced and manifested at the levels of individuals, households, and institutions and for certain marginalised groups- women, gay men, CSWs.
2. Understand the broader socio-cultural contexts in which HIV & AIDSrelated DSD operates.
3. Document and analyse the outcomes or responses to DSD associated with HIV & AIDS.

This exploration was organized by focusing on a range of key settings- hospitals, workplace, home, and community. Research was done in Greater Mumbai and Bangalore. Mumbai was chosen for two main reasons- *firstly* because it has a high prevalence of HIV, both historically and currently, *secondly,* good working relationships and networks were already established with medical practioners, AIDS workers, NGOs, and community based organizations as well as groups of HIV positive people and those living with HIV & AIDS. Bangalore was chosen because the recognition of the epidemic locally has led to AIDS related interventions, the mobilization of HIV positive people, networks among individuals and organizations associated with AIDS related activities and a growing interest in research on AIDS-related topics.

There were three main methods used for data collection- key informant interviews, in-depth individual interviews, and focussed group discussions.

Key informant interviews –31 informants were interviewed in Mumbai and 54 in Bangalore. They comprised of doctors, NGO staff, CHWs, AIDS counselors, lawyers, Industry Personnel etc.

In- depth interviews – were taken of 31 respondents in Mumbai and 13 in Bangalore. Their age ranged from 20-35 years, of lower and lower middle class. Men were mostly married and women widows. HIV positive household members (main care providers), people from marginalised groups – CSWs, hijras', gay men, were also interviewed.

Focussed group discussions—20 groups in Mumbai and 15 in Bangalore were taken. Each comprised of 5-8 people especially of hospital staff. 6 FDGs were held with HIV+ support groups. Along with this direct observation & case studies of HIV positive individuals were also done.

It was found that Individuals with HIV & AIDSwidely reported fear of social isolation, judgemental attitudes, severing of relationships, and denial of support and care. As the number of negative experiences increase, HIV positive individuals became more and more distrustful in their relationships, both personal and social. Depression, anxiety, isolation, and suicidal thoughts or self harming tendencies are recurrent thoughts reported by HIV positive individuals. In *hospitals* there was refusal to provide treatment, admission, operation, restricted access to facilities like toilets, and common eating and drinking utensils, physical isolation in wards, mandatory testing, refusal to lift or touch the dead body of HIV positive patients etc. In *home and community*, severed relationships, desertion, separation, denial of share in property or access to finance, blocked access to spouse, children, etc., physical isolation, denial of death rituals, labelling and name calling were the experiences which the patients and there families had to go through. At *workplace,* positive persons often experienced removal from job, forced resignation, social distancing, labelling, and name calling. There was also clear evidence in this research, that HIV related DSD in India is a gendered phenomenon. Issues such as inheritance, housing, and care giving were found to be particularly fraught for women. Women were often blamed by their parent- in-laws for infecting their husbands, or for not "controlling" their partners' urges to have sex with other women. The quality of care provided to women in the family was significantly poorer than the care provided to men.

This study managed to cover a number of aspects of DSD related to HIV & AIDS. However, the sample taken in this study were people from lower and lower middle class and not from the "better off" middle and higher middle class or high class. Thus the differences across the socio-economic class especially, the higher and lower class could not be seen. *Secondly,* the research site chosen for the study already had a high prevalence of HIV & AIDSso the severity of the DSD reported may be of a lesser degree in comparison to the areas where HIV & AIDSis not very prevalent. Thus many of the aspects may have remained hidden. *Thirdly,* the sample was from lower and lower middle class, so it is possible that they may have already been experiencing DSD because of being of the marginalised group and with added problem of HIV & AIDS, thus they may be experiencing 'layered stigma' and thus their negative experiences may be more pronounced.

However, the study has been able to delineate the HIV & AIDS- related DSD that generate numerous fears for people living with HIV. These include—

- Fear of being judged and categorized as a member of a 'deviant' group such as promiscuous.
- Fear of AIDS stigma (of being identified with 'deviant', 'morally sinful', behaviour, mainly sexual promiscuity and visiting sex workers).
- Fear of loss of reputation in the family and society.
- Fear of damaging the family's social reputation.
- Fear of social discrimination and isolation, of being avoided or shunned by others.
- Fear of social ridicule.
- Fear of dying uncared for, and being denied last rites.
- Fear of death and of dying early.
- Fear of various illnesses and debilitating ill-health, of painful conditions, of not receiving medical attention, and of being denied admission to hospital.
- Fear of being deserted, of loss of significant relationships, and of trust and confidence.
- Fear of loosing one's job or source of income.
- Fear of passing the infection to others, whether spouse, children, or other family members.

The findings of this study are not limited to a particular region or country only but are generalizable to other parts of the country and the world also. The severity of stigma and discrimination that people living with HIV & AIDS(PLWHA) encounter is profound.

In United States, although the level of stigma connected with HIV has diminished over the last decade, some people still avoid PLWHA and many still fell uncomfortable around them. In a recent national survey, 18.7% of people endorsed the statement, "people who got AIDS through sex or drug use gotton what they deserve" (CDC, 2000). Other studies have shown that the stigma associated with HIV is greater than that of other stigmatized illnesses, eg. Cancer, leukaemia, herpes (Crowford, 1996, Peters et al., 1994). This stigma extends to family members of PLWHA and even to volunteers working within AIDS organizations (Snyder et al., 1999).

HIV-AIDS has four characteristics that account for why it is so highly stigmatized (Herek, 1999).

1. It is a disease that is perceived as the bearer's responsibility because the primary modes of transmission of the infection are behaviours that are considered voluntary and avoidable.
2. It is perceived as a condition that is unalterable and fatal.
3. Conditions that are contagious always have greater stigma attached to them.
4. Conditions that are apparent to others, such as advanced stages of AIDS, are more stigmatized. In addition, HIV related stigma is heightened because it is "layered" upon the stigmas associated with homosexuality, drug use, sexual promiscuity (Crowford, 1996).

Studies on impact of HIV stigma have shown that it harms both HIV-positive and HIV-negative persons. It determines peoples decision regarding whether they should get themselves tested for HIV or not. It also deters many HIV positive people from seeking medical care and from disclosing their HIV serostatus to others because doing so can lead to rejection, discrimination, hostility, and physical violence (Chesney and Smith, 1999). In turn, the choice not to disclose one's serostatus can lead to an increased sense of isolation and psychological distress among HIV-positive people (Cradall and Coleman, 1992), and increased likelihood of engaging in unsafe sexual practices (Wenger et. al.,1994). Stigmatized individuals are also vulnerable to feelings of self-hatred, which can result when they internalize society's negative views of them (Herek, 1990, Novick, 1997). Similarly, PLWHA may be at a risk of internalizing the stigma associated with their disease and holding a negative view of HIV disease and of themselves as a result. In addition, internalized stigma is likely to make an individual more sensitive to both actual and anticipated rejection and stigmatization by others, which negatively affects disclosure and their ability to effectively manage their disease.

INTERNALIZED STIGMA:

A study done by R.S. Lee, A. Kochman and Kathleen J. Sikkema in Dec. 2002, titled, ***"Internalized Stigma Among People Living with HIV & AIDS"***, examines this concept of 'Internalized HIV stigma'(IHS) and its role in the mental health of PLWHA. A secondary analysis of baseline data from a sample of bereaved, HIV-positive men and women, who had been recruited for a coping skills intervention study, was done. Indicators of internalized stigma among HIV positive men and women were examined with an emphasis on examining the prevalence and degree of internalized HIV stigma (IHS) experienced as well as the relationship between IHS and several measures of psychological distress. Confounding effects of variables like higher levels of physical symptoms and faster progression to AIDS, passive or avoidant coping strategies and lower levels of social support were controlled for the examination of relationship of IHS to levels of depression, anxiety, and hopelessness. As it was a bereaved sample, grief was also controlled which is positively associated to psychological distress.

The following research questions were examined:

i. How prevalent is IHS in this population?
ii. Are there demographic or psychological characteristics that distinguish those individuals who may experience a high versus a low level of IHS?
iii. What is the relationship between IHS and other behavioural and psychological variables?
iv. Is IHS related to levels of psychological distress?

A total of 268 HIV positive individuals, 94 women and 174 men, from Milwaukee and Madison, Wiscosin(n=164) and New York City (n=104) participated in the study. Mean age was 40.1years (range 21.1-60.5years) and mean educational level was 12.8years. Sample was racially and ethnically diverse. 53.7% were bisexuals, gay, lesbians or transgender and 45.9% were heterosexual. Participants included those who had lost their partners, lovers, spouses, family member or friend to AIDS and those who met the following criteria—

a) Health provider's verification of the participants HIV- positive serostatus.
b) Experience of an AIDS related loss no less than one month ago and no more than two years prior.

The assessment battery consisted of a structured clinical interview and self administered questionnaire including following measures—demographies (age, gender, race, sexual orientation, income, sexual relationship status, whether they had attended any HIV support group), current health status, Grief Reaction Index(GRI), coping with illness inventory, perceived social support –which included dimensions like –tangible support, self esteem support, structured interview guide for the Hamilton Depression and anxiety Scale, Beek hopelessness Scale and Functional Assessment of HIV infection.

Data was analysed in three areas—

a) To access the prevalence of the IHS among men and women.

b) To identify the characteristics of individuals with characteristics of individuals with high and low levels of IHS.
c) Examine the association between IHS and psychological distress—depression, anxiety and hopelessness

It was found that the majority of HIV-positive people in this sample reported experiencing some level of internalized stigma related to their serostatus. Many experienced high levels of IHS, but many also reported experiencing no IHS at all. Individuals high on IHS were the ones who had been recently diagnosed as HIV seropositive, their families were less accepting of their illness, they were less likely to ever have attended an HIV support group, and they knew fewer people with HIV. Individuals with higher IHS also worried more about spreading their infection to others. Heterosexuals experienced higher levels of IHS, contradictory to the earlier findings of homosexuals experiencing more IHS due to layered stigma. Hierarchical regression analysis showed that IHS contributed significantly to the levels of depression, anxiety and hopelessness after controlling for the effects of key behavioral and psychological variables.

However, it was found that there was no significant difference in sexual relationship status between the high and the low -IHS groups. This was unexpected since one might assume greater isolation and less sexual activity among those experiencing a high degree of IHS. With the finding that recently diagnosed HIV positive experienced higher level of IHS, the question arises that, is there a progression over time from higher to lower levels of IHS with the increase in duration of time of having been tested HIV positive, or is IHS more stable and trait like with people being predisposed to experience it. Another important finding was that the only significant demographic differences in the level of IHS experienced was based on site, with participants in Milwaukee and Madison reporting higher levels of IHS than those in New York City. It may be because of higher levels of stigma in those areas of the country.

However, due to the cross-sectional design of the study, casual interpretations of the results cannot be made; moreover the data are based on self-report. It is possible that those individuals who experienced higher levels of IHS were simply more likely than others to endorse items measuring psychological distress. There is also a possibility of the demand characteristic operating while responding which might have altered the results. Moreover, the sample was a bereaved sample, which limits the generalizability of the results to the non-bereaved people with HIV, also, a longitudinal study would have helped to tap the course of changes in the level of IHS with the progression of the disease and to determine how these changes may be related to interpersonal processes with family, friends, and professional sources of support.

SOCIAL SUPPORT:

People with HIV may be receiving both supportive and unsupportive responses from their social networks, but negative social interactions may be particularly salient for them, given the stigma associated with the virus (Bennet, 1990; Cradall & Coleman, 1992). Social network members may experience feelings of vulnerability, helplessness, and fear in response to a person with HIV, and may therefore, have difficulty providing effective support. In addition, many people have little experience dealing with people with HIV, and may feel uncertain about how to act or what to say. Thus to develop a clearer picture of the nature and effects of unsupportive behaviours experienced by PLWHA, a study was done by *Ingram et al;(1999)*, titled, ***'Social support and Unsupportive social interactions:* their association with depression among people living with HIV'.**

Several hypotheses were tested—

1. It was expected that participants reporting more HIV related unsupportive social interactions would report greater levels of depression.
2. It was predicted that the observed correlation between unsupportive social interactions and depression would remain significant after controlling for trait negative affectivity.

3. It was expected that unsupportive social interactions would correlate only moderately with social support.
4. Unsupportive social interactions would account for a significant amount of the variance in depression beyond the variance accounted for by both physical functioning and positive social support.

The sample was drawn from two sources—The Ohio State University (OSU) adult AIDS Clinical Trials Unit and the Medical College of Virginia, Infectious Disease Clinic at Virginia Commonwealth University (VCU). The OSU sub-sample consisted of 96 individuals with HIV, 90% of whom were male. The age ranged between 21-62years, with a mean age of 36.03years. 68% of men were gay, 27% heterosexual, 4 were bisexual. Mean length of time they knew about their HIV status was 4.21years. Unsupportive social interaction inventory was used and factor analysis was done for 175 HIV positive individuals recruited from VCU as apart of a separate study of coping with HIV. Based on the data from the combined sample of 271 people with HIV, a principal factor analysis was conducted on 30 items from USII. 4 factors were identified labeled *insensitivity, disconnecting, forced optimism, and blaming.* Almost all participants (96%) reported having experienced at least one form of unsupportive social interactions, 90% experienced insensitive responses and some forced optimism, 87% experienced disconnecting responses, 70% reported blaming behaviour, 56% exceeded the cut-off score of 16 for probable depression compared to 15-20% in general population. However, no evidence was found for an interactive effect between social support and unsupportive social interactions. Thus, the extent to which unsupportive social interactions predicted depression did not depend on the individual's level of social support, but this may be because HIV specific support was not assessed, instead global perceptions of satisfaction with available support were assessed. Statistically significant correlation between unsupportive social interactions and depression was found even after the effect of trait negative affectivity was partialled out thus the situation or state is important especially chronic medical conditions or HIV. However, being a cross-sectional study, no causal inferences can be drawn, also it would have been useful to determine whether certain coping strategies buffer or amplify the effects of unsupportive social interactions. Behavioural data could have been taken to support the self report measures data from clinicians or members of the network group. Results of the study also depend on the environment of the sample from which data has been drawn thus generalizability is limited.

Disclosure to family and friends:

At times of crisis such as illness, just as at other times, a close social environment provides the individual with an opportunity to discuss feelings, develop intimacy by disclosing private information, and express emotions. A good deal of evidence suggests that self-disclosure (including the expression of feelings) to a few close persons is an important component of healthy personality adjustment (Gottlieb, 1981). Individuals with HIV & AIDSwidely report of fear of social isolation, judgmental attitudes, severing of relationships, and denial of support and care. As a number of negative experiences increased, HIV positive individuals became more and more distrustful of relationships, both personal and social.

Concealing HIV infection decreases the availability of social support. Stress caused by efforts to conceal a HIV positive status is partially due to the necessity of structuring interactions to minimize the risks of disclosure. Selective disclosure of HIV infection tends to divide one's world into those who know and those who do not know. Living "double life" can involve lying about recurrent illnesses, hiding medications, and covering up symptoms. In a study of Hispanic men with HIV infection, Marks et al, (1992) found disclosure of HIV status to be a highly selective process and that disclosure increased as HIV disease advanced. In this study, men disclosed to their sexual partners and close friends more often than to their families. Disclosure of HIV serostatus and communicating about HIV infection with friends and family can lead to greater satisfaction with the social supports one receives. As people approach the later stage of infection, hiding their HIV status become increasingly difficult. Greater frequencies of medical visits, a mass of medication, deteriorating health, changes in appearence, and occupational disability can force disclosure. AIDS therefore threatens to uncover a life-style that may have been hidden for years, leading to a cycle of emotional distress and loss of social support. (Kalichman, 1998)

Kalichman et. al ;(2003) did a study on, **'*Stress, Social support and HIV-Status disclosure*'** to family and friends among HIV positive men and women.

They hypothesized that—

1. Disclosure of HIV would vary for different relationships, with greater disclosure occurring to friends, mothers, and sisters then to fathers, brothers or other family members.
2. Perceived stresses of disclosure were expected to be associated with relationship specific social support.
3. Perceived stress of disclosing HIV in specific relationships would be related to disclosing HIV, relationship specific social support, and depressive symptoms.

A pattern of selective disclosure was found. Rates of disclosure were associated with social support. Friends were disclosed to most often and perceived more supportive than family members, and mothers and sisters were disclosed to most often than fathers and brothers, and were perceived as more supportive than other family members. Perceived stress of disclosing HIV status was associated with disclosure, and disclosure was related to social support. Disclosure and its association with social support and depression varied for different relationships. Thus, at times of crisis such as illness, a close social environment provides the individual with an opportunity to discuss feelings, develop intimacy by disclosing private information, and express emotion. A good deal of evidence suggests that self-disclosure (including expression of feelings to a few close persons is an important component of healthy personality adjustment (Chelune et al., 1979). Close individuals such as family, friends, and health professionals who have come to know the patient intimately are likely to be much better able than those who only know him or her superficially to understand his or her emotional communications and expressions of needs. They are also likely to communicate better with the patient. This is primarily because repeated exposure and experience contribute to the support person's ability to understand the non-verbal cues of the patient—particularly the facial expressions, body movements and postures, and voice tone—to recognize which of his or her own non-verbal behaviours will be most effective with the patient (Rosenthal et al., 1979).

Social support may also undermine the patient's self esteem, to the extent that it reflects his/her status as an "impaired person" vis-a-vis the supportive other. Two aspects of this problem are particularly noteworthy. First, there is evidence that patients are often distressed by the "burden" (emotional, physical, and financial) that they place on their loved ones as a result of their illness. Tangible and even psychological supports are seen by some patients as infringements on their loved one's time and energy. Secondly, receiving support from others requires the patient to recognize his or her status as an impaired person. In order to conceal their "stigmatized" identity from others, some patients may exhibit social detachment and not disclose information about themselves and their feelings. Unfortunately, this social detachment may have effect of alienating family members emotionally from one another, straining interactions, and eroding trust (Gottlieb, 1981).

A study was done to study, ***'Barriers to social support for persons living with HIV & AIDS'*** by *Serovich, Brucker and Kimberly (2000)*. The purpose of the study was to test a barrier theory of perceived social support to HIV-positive gay men. The model was tested for friends and family separately in order to understand the uniqueness each provided for HIV-positive persons. In both models, the presence of barriers to social support (operationalized as availability, intimacy and disclosure) was hypothesized to diminish perceived social support. It was also hypothesized as more support was received from social network members, the better the health outcomes, as measured by lower levels of depression, less severe symptoms and disease progression.

For this study, barriers were measured in terms of relationship satisfaction, disclosure and social network availability using an adaptation of Barrere's Arizona Social Support Interview Schedule (1982). The results of this study indicate support for the principal assumption of barrier theory proposed by Smith and Rapkin (1996) according to which, 'there are obstacles individuals must traverse when seeking access to family members, lack of acceptance, lack of intimacy, negative interactions, feeling smothered, and wanting to protect family members.' However, the theory fails to differentiate between friend and family support. Thus, barrier theory appears to be much more generic and cannot solely be used to explain reduced family support. Level of satisfaction with family was a significant predictor of perceived social support for family but not for friends. It seems likely that to be considered a friend the relationship would inherently be satisfactory. Family relationships are non-volitional and less likely to be automatically satisfactory. It is also possible that if the individual is satisfied with a family member, he is more likely to feel supported. Thus, the quality of relationship is more important than the number of relationship, that is, there may be other barriers that discriminate between friends and family support which have not been explored in the study. Another interesting finding from this study was that barriers did not moderate the relationship between social support and health outcomes for family and friends. Only two indicators of health outcomes were taken namely depression and t-cell count and a direct relationship between them and social support was seen. There may be a host of other health indicators which are more germane to a moderating relationship.

A family systems approach to HIV may prompt individuals to view some problems and their solutions in a wider context of the family and other relationships. While psychological adjustment to HIV can be the presenting problem, it often reveals previously repressed problems pertaining to relationships, particularly secrets within the family. HIV can also bring forth new problems stemming from a role reversal in an established pattern of relationships. *Premilla D'Cruz*, in her book, **'In Sickness and in Health', The Family Experience of HIV & AIDSin India (2002)** has used the four-dimensional modified Rolland's family systems illness model having the patient, illness, family and the health care system as the four dimensions of the model which was employed as a baseline against which the findings were compared. The study's mandate was to understand the family experience of HIV & AIDSbased on the respondents' subjective meanings and interpretation. Seven nuclear families (households) participated in the study that was conducted in Mumbai. Out of these, three families belonged to the lower economic class, three were from lower middle class and one from the middle income group. In these seven households, three couples were discordant (husbands were HIV positive and wives HIV negative) and four were concordant (husband and wife both HIV positive). The units of conceptualization and analysis were the family unit, the marital dyad and the family members as individuals. The unit of enquiry was the marital dyad. In-depth interviews and observation was used as tools for data collection. It was found that the middle class household did not report any substantial economic impact of the HIV infection, because their more stable economic condition was able to absorb the costs in contrast to the poor household where the economic impact of the disease was severely felt. The first source of treatment for six couples was the private health sector in their undiagnosed phase while in the post-diagnosis phase they shifted to the public sector. However, the reason behind the shift from private to public sector was the refusal of the private sector to treat HIV positive individuals. The indirect costs were found to be very high due to the presence of very few organizations/hospitals providing HIV & AIDS-related services. The provisions of materials and financial support from both traditional and formal sources cushioned the intensity of the economic impact to some extent. Four households got support from relatives, while three were in receipt of formal support from an NGO providing services to sero-positive individuals and their families. Formal support provided some stability to the household's quality of life, putting an end to their need to borrow. However, the discordant couple did not appear to consider social resources to be of critical significance, since the surviving spouse would be present to manage the family either through available resources and/or earning capacity. Two changes in family structure were evident—growing female headedness and increasing dependence on informal support networks. Female-headedness was more in terms of the assumption of the earner role and of economic responsibility, but in terms of an increase in her decision making power. Greater enmeshment with the social support network was directly correlated with the pressing economic necessity and with concordant couple's need for social resources for the future of their children (D'Cruz, 200-)

Support for people living with HIV & AIDSinfection can come not only from family and friends, but also from others like relationship partners, professional care givers, and others (Johnston et al. 1995). There are three functionally distinct types of social supports:

Emotional support—consists of affection, confronting and encouragement that result in a sense of belongingness and personal worth.

Informational support—increases one's knowledge base.

Instrumental support—practical assistance with daily living.

Research has shown that emotional, informational, and instrumental support can directly alleviate psychological distress associated with chronic illness and can indirectly buffer the effects of stressful life events (Cohen, 1998). Even the theories of social support state that needs are met through much more interpersonal contact (Cohen and Willis, 1985). Social support plays an important role in terminal illnesses as well. In one study, cancer patients who lived significantly longer than was the norm for patients with their condition tended to maintain cooperative and mutually responsive relationships with others (Weisman & Worden, 1975).

Social support is actually not a single concept; instead, it is interpreted in several different ways and includes a range of phenomena. In fact, Carveth and Gothlieb (1979) concluded that "there is little agreement about the definition of social support nor is there consensus about the utility of distinguishing among sources of support." *Sidney Cobb (1976)* has specified three kinds of social support, all of which focus on the interpersonal aspects of a person's life. ***Emotional support*** is "information that one is cared for and loved," ***Esteem support*** is "information that one is valued and esteemed" and ***Network support*** is "information that one belongs to a network of mutual obligation". *Kahn (1979)* defined social support as "interpersonal transactions that include one or more of the following: the expression of positive affect of one person toward another; the endorsement of another person's behaviour, perceptions, or expressed views: and or the giving of symbolic or material aid to another". All of these definitions, while instructive, are not entirely complete.

The human environment provides a means for the individual to engage in "social comparison". By looking at the reactions of others, individuals can judge the appropriateness of their own reactions. They may learn from others how to define their own emotional arousal, and to assess the threatening quality of a situation based on the emotional expression of others around them (Schacter, 1959). This suggests that the emotional states of individuals who interact with the patient (family, friends, health professionals) have a profound influence on the emotional state of the patient. Therefore, social support in the form of calmness, caring, and reassurance may operate to reduce anxiety and modify debilitating emotional arousal in the patient. People usually look to others, particularly members of the primary reference group, for validation of their value and worth, for assessment of their personal characteristics, and for feedback about their behaviour. This is particularly true when the person is physically ill or disfigured. The reaction of others to the patient (social validation) can have an important effect on his or her self-image and feelings of self-esteem (Gottlieb, 1981).

One of the hallmarks of self-help functioning is the reduction or elimination, through social comparison and consensual validation, of members' sense of isolation or uniqueness regarding their problems and experiences. Self-help groups also provide members "an opportunity to build a new identity, and hence, a new base from which they can face the world and their predicaments". In the case of HIV positive individuals, relations between HIV positive individuals are qualitatively different from those between positive and negative persons. Goffman recognized these distinct forms of interactions, with normals and with peers, as critical in shaping both the "personal identity" of the stigmatized, the sense of the self, and the "social identity", the self as defined by others. He also situated this sociality within a key sociological theme: "the nature of an individual, as he himself and we impute it to him, is generated by the nature of his group affiliations" By beginning to associate with other infected individuals, the HIV-positive man learns a new meaning to being HIV infected. As Goffman notes, "in-group" alignments teach the individual to begin to conceptualize his predicament as normal, as shared by others, and to see this alignment as more "natural" than any form of alignment to "normals" (Goffman, 1963).[1]

Kalichman et al.(1996) studied, ***'people living with HIV infection who attend and do not attend support groups'*** which was a pilot study of needs, characteristics and experiences in U.S.A. they examined the differences in the psychosocial functioning among HIV seropositive men and women who have and have not attended support groups. They examined the utilization of support groups for meeting support needs among people living with HIV infection and AIDS. Standardized self-report measures were collected and in-depth interviews conducted in order to—(a) describe the characteristics of HIV seropositive persons who have and who have not attended support groups, and (b) to examine the group experiences of people who have attended HIV support groups. Fifty-five men and eight women were recruited from health care clinics and HIV & AIDSservice organizations. Flyers announcing the study were distributed and interested persons phoned in for an appointment. Seven individuals living in a residential centre for PLWHA also participated, assuring representation of persons across the HIV disease spectrum. Participants were compensated $25 for their time and expenses. These data were collected as a part of a mental health needs assessment. Participants were recruited over a three month period. Interested men and women were told that the study involved completing a survey and an audio tape recorded interview, both of which concerned coping with and adjustment to HIV infection. After taking their informed consent, participants completed a semi-structured 30-45 minute interview concerning their experiences with medical, case management, and psychosocial interventions. Questions included whether or not the participants ever attended support groups. Those who had been

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[1] Goffman, pp 65 in 'Against Death- the practice of Living with AIDS',Ariss R, (1997)

members of support groups were asked to describe their experiences, their perceptions of the group leaders, and the positive and negative aspects of support groups. Individuals who had not been in a support group were asked about issues of access, perceptions of the support groups, and interest in attending groups in the future. All interviews were conducted by a male doctoral-level clinical psychologist and interviews were audio-taped and transcribed for data coding. Following the open-ended interview, participants completed self-report measures of psychological functioning, social support, and mental health service utilization by individuals.

Interviews with women in the present study suggested that support groups can be helpful, particularly groups designed for women. People who had not attended support groups reported more emotional distress including depression, than those who had attended. Non-attendees were also more likely to endorse avoidant coping strategies than group attendees. This finding may explain their reluctance to seek support groups and thus there is a need for further research of the emotional, informational, and instrumental support needs of the people with HIV who do not seek services. People who do not attend support groups were also aware of their HIV serostatus for a shorter period of time. Duration of knowing one is sero-positive accounted for a significant proportion of the variance in anxiety and cognitive depression, and accounted for virtually all differences between support group attendees and non-attendees on measurers of social connectedness.

However, the study had few limitations. Firstly because of the small size, it is regarded as a pilot study. Secondly, although the sample was diverse with regard to ethnic backgrounds, gender, and sexual orientations, the small number of people within subgroups did not allow for statistical power necessary to characterize these groups. The study also does not tell us how the support groups have helped in psychological adjustment but only describes the characteristics of the people who attend and do not attend support groups. Also the interviews taken were audio taped which would have altered some responses of the respondents. Secondly, the interviews were taken by a male psychologist and so women may not have felt very comfortable and thus not given honest answers as they reported that they viewed support groups as beneficial when it was exclusively for women.

After reviewing the above studies, following conclusions can be drawn—that negative responses and attitudes toward PLWHA are linked to incomplete levels of knowledge about AIDS and HIV and to the causes of AIDS and routes of HIV transmission. Also HIV related DSD in India is in some respect a gendered phenomenon, that is, DSD is experienced more profoundly by women than by men. The fears and stigma related to HIV & AIDShave been found to be internalized by the vulnerable groups or those affected which directly affects their adaptability to the problem and how they deal with it. The cause behind the high levels of internalized stigma is the still persisting unsupportive social interactions with others and less of social support. Social support not only depends on number of social interactions but the quality of relationships, be it family or friends, support groups members or others. Also, willingness or participation in support groups is related to the duration of having been tested HIV seropositive. A need was felt to study the role of support and support groups longitudinally to see how these support groups and social support help in lowering psychological distress and providing other instrumental support and secondly, to see whether the area or environment in which the HIV positive person resides changes his likelihood of seeking support from support groups.

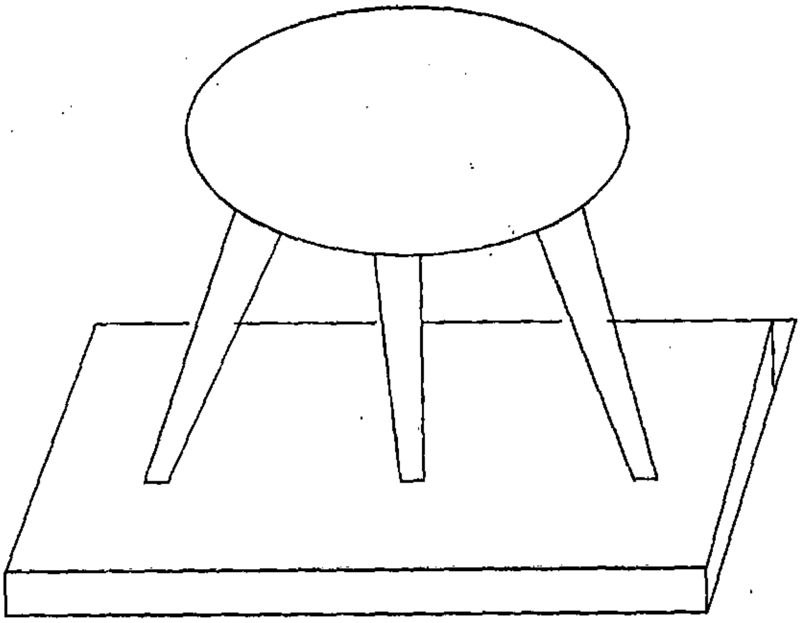
The ARV Treatment:

The suffering due to HIV warrants focusing on treatment and care, its integration with prevention being long overdue. The infection requires a long initial period of supportive and preventive measures with monitoring to assess when ARVs are to be started. Once ARV is started it requires continuous monitoring for side-effects and resistance with appropriate change of drugs. 'Adherence' of the patient to the regimen has often been discussed as the major problem but it is being recognized that it is more an outcome of health service issues such as communicating complete information, regular supply of drugs, visible clinical improvement and handling of side-effects. Given all these complexities, free treatment with regular drug supply through a structured system should be available to lower the sufferings due to HIV (Priya R., 2004).

A report on the role infrastructure plays in blocking or facilitating access to HIV care, treatment and support, was published by *International Council of AIDS Service Organizations (ICASO)* in 2002 titled, **'Adding Infrastructure to the Advocacy Agenda'**. The ideas presented in it were based on the results of an international, community based research study examining the experiences of PLHA in low income countries who have been able to access anti-retroviral treatment or therapies. Sixteen people living with HIV from 11 countries participated in in-depth interviews on how different elements of infrastructure have blocked or facilitated their access to ARVs. Thus, an expanded framework for infrastructure was prepared on the basis of the data from this research study.

Infrastructure, as defined in the report, includes *everything that it takes to get HIV care, treatment and support, to people who need it.* The framework may be thought of as a three –legged stool that sits on a base. The seat of the stool represents all of the HIV services that people may need and the three legs and base are the infrastructures that support these services. The three legs represent:-

1. Human resource (the people required to get the services to the people who need them).
2. Commodities/supplies (all of the things required to make these services possible)



3. Systems/facilities (all of the processes required to make these services possible).
4. The entire stool sits on a base which represents policy and law.

   1) Human resource- includes all of the people required making these care treatment and support services possible, including but not limited to: physicians, nurses, psychologists, social workers, family members, counselors, pharmacists, traditional healers, community support workers etc. health care providers can be a source of strength or weakness for the PLWHA. One of the physician reported in the study that they are often under-prepared to care for the PLWHA. Unsupportive and hierarchical relationship between the patient and the health provider can also act as a barrier to adequate care, support and treatment of PLWHA. Information provided by health care professionals can be, at times, inadequate and

misleading. Lack of collaboration among the relatively few physicians providing care to PLWHA can also be cited as a concern. Health care providers can also play an important role in facilitating medication adherence amongst patients and giving them hope for the future which, in turn, leads to greater confidence and persistence in seeking HIV care, treatment and support. PLWHA, the community and NGO activists are instrumental in enhancing access to HIV care, treatment and support. The creation of international contacts and networks was also seen as important in raising awareness of the treatment options available to people as well as sharing a sense of solidarity, especially when the support is absent at home. Where health resources are limited, family members play an essential role in caring for the PLWHA. Family is also a place where unequal relations between men and women impact negatively on a woman's ability to care for herself and her children.

2) Commodities/Supplies- commodities comprise another element of the infrastructure. This includes all of the things required to make care, treatment and support services possible. Drug costs continue to be a major barrier to access for PLWHA and thus have received much attention within the advocacy world. A major concern for the study participants was the uncertain sustainability of their ARV supplies-which was generally one month at a time. Unavailability or irregular supply of ARVs even to the hospitals was found to be a key barrier to access to ARVs.
3) Systems/Facilities—it includes all of the processes required to make HIV care, treatment and support services possible. These include community-based organizations (CBOs) and treatment activism, clinical trials and information systems. CBOs and treatment activism covers a range of activities including

- Advocacy with the governments
- Advocacy through court systems
- The importation of drugs and development of delivery systems.

- Information targeting and supporting PLWHA to access and maintain a treatment regimen, including information about side-effects.
- Financial, emotional support and support to families and partners.
- Geographic accessibility to adequate health services.
- Appropriate hospital services and facilities.

The importance of activists' networks and the access points they provide was underlined by the experiences of the participants of the study. However, it was found that not all HIV NGOs and community organizations were able or willing to take a positive role in advocating for access to treatment. Where there was little community organizing or advocacy for access to ARVs, people were denied a critical resource. Many NGOs have been focusing prevention and have only recently begun to turn their attention to issues of treatment and care.

Another issue regarding PLWHA is that of clinical trials. Access to ARVs through clinical drug trial is only option for many PLWHA in developing countries. Major concerns lie in the fact that although access through a trial gets people onto drugs, there is less certainty about the sustainability of supply or the quality of information they receive about the trial and the drugs they are taking. Some patients reported that the companies sponsor ARV Treatment on the condition that they would pay only for the drugs and the tests, but not for any side-effects as a result of the drug.

How well a person adjusts after being diagnosed as HIV sero-positive depends on both psycho-social support and access to information about the disease. Access to good quality information near or at the point of diagnosis is a critical element in a person's ability to cope with the complex physiological and social implications of a diagnosis. As such, information systems play an essential role in access to HIV care, treatment and support.

One of the patients in the study reported that he found a distinct absence of information in his community. Much of the information available was on internet and generally in English. Very little information was available in the regional or national language. A related concern was raised by some patients regarding culturally appropriate information. They described the need to provide resources and services including information about ARVs grounded in an awareness of the wider economic, social and health context of the indigenous communities. As HIV is seen as one of the number of health issues among many for the indigenous communities, it seems to be poorly integrated into community health educational activities and programs which remain a problem for the communities and for the government organizations and agencies responsible for implementing policy.

4. Policy/ Law – Returning to the stool metaphor, policy and law form the base of the stool, providing foundation and support for the other elements of infrastructure in the "legs" of the stool. This category that create the environment in which HIV care, treatment and support services maybe delivered. This includes national and international laws regarding stigma and discrimination, access to health care, treatment and support as well as regulations for accessing ARVs.

The Commission on Human Rights (2002 Session) called upon states to pursue policies, in accordance with applicable international law, including international agreements, which would "promote accessibility to all without discrimination, including the most vulnerable sectors of the population, of such pharmaceuticals or medical technologies and their affordability for all, including socially disadvantaged groups". Thus international law can also represent other advocacy tool within the expanded framework for infrastructure.

The International Guidelines on HIV & AIDSand Human Rights articulate the implications of viewing health as a human right, which includes accessing "safe and effective medication at an affordable price" (Guideline 6, UN Doc. 1997). The WHO has recently added ARVs to the Essential Drug List, (WHO, 2002), further strengthening the momentum access to ARVS as a human right. Human Rights policy is thus relevant to deliberations on policies and laws that facilitate access to HIV care, treatment and support. Furthermore, the U.N. Commission on Human Rights in its 2002 Session recognised that access to medication in the context of pandemics such as HIV is one fundamental element for achieving progressively the full realisation of the right of everyone to the enjoyment of the highest attainable standards of physical and mental health.

In the context of this study, human rights violations also emerged in participants stories of attempting to access treatment. Some reported of taking pills which seemed to be a part of the 'Virudene' (a so-called anti- HIV drug) trial that was discontinued in South Africa, ostensibly for being unethical. As part of the research trial, participants were also to receive money to buy fresh food, but they receive only medications. They also reported that some physicians involved in the trial sold the medication to private pharmacies. Some participants also reported that they were unsure of which drug they were taking, and did not have any options about drug regimes. Further, the process of gaining informal consent in these interactions was non-existent. They were told, "You are just lucky to be getting the drugs at all". Informal consent, understanding the pros and cons of taking certain regimens over others adequate nutrition, etc. were considered to be luxuries that they did not deserve. They feared that if they demanded those things, their supply of drugs would likely be cut-off, and so had the choice of taking the drug blindly, or not taking the drug at all. Furthermore, the integrity of the drugs that they were access is in question. They also reported of lot of people dying after taking these drugs. Another human rights issue involved the social patterning of health as raised by some of the participants that some of the people are disadvantaged relative to others with respect to a number of social and economic factors, such as education, income, employment and housing. This places them at a greater risk of poverty, violence, ill-health and reduced well-being which results in limited life-span and to them good health, regardless of HIV, is a bonus. HIV is one of a number of health issues that threaten them.

Despite the realization and protection of human rights at the international level, human rights guarantees are lacking at national and local levels. In some cases where there is no government policy or regulatory framework on ARV treatment, doctors and other healthcare providers can find themselves in a difficult legal position. In some countries (eg. Swaziland) ARVs are not in the government list of medicines that practitioners can legally prescribe to their patients. Nevertheless, doctors do prescribe these drugs, which are available in the private sector. One of the physicians reported that they have "to proceed very cautiously and have the possibility at the back of their minds that they could face disciplinary measures if the government decided to take up the issues".

Because of situation like these, the U.N. Commission on Human Rights (2002) has called states to refrain from taking measures which would deny or limit equal access for all persons to preventive, curative or palliative pharmaceuticals or medical technologies used to treat pandemics such as HIV or the most common opportunistic infections that accompany them. These examples demonstrate how the base of the infrastructure stool, policy and law, play out in the experiences of the participant PLWHAs.

Thus to conclude, access to care, treatment and support is a central concern for HIV advocacy. Drug pricing is a key barrier to access and has appropriately received much attention. Another focus of attention in the access debate is infrastructure. Lack of infrastructure is broadly cited as a barrier to HIV care. Furthermore, the Declaration of Commitment on HIV & AIDS, a powerful advocacy tool, views infrastructure as "imperative" for HIV prevention, care, treatment and support. This research demonstrates how various people living with HIV from around the world have viewed various elements of infrastructure as crucial in blocking or facilitating their access to HIV treatment. This report also demonstrates how communities may capitalise on the infrastructure dialogue to advocate for the needs of their members. The advocacy challenge is to identify which elements of infrastructure, if enhanced, could best improve access to care, treatment and support in particular settings, and then to use the infrastructure discourse spelled out in the Declaration of commitment and other reports to demand those improvements. However, the PLWHA need more than infrastructure and drugs. Social support is necessary for utilizing these as well as for ensuring a mindset of the PLWHA that is conducive to his/her remaining health.

Social support is provided by other people and arises within the context of interpersonal relationships. Different types of relationships provide different types of support. Categorizing relationships as being with family or friends is by itself only an initial, rudimentary characterization. We need as well to be able to differentiate relationships according to their content, process, and development. This can be accomplished only by identifying and studying a variety of specific network relationships. If we do not identify specific network members, we also will be unable to obtain precise data regarding relationships among network members. Failure to obtain these data precludes study of how social networks may function as support systems (Gottlieb, 1981)[2].

Social networks can be conceptualized as a personal community that embeds and supports critical social identities. Achieving meaningful participation in one's culture and society is an important task confronting us throughout our lives. The nature of our participation can be suitably captured or characterized by our social identities. Social identities are thus related to roles and roles to role performances, as well as to other relevant aspects of the self concept. The viability of a social identity depends significantly on its recognition in the social network. They are recognized and supported by being embedded in relationships. By expressing and embedding our social identities in a social network, we make our social network a personal community. These personal communities reflect our involvement in the major spheres of life, as well as the degree to and the manner in which these spheres are integrated

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[2] .Hirch B.J in 'Social networks and social support' ed. by.Gottlieb B.H (1981), cht.6 pp 151.

and segregated. These personal communities also reflect our values and choices. In creating and maintaining a particular personal community, we are at least choosing from among feasible alternatives, how we seek to achieve meaningful participation in our culture and society[3].

A social network that reflects and supports a repertoire of satisfactory social identities and over time provides opportunities for further development and enrichment is a healthy outcome. A less healthy outcome consists of either the lack of a sufficient repertoire of personally valued and developmentally appropriate identities, or their failure to find adequate expression and support in the social network.[4]

Positive People's Network:

After the first incidence of HIV infection was reported in 1986 at Chennai, HIV has started spreading rapidly from urban to rural areas and from situations of risks to general situations. Every person identified as HIV-seropositive has to suffer stigma and discrimination in the society. People living with HIV & AIDSwere denied treatments, retrenched from jobs, severed from family and the community. The problems and issues the PLWHA faced were unique to them and a few sensed the need to break the silence and speak out. As in most other countries, some people living with HIV in India had also begun to organize themselves into support groups. The first such group- **the Association for People Living with AIDS and HIV Infection** was started in Pune in August 1992. The association provided its members with group therapy and legal advice, and members visited one another at home in the event of illness. From the year 1994, PLHA started meeting informally at Chennai, Pune, Delhi and different places to share and discuss the predicament they were facing.

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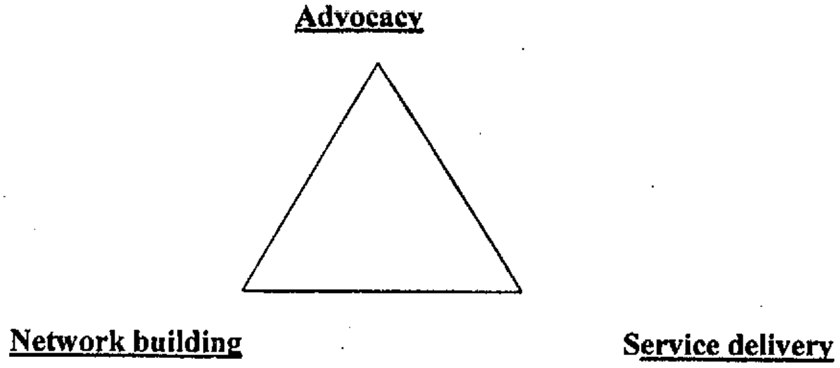
[3] ibid, pp 160.

[4]. Ibid, pp. 163

On 20th February 1997, 12 PLWHA representing various states of the country met at Chennai and affirmed the need of a platform to collectively voice the concerns of PLWHA in India. The deliberations of these PLWHA subsequently gave birth to ***Indian Network for People Living with HIV & AIDS***(INP+). The network got registered under the Tamil Nadu Societies Registrations Act, in May 1997. From then it has been working under the leadership of various presidents, the first being Dr. Tokugha Yepthome (1997-1998) and the present being Mr. Abraham Kurian (2002-till date). INP+, in its evolution as the singular national movement of 'People living with HIV & AIDS' in India, has ushered a triangular strategy, to meet with the emerging challenges



Advocacy, Network building and Service delivery has gained foothold as inseparable axioms of the network's mission. The triangular approach provides PLHA with choices and the ability to choose, as well as, an attempt to gain more control over resources people need to improve their conditions.

The functional structures of INP+

i. Governing board- the apex governance apparatus of INP+ is composed of elected representatives from the State level networks. The board is constituted for tenure of two years.

ii. The National and State secretariats are the administrative setups, comprising of professionals and staff from various fields supporting the national and the state governing boards. INP+ president is a part of the national secretariat.

iii. A working group- is made up of representatives of IV Drug users, MSM, Women and children, and CSWs, is in place at the national level with a consultative status to ensure adequate voicing of interests from all segments affected.

iv. Positive Women Network (PWN+) is afflicted to INP+ and work with the State Level Networks and the District Level Networks focusing on issues of women and children. PWN+ secretariat helps the organization to handle professional tasks.

v. INP+ gives affiliation to State level networks (SLN), SLNs to District level networks (DLN) and DLNs to Taluk level networks (TLN). A memorandum of understanding on affiliation is signed between INP+ and all levels. As a result of the network building initiatives, INP+ has spread across 18 state level networks and 80 district level networks.

Thus, INP+ provides a voice for PLWHA at local, regional and national level in order to facilitate systemic changes in areas like care and support, access to treatments and addressing issues of discrimination faced by PLWHA in Indian society.

Six objectives of INP+

1. To facilitate and improve access to treatment for PLWHA.
2. To improve access to information.
3. To promote and protect human rights of PLWHA.
4. To promote involvement of PLWHA in all levels of decision making.
5. To promote social acceptance of PLWHA and to end stigma and discrimination.
6. To provide opportunities for networking for people with HIV.

The national strategies for implementation of GIPA developed by INP+ have been accepted by NACO and INP+ is looking forward to seeing NACP third phase find adequate reflection of voices raised by PLWHA

PLWHA Networks in India

INP+ Indian Network of Positive People (National level network of positive people)

State wise list of PLWHA Networks recognized by NACO

ANP+ Assam Network of Positive People

CPK+ Council of People Living With HIV & AIDSin Kerala

GSNP+ Gujarat State Network of People living with HIV & AIDS

HPPWS HIV Positive People Welfare Society, Chennai

KNP+ Karnataka Network of People Living With HIV & AIDS

MNP+ Manipur Network of Positive People

NMP+ Network of Maharashtra by People Living with HIV&AIDS

PNP+ Pondicherry Network of Positive People Welfare Society

RNP+ Rajasthan Network of Positive People

ZINDAGI Goa

PWN+ Positive Women Network

TNP+ Telugu Network of People living with HIV / AIDS.

The Emergence of the Greater Involvement of PLWHA (GIPA) Principles

During the early phase of the HIV epidemic, People Living with HIV & AIDS(PLWHA) helped each other and drew support from friends, family and sympathetic community members. The idea that the personal experiences of People Living with HIV & AIDS(PLWHA) could and should shape the response to the epidemic found a public voice in 1983 when a small band of PLWHA gathered at a national medical conference on AIDS in Denver, Colorado, protesting their exclusion from the planning process of workshops related to AIDS. These have since become widely known as The Denver Principles and they constitute the original manifesto of the PLWHA self-empowerment movement.

The Denver Principles Statement from the Advisory Committee of People with AIDS

"We condemn attempts to label us as "victims", a term which implies defeat, and we are only occasionally "patients", a term which implies passivity, helplessness, and dependence upon the care of others. We are "People with AIDS".

Recommendations for Health Care Professionals

1. Come out, especially to their patients who have AIDS.
2. Always clearly identify and discuss the theory they favor as to the cause AIDS, since this bias affects the treatments and advice they give.
3. Get in touch with their feelings (e.g. fears, anxieties, hopes, etc.) about AIDS and not simply deal with AIDS intellectually.
4. Take a thorough personal inventory and identify and examine their own agendas around AIDS.
5. Treat people with AIDS as whole people, and address psychological issues as well as biophysical ones.
6. Address the question of sexuality in people with AIDS specifically, sensitively and with information about gay male sexuality in general, and the sexuality of people with AIDS in particular.

Recommendations for all People

1. Support us in our struggle against those who would fire us from our jobs, evict us from our homes, refuse to touch us or separate us from our loved ones, our community or our peers, since available evidence does not support the view that AIDS can be spread by casual, social contact.
2. Not scapegoat people with AIDS, blame us for the epidemic or generalize about our lifestyles.

Recommendations for People with AIDS

1. Form caucuses to choose their own representatives, to deal with the media, to choose their own agenda and to plan their own strategies.
2. Be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations.

3. Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.
4. Substitute low risk sexual behaviors for those which could endanger themselves or their partners; we feel that people with AIDS have an ethical responsibility to inform their potential sexual partners of their health status.

Rights of People with AIDS

1. To as full and satisfying and emotional lives as anyone else.
2. To quality medical treatment and quality social service provision without discrimination of any form including sexual orientation, gender diagnosis, economic status or race.
3. To full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment and to make informed decisions about their lives.
4. To privacy, to confidentiality of medical records, to human respect and to choose who their significant others are.
5. To die – and to live – in dignity".[5]

The rhetoric of "coming out" signaled a commitment to an established gay liberation agenda. It was assumed that the political and phenomenological benefits demonstrated in coming out as gay would transfer unproblematically to the situation of being diagnosed with AIDS. Sensitivity of professionals to welfare client's sexuality was demanded. The rendering of a previously medically defined identity as a social one was borrowed directly from gay and women's liberation. The concepts of "patients rights" emerged in demands for control over medical treatment regimens, to freedom from discrimination, to representation on decision-making bodies, and the recognition of non-biomedical forces ("psychosocial issues," personal "agendas", "feelings") within the healing/illness complex.

Experiences from around the world make it clear that no community or country can tackle the negative fall-out of HIV & AIDS without building on the strengths and the

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[5] Callen and Turner (1988) in 'Against Death-The Practice of Living with AIDS', 1997. Cht.8 pp. 136

first hand knowledge of those living with the infection. In countries where PLWHA have taken the initiative to mount constructive responses, such as Brazil, Thailand and Uganda, there has been a slow-down in new infections and a more sensitive approach to care has emerged. The strategic change from top-down to more participatory approaches not only meant the inclusion of PLWHA but also youth, communities and especially vulnerable populations in the design and implementation of responses to HIV & AIDS.[6] Although this approach has still to become the norm in all efforts to contain the HIV epidemic and provide care and support to those infected and affected by HIV & AIDS, there has been a clear movement towards adopting it. Policies, projects and initiatives of this kind could be categorized as the 'second generation response' to HIV & AIDS. Thus, in the present time it is internationally recognized that a crucial goal and hallmark of HIV & AIDS advocacy is the meaningful involvement of People Living with HIV & AIDS(PLWHA) in all aspects of programmatic and policy related responses.

Greater Involvement of People Living with HIV & AIDS (GIPA)

The acronym GIPA was publicly vocalized for the first time during the preparatory meetings of the Paris AIDS Summit in 1994. The term was used in the Declaration that was signed by representatives of 42 countries which undertook to "fully involve...People living with HIV & AIDS in the formulation and implementation of public policies..." and to "...support the greater involvement of people living with HIV & AIDS (GIPA)." The principles of GIPA were later reinforced by the UNGASS Declaration in 2001 signed by almost all members of the United Nations. They have been adopted by UNAIDS and GIPA is presently an integral, indispensable part of all major international declarations pertaining to the epidemic.

– Declaration of the Paris AIDS Summit, 1 December 1994.

GIPA PRINCIPLES

1. To support the greater involvement of people living with HIV & AIDS (PLWHA) through initiatives to strengthen the capacity of and coordination of

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[6] Asia Pacific Resource Centre.http://www.plwha.org/

networks of PLWHA and CBOs stimulating the creation of a supportive political, legal and social environment;

2. To involve PLWHA fully in decision making, formulation and implementation of public policies;
3. To protect and promote the rights of individuals, in particular those living with or most vulnerable to HIV & AIDS, through legal and social environments;
4. To make available necessary resources to better combat the pandemic including adequate support for PLWHA, NGOs and CBOs working with vulnerable and marginalized populations;
5. To strengthen national and international mechanisms connected to human rights and ethics related to HIV & AIDS.

Asia Pacific Region: Involvement of PLWHA

In the Asia Pacific region where the majority of PLWHA live in constant fear, battling stigma and discrimination in their daily lives, the criticality of Greater Involvement of People Living with HIV & AIDS (GIPA) as a strategy to alleviate their condition cannot be overstated. For most countries in this region where the HIV epidemic has not yet matured, the first generation, top down interventionist responses still dominate efforts to stem the spread of HIV or care for those affected. Public visibility of the active involvement of PLWHA at all levels can challenge existing HIV related myths and derogatory stereo-typing and help reduce stigma and discrimination. GIPA can promote a positive shift in the way society perceives PLWHA and can sow the seeds for an enabling environment wherein PLWHA, their families and communities may live with self respect and dignity.

There is increasing recognition of the importance of PLWHA involvement in the campaign against the HIV epidemic; responses in the Asia Pacific region have not yet accorded adequate importance to the need for involvement and empowerment of PLWHA in prevention efforts.

The vast majority of countries in the Asia Pacific region are in the early stages of the epidemic the lessons learned from Africa where GIPA had been successfully implemented in partnership with the Government, civil society and private sector, could not be immediately replicable. Therefore, a pilot project focusing on the five South Asian countries - Bangladesh, India, Nepal, Pakistan and Sri Lanka - was initiated in 2001, named the Greater Involvement of People Living with HIV & AIDS (GIPA) Project. The project aimed at meaningful participation of PLWHA in response to HIV & AIDS in South Asia and was implemented jointly by Sahara - a New Delhi based NGO and UNDP, through the establishment of a close partnership with 17 PLWHA groups in the sub-region. This was the first regional project aimed at raising the profile of GIPA in South Asia. It also hoped tc build a participatory process where the PLWHA groups identified activities in the areas of organizational development, awareness building and sensitisation, care and support activities and employment - issues which they felt were crucial for enhancing their capacity to gain influence. The project provided a unique opportunity for PLWHA to network and implements small-scale activities together and signaled the beginning of extensive networking among PLWHA across the Asia Pacific region. By the close of this pilot project in 2002, the process of learning about GIPA and the difficulties of implementing these principles had already begun.

Many PLWHA had expressed the frustration that although GIPA was an integral part of international declarations relating to HIV & AIDS and national policies, the intent of the principles, namely, to improve responses to HIV & AIDS and better the situation of PLWHA, has not been realized. PLWHA are still not fully included in prevention and care responses and all too often, their inclusion is a token one. PLWHA from the region who have been able to exchange their perceptions about GIPA and share their experiences were unanimous in their conclusion that the implementation of GIPA has failed to live up to their expectations.

The implementation of the GIPA principles would bring about their meaningful empowerment at all levels, enabling them to address their basic needs. The GIPA Project identified some of these needs as being:

- access to information on HIV-related issues; testing facilities where confidentiality is respected; counseling services, quality treatment and community care;
- skills to live positive lives and opportunities to ensure sustainable livelihoods for them and their families; and
- capacity to carry out advocacy and make an impact on the epidemic reducing stigma and discrimination in an atmosphere where people can work together for a better future, regardless of their sero-status.

The lack of initiative on the part of NGOs and governments to implement GIPA is of concern to PLWHA. Many PLWHA have expressed anxiety that NGOs neither understand the need for independent and strong PLWHA groups, nor believe that PLWHA have the potential to become an equal partner, given their limited capacity. Governments, while adopting sensitive policies, face difficulties in implementation in many countries of the region. At the same time PLWHA groups have recognised that they need significant strengthening of their organisations and members in order to breathe life into the GIPA principles. The culmination of the piloted GIPA-Project yielded a vision statement formulated by all the PLWHA from South Asia who participated in the pilot phase.

Empowerment of PLWHA: A Third Generation Response to HIV?

The learning from the pilot phase of the GIPA-Project is that a new GIPA initiative needs to be developed - one that shifts the focus from the limited understanding of GIPA as "***genuine involvement***" to an expansive vision aimed at the ***overall empowerment*** of all PLWHA, their groups and networks.

The pilot phase had made it apparent that PLWHA did not view GIPA as an end in itself, but as a tool to achieve the objectives they had set for themselves and their networks. This distinction was crucial in formulating the next phase of the project. Named the *Asia Pacific Initiative for Empowerment of PLWHA*, the second phase of the GIPA project was conceived as a three-year effort and initiated in 2002. Despite the global acceptance of the GIPA principles expressed in the Paris AIDS Summit Declaration as well as the international guidelines on HIV & AIDS and human rights, it had become painfully clear to PLWHA that even when implemented, GIPA by itself would not stimulate a change in their living conditions. In some instances, PLWHA felt that they were being 'used' by civil society and that their representation in official committees did not necessarily translate into a truly significant manifestation of their rights or influence.[7]

HIV infected have expressed different ideas of what empowerment means. Infected gay men stress "taking control of myself," being a "survivor," and express interests in organization building. In contrast, the women emphasize "support", reproduction and relationship issues. Despite the ideal of unity, therefore, gender appears to be a force working to fracture the unifying signifier of HIV. The 'long term survivors define it as, "Empowerment begins, therefore, in redefining one's status from that of a dying patient to that of a person living with AIDS." The ontological focus has shifted from the threat of death implicit in the medical meanings of AIDS to the promise of life implicit in the philosophy of empowerment. This is the essential intention of this new discourse: to disengage from a negative medical identity and reconstruct the self in life-affirming terms. (Ariss, 1997).

Research Question

Thus through my research study, I purport to enquire –

> *What is the role of a PLWHA network in increasing involvement of PLWHA in AIDS control efforts and in the empowerment of the PLWHA themselves?*

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[7] Asia Pacific PLWHA Resource Centre. http://www.plwha.org/

Methodology

Research Objective-- To study a 'People Living with HIV & AIDS' (PLWHA) Network in Allahabad and examine its efficacy in addressing the needs of PLWHA in the context of differing social backgrounds of the PLWHAs in

Specific Objectives—

1. To study the structure, objectives and the functioning processes of a PLWHA network in relation to social structures as reflected in the composition of the membership (caste, class, and gender) and their impact on the dynamics of the group.

2. To study the impact of the structure, objectives, and functioning processes of the network, on the'quality of life' of the PLWHA members. Assessment of the changes in the, as perceived by the PLWHA themselves, and in the context of social differences of economic status, caste and gender.

3. To assess the responses of the '*help providers*' to the PLWHA to see how the network fulfils the objectives delineated by the INP+ and hence the role of the network in creating a positive attitude and effectiveness in improving access to quality and comprehensive treatment and care.

Conceptualization

Social stratification

This study looks into the socio-economic composition of the network and hence an attempt was made to study the social stratification and how it determines the functioning and dynamics of the network. Social stratification refers to the division of society into layers or strata. It refers to the unequal positions occupied by individuals in the society due to their social and economic positions as well as gender. In this study, the members have been classified into the economic categories of high class, middle class and low class. They have also been classified into three different categories of caste- high caste, Other Backward Caste (OBC), and low caste. Members have also been classified into male and female. Analysis of the data according to these categories has enabled the researcher to place the findings in the larger socio-economic and cultural milieu of the society.

Quality of life

Quality of life (QOL) of the members has been studied in this study in a before-after design comparing the QOL of the members, as reported by them, just after their being diagnosed HIV positive and their QOL after joining the network. Various dimensions of QOL have been explored, namely, the physical-which meant the symptomatic/asymptomatic stage of the members, emotional-the emotional reaction to the diagnosis of HIV and their emotional state after joining the network, and social which included economic, emotional, instrumental and informational support.

Research Design —

Data required

Detailed data was required on social composition of membership, organizational history and experiences of PLWHA after diagnosis of HIV status and after joining the network. With limitations of time and a single researcher, a one network case study design was adopted to explore the various dimensions in an Indian setting. Allahabad city in Uttar Pradesh was selected for the research purpose due to the researcher's familiarity with the area and her work experience as an HIV counselor in the city.

The Study Area

The State of Uttar Pradesh

During the one and a half decade ago or so, the HIV & AIDS epidemic has been posing a major health and development challenge at the international level. India is experiencing a steadily increasing epidemic with varying levels of prevalence in different states of the country. Uttar Pradesh (UP), with a population of 166 million, is one of the most vulnerable states in India due to its sheer size and not so favorable socio-economic indicators. Identification of the factors that help in the spread of the scourge and development of a timely and adequate response are the needs of the hour so as to prevent its adverse impacts. Overall prevalence based on the surveillance of all the STD and ANC clinics in UP has shown that there was a significant decline in percentage of HIV positive cases from **2.21 percent in 1998** to **0.85 percent in 2004** at **STD clinics**. On the other hand, a slight increase has been noted in HIV positive cases in **ANC sites0.18 percent in 1998 to 0.23 percent in 2004.** UPSACS data on sentinel surveillance shows the presence of HIV at low levels all over the state, with comparatively higher prevalence in Eastern belt of the state. The epidemic shows a slow, but progressive, increase. The primary reason for the spread of infection in this region is migration. Spouses and children of infected migrants are at risk of infection through them. While the mode of transmission is mainly heterosexual, other modes of transmission- though only in a very small number of cases, are also seen.

Poverty, illiteracy, and ignorance render the population of Uttar Pradesh highly vulnerable. This, coupled with the presence of high-risk groups and bridge populations across the state, displays a potential for further increase. As per 2001 Census, 80.16 percent of the state population lives in rural areas and thus only 19.78 percent of the population lives in the urban areas. The sex-ratio in U.P. is 882 as per 2001 census, which is much below the national figure of 933. The literacy rate of U.P. as per 2001 census is 57.36 percent with the rate being 70.23 percent for males and 42.98 percent for females. There is in-migration to large towns in search of livelihood. Besides that, the out- migration from U.P. to other states is also significant. This transit population based in slums generally on the outskirts of the towns is largely unaccounted and has low access to health services. A large proportion of this floating population in the industrial towns and religious congregations like Varanasi and Allahabad is sexually active and thus vulnerable. (Resource mapping for HIV & AIDS in UP; SHRC report 2004).Thus taking into account the above factors which render Uttar Pradesh most vulnerable to an increase in HIV positive persons in the near future, it becomes an important state to be monitored.

The study participants-- the study was conducted in the city of Allahabad in Uttar Pradesh. The study was conducted at the head office of an upcoming PLWHA network, 'U.P. Welfare for People Living with HIV & AIDS', and now known as 'U.P. Network of Positive People' (UPNP+). At the time of data collection, the network comprised of 130 members hence the demographic data of these 130 members was taken. However, narrative accounts of only 22 members could be taken as they were the regular members and readily available at the network office for the study. Field visit was made to 3 villages with the team of UPNP+ members to the villages and families of four members of the network. However, field visits to the houses of passive members could not be made as confidentiality about their HIV status had to be maintained.

1. Baseline data— demographic data of 130 members was taken from the records of the network which included information about their age, sex, marital status, caste, economic class and area of residence.

   demographic data and treatment history of 22 members was taken through a schedule which included—name, age, gender, sexual orientation, marital status, address, caste, occupation, income, family size, migrant/non migrant, educational status, period of infectivity, presenting symptoms, number and types of medical institutions visited, whether on ART or not and from where, duration of having been on ART and their financial impact.

2. History of the group and information about its composition (caste, class, gender, age group etc.), medical and other services facilitated by the group to its members were taken from the records of the network and by interviewing the founder members of the network as well as members of Swarg, an NGO that was the network's founding support base.

3. Dynamics of the PLWHA group were studied as a participant observer.

4. Perceptions of roles and functions of the network, its office bearers and members were elicited through group discussions.

5. Case studies of the 22 members were analyzed on the basis of economic class, caste, and gender to understand the socio-economic and cultural determinants of their behavior, situations and needs

6. In-depth, semi-structured interviews of the *help providers* i.e., family, friends, medical persons, network members were taken using a checklist of issues to be explored.

7. Feedback to the members of the group was given and group discussions were held with the members of the group, to cross-check the researcher's interpretation of their status and situations and giving them an opportunity to make any changes in the researcher's interpretation and understanding.

The Process

The study was conducted in two phases, firstly for one month, in the month of August, 2006. The researcher remained in the field setting, establishing rapport with the network members and observing their day to day activities. Gradually, the researcher was able to establish a good rapport with the network members and the other organisations working with them. The researcher also worked as a counselor with the network on a voluntary basis.

The second phase of the study was conducted for a period of three months from 1st December 2005 to 1st March 2006. The researcher made regular visits to the network office and was actively involved in their day to day activities assisting them in their work and counseling the old and new members. In addition, the field visit also included the VCTC centres in the city, the district hospital and the medical college, the offices of the other prime NGOs working on the issue of HIV & AIDSin the city, home visits in the villages of four members, and accompanying the members to a few workshops and seminars which they were attending.

In the study, although the network member was the main information provider, in some cases, the family members and other network members were also sources of data. The data from other family members and network members revealed their concerns and how these shaped the experience of the network members and their significant others. Therefore, the data from other family members, and network members offered the opportunity to the researcher to do triangulation and to knit their stories together.

The data collection methods included interviews and participant observation. Three forms of interviews were used: structured interviews, semi-structured interviews and focused conversation. Demographic data of the network members as well as their illness history was collected in a structured interview format. Semi-structured interviews were conducted with the help of a checklist of issues during the initial stage of the data collection when the members were not comfortable sharing their personal histories with the researcher. Gradually, as better rapport with the researcher developed, the members and their family members became active and started telling their own stories more freely. As a consequence, the form of interviews changed to 'focused conversation'. Through focused conversations, the members were asked to describe their experiences or sufferings from the time they were tested for HIV for the first time and what led to their being tested for it and their journey from that stage to being a member of the network. Encouraging comments and probes were used to help pursue their narratives further. Members talked about their concerns, other people and everyday situations surrounding them and how they deal with them. In this way personal stories were used as a tool to lead the conversation about how the members perceived issues faced by PLWHAs in general as well as what role they saw of the network. Data from these conversations provided the researcher an opportunity to better understand how the members made sense of their situation and provided the background to the cases.

Participant observation was another method of data collection to gather comprehensive and exhaustive information about the network and its members. The main focus of observation was on the ways the members of the network interacted among themselves and the concerns they expressed to each other; their belief about health, life and what changes have occurred in their lives after they became a member of the network. Working of the network was keenly observed by the researcher to see in what ways the members participate in its working, in fulfilling its objectives and how the network in turn acts as a support system for them, fulfilling their needs and their aspirations. The researcher also observed how the network, as a group, interacts with the outer world i.e. the media, other NGOs and those who provide assistance to them, the health care providers, the government officials and other organisations.

Informal group discussions were also held in order to tap the experiences of the network members within the group and how do they define their identity as a network member in comparison to their earlier identity and how this new identity has changed the way they perceive their surrounding, their aspirations and their life. The observations coupled with the narrative accounts of the members enabled the researcher to get a feel for the natural flow of events which lead to the formation of the network to fulfill the needs of the PLWHA and how the network is making efforts to fulfill those needs.

Field journals were prepared at the end of each day of the field visit. It consisted of the description of conversations and situations and researchers interpretation of the inter-subjective meaning hidden within those situations, thoughts and feelings of those involved in the conversations and interactions.

Data analysis:

Data analysis was done after the fieldwork was completed. The 130 members were classified into three different economic categories and other demographic categories and were compared accordingly. The narratives and the field notes of 22 case studies were read several times to delineate the issues in the data. On the basis of the issues coming out of the existing review of literature and the narratives, relevant sections of the narratives were coded based on the diversity of experiences found in the narratives. A comparative table of the demographic data and medical history related to HIV of these 22 cases was constructed. A comparative table of the narratives of these 22 cases categorized into three economic categories—high class, middle class and low class, was constructed in order to see the similarities and diversities in each case on the different issues. This helped the researcher to identify an overall pattern of complexity and causal links to be analyzed.

Ethical Issues –

1. For the study, the researcher contacted the President of the UPNP+ network and explained to him the objectives of her research. A request letter duly signed by the researcher was submitted to the network office specifying that confidentiality would be maintained about the links of the network and the names of the network members. A consent form was signed by every member of the network whose narrative had been taken before the interview to ensure that they were willing to share their stories with the researcher.

2. Even though the office bearers of the network and other members who formed the part of the 22 case studies had said they did not mind their names being revealed in the text, it was decided to use alphabetic pseudonyms which would allow linking data of each individual member and yet maintain confidentiality. Names of the office bearers of the network have been given in the text with their consent.

3. The narratives were translated from Hindi to English by the researcher herself to maintain the confidentiality of the data and to retain the contextual meaning. The narratives were paraphrased back to the members in order to cross-check the researcher's interpretation of their situation and feelings.

Limitations of the study—

1. As the field work was done by one person over a period of three months, the different processes that could have been examined if it were a longitudinal study still remain unearthed.
2. Since it is a case study of only one PLWHA network, its generalizability is limited.
3. The sample taken for the case studies is of PLWHA who are regular members of the group, so data of the passive, not so regular members, could not be taken.

Chapterization:

The first chapter looks at the review of existing literature on various issues in HIV & AIDS, like stigma, discrimination, support and support groups, the services needed by the PLWHA, the emergence of PLWHA groups and networks, the GIPA principles and their policy implication.

The second chapter gives a brief introduction to the U.P. Network of Positive People (UPNP+), its structure and perspectives. It looks into the history and formation of the network, it membership and composition, its objectives and structure and the functions of its office bearers.

The third chapter looks into and analyses the social composition of the network and its role in the dynamics and setting up of priorities of the network. It also documents and analyses the interactions of the members within the group and their interaction as a group with the outer world in the light of its socio-economic composition.

The fourth chapter analyses the narratives of the members of the network in the light of the issues coming out of the existing review of literature on HIV & AIDS. It compares the experiences and quality of life of the members after their diagnosis with their quality of life after joining the network.

The fifth chapter sums up the findings of the study and discusses them in the light of the existing literature and their implications for strengthening of PLWHA networks and defining their role.

CHAPTER TWO

Chapter 2

The UPNP+: Structure and Perspectives

After being diagnosed HIV seropositive in June 2003, the first and the currently continuing president of the UPNP+ network, Mr. Naresh Yadav felt the need to find a solution to the uneasiness he was going through. He thought, "The most important thing to do was to deal with the *fear* and *loneliness* that surrounds the person living with HIV/AIDS". He came back to Allahabad from Bombay, where he had shifted to after marriage to set up his own business. He had been consulting a doctor in Allahabad on the recommendation of his doctor in Bombay, who was treating him for HIV. After coming to Allahabad he came to know that this doctor, who was Dr.Amitabh Upadhyay, was working with 'Swarg', a Trucker's Intervention Project. The doctor told him to come to the office on the highway. There he got introduced to Mr. Anil Yadavendu, who was running the project. Mr. Yadavendu persuaded him to attend the conference organized by The Lawyers' Collective in New Delhi in January 2005. After much thinking, Mr. Naresh Yadav attended the conference. There, he met many more people like him who were working in this field. He met some members of the Indian Network of Positive People (INP+) and the president of Rajasthan Network of Positive People (RNP+), who urged him to give shape to his willingness to work for HIV positive people. They motivated him to form an organization of HIV positives and collectively address the needs of the people who are ignorant and do not know where to go and whom to approach for help after being diagnosed as HIV sero-positive and to give them an enabling environment in which they can express their feelings openly without the fear of being discriminated or blamed.

In Delhi, when he met people who were HIV positive and were very healthy and working on different issues related to HIV, he decided to work for organizing HIV positive people. He came to know that many HIV positive organisations have been formed in different states but none of such kind exists in Uttar Pradesh, he decided to form one. In the conference, he was on a look out for people who hailed from U.P. and were willing to work on this issue. He met some people there who had the similar quest and a willingness to do something to improve their condition, as well as of those who were in a similar situation. He came back to Allahabad where the members of Swarg and Dr. Amitabh Upadhayay helped him to find other such people who were willing to work on this issue. Swarg, which had been working on the issue of HIV for the past six years, providing counseling, treatment for opportunistic infections and getting the people, especially the truck drivers and their families tested for HIV at the VCTC centers, also felt the need to organize the HIV positive persons they were in contact with as they felt that they themselves were unable to cater to all needs of the PLWHA. They could only provide them with the counseling, testing and medication for the opportunistic infections but were unable to pull them out of the fear and loneliness in which they were living. The members of Swarg helped Mr. Naresh Yadav in the formation of the network by bringing the PLWHA they knew in that area. He also had regular consultations with INP+ president Mr. K.K. Abraham and Mr.Brijesh Dubey, president, Rajasthan Network of Positive People (RNP+) and board member of INP+, who guided him in the formation of the network.

Finally, after three months of hard work he was able to find eleven members who formed the board members of the group. The group ***initially included five women and six men.*** On March 30th 2005, they submitted the application for registration under the Society Act, clause 180, with the signatures of all eleven members on the form as this was the minimum required number of members for an organization to be registered. On 7th April, 2005, they received the certificate of registration where the organization was registered as **U.P. Welfare for People Living with HIV/AIDS (UPWPLHA).** Later, the network lost two of its board members to HIV infection and AIDS. Two other board members could not maintain their regular contacts with the network as one of them became severely ill and the other member went to live with his relatives in Bombay for treatment Thus new members were "elected" in place of these four members. The "election" of these four board members took place in a meeting of all members (twenty members) of the network in Lucknow. After the elections, the network comprised of ***four women and seven men*** who are working as board members till date. The board members are also those who the other members feel are *"good persons who can work and are willing to work for the welfare of the PLWHA and who respect all members".* In June 2005, the organization was affiliated to INP+ and a Memorandum of understanding (MoU) was signed between the president of INP+ and the president of UPWPLHA and since then UPWPLHA came to be known as **'U.P. network of Positive People' (UPNP+).**

Since this was a new kind of initiative in U.P., there were several obstacles to face. UPNP+ members had to face a lot of résistance in the community in which they moved to identify and look out for the PLWHA. Given the stigma attached to the disease, it was very difficult for the members to go and convince the people whom they came to know that they were HIV positive in their community and bring them to the office of the organization and help them in any way. It was difficult for them to win the confidence of the people and establish a good rapport with them as they were looked upon with suspicion. At the institutional level also, they had a hard time making the government officials and the other organizations working in this field understand what they were trying to do and how would it be helpful to the PLWHAs and would improve their condition. The concept of ***networking*** was very new to the people and especially to the government officials who could have provided the maximum help to the group of PLWHA which was in its evolution stage. It was a difficult task to make them understand the concept of networking and convince them that a network of PLWHA could be formed successfully in a state like U.P. which has a very conservative society. The most often asked question was, *"why do you want to form a network of HIV positive people?"* The members common reply was that they need an enabling environment where they can share their feelings openly with others and thereby reduce their loneliness and fear.

Mission of UPNP+

The mission of UPNP+, at present, is to make all treatment facilities easily available and accessible to the PLWHAs and correct information about HIV/AIDS to be propagated in the general public to generate positive attitudes toward the PLWHA and lower the stigma and discrimination related to HIV/AIDS.

In its initial stage, the network adopted a four dimensional approach. The four dimensions were—*advocacy, networking, service delivery, and care and support.* Later on, as they started to work and gained experience working with other organizations, they felt that the "advocacy dimension included care and support" so they finally adopted the triangular approach which included ***advocacy, network building and service delivery.*** The triangular approach is the approach followed by the INP+. ("Untrodden Path" INP+ Annual Report, 2005).

Objectives of UPNP+

At the time of registration, the network had formulated nine objectives—

1. To organize workshops to inform the HIV infected people about their rights.
2. To organize educational, social, ethical, artistic and cultural programmes for the overall development of the PLWHA.
3. To reduce the fear in the PLWHA and to make them aware of the injustice being done to them.
4. To improve the 'Quality of life' of the PLWHA and to develop a positive attitude through exchange of ideas and experiences.
5. To inform the PLWHA about ARV treatment and to make information easily accessible to them.
6. To organize yoga and meditation workshops for PLWHA to infuse strength and will power in their minds.
7. To build a hospital for the treatment of PLWHA.
8. To arrange for education, employment, and means of livelihood for HIV infected women and children.
9. To organize awareness campaigns through the PLWHA.

Presently the network works on ***four*** broad objectives which incorporate the above issues. They are--

1. To bring together HIV infected people and make them aware of the issues involved in HIV/AIDS and provide them knowledge about HIV disease, its treatment, and prevention.
2. To make the various treatment facilities provided by the government available and accessible to the PLWHA.
3. To make the society aware about HIV/AIDS through the PLWHA.
4. To do advocacy on behalf of the PLWHA with the government.

When the network started functioning, its thrust was on network building, advocacy and service delivery with special emphasis on care and support. The network attempted to make the testing and treatment facilities easily accessible to the PLWHA. They counseled the PLWHA coming to them on different aspects of the disease and tried to create an enabling environment for the PLWHA in which they could openly express their feelings. They tried to eliminate the feeling of fear and loneliness in the PLWHA and provided them with a supportive environment. At first, the members felt that ARV treatment was the most important thing for a PLWHA whether he/she was symptomatic or not. Later, as the group progressed in their work and with increasing interactions with the other government and non-government organizations, they felt that a proper health service delivery system was more important for the availability of any kind of medical facility. Thus a need was felt not only of regular drug availability but also of proper counseling and testing facility for proper treatment and management of HIV/AIDS and HIV positive people. The network later realized that counseling is a very important component in management of HIV positive persons. They also realized that women and children form an integral part of HIV support and care issue and thus required special care and support. Thus their vision has broadened and their thinking expanded with increasing interactions with other national and international agencies and with their own experiences working at the grass root level with PLWHA coming from different regions, classes, castes and creed. They also realized that the easy accessibility to the various welfare schemes of the government were also very important for the PLWHA. They prepared a list of their demands on priority basis in June 2005 in a meeting in Lucknow in which twenty- five PLWHAs were present--

1. Employment to PLWHA and implementation of GIPA
2. Free education and scholarship to the children of PLWHA
3. Priority to be given to HIV positive people in the area of—
    a) BPL card
    b) Widow pension
    c) Housing
    d) Government aid
    e) Free treatment
    f) Treatment, testing and admission facility to be available in the medical colleges
    g) Treatment, testing and admission facility in the T.B. hospitals
    h) Admission facility in the nursing homes in case of emergency
    i) Policies to be formulated by the government and be properly implemented in order to reduce the stigma and discrimination in the society and to bring the PLWHA in the mainstream of the society.
    j) Free travelling facility for the PLWHA by the government.
    k) UPSACS to have transparency in their policies and to make all facilities available to the PLWHA.
    l) A healthy and confidential environment at the ART centres and good knowledge to be available about the ARV treatment.
    m) To appoint PLWHA as counsellors at the VCTC centres.
    n) To have proper communication among the NGOs and other organisation working in the area of HIV and AIDS.

Operationalizing the Triangular Approach

Building a support network

Initially when the members started working, the president Mr. Naresh Yadav took the lead in meeting different people working in the area of HIV/AIDS in Allahabad as well as in U.P. to inform them about the PLWHA network which was being formed by a group of PLWHA.

The Health care providers—

He made personal visits to the VCTCs, RTI/STI Clinics, specific doctors treating HIV patients in the city and the NGOs working in the area of HIV/AIDS. He also made personal visits to the ART centers in Varanasi and Lucknow. He tried to establish a good rapport with them and tried to convince them about the need and the usefulness of a network of HIV positive people. At first, he was looked upon with suspicion by the concerned persons but after regular meetings and consultations they have now started to take the network under consideration. Till date, the network does not have full support of the VCTCs and the NGOs working in the city. They occasionally refer HIV positive persons to the network whoever they feel is very needy and needs the support from the network, especially in getting the CD4 and other tests done and the ARV treatment from BHU Varanasi.

The State AIDS Control Society (UPSACS) —

To get any kind of help from U.P. State AIDS Control Society (UPSACS), advocacy had to be done. The UPNP+ president wrote letters to the different office holders of UPSACS explaining them about the concept of network formation of PLWHA and giving them a detailed account of the network which was in its formation stage in U.P. He explained to them the objectives of the network and asked them for their support. After repeatedly sending letters and trying to contact the UPSACS officials to get help from them, he was able to meet and convince the Project Director of UPSACS about the concept of a PLWHA network. After many meetings with UPSACS and other NGOs working in this field, the network members have been able to build a considerable level of understanding and trust in their eyes. The UPNP+ network now has support from UPSACS, which provides them, at present, ***only*** with IEC material. The UPSACS, till date has not officially recognized UPNP+ as a PLWHA network working in U.P.

The Funding Agencies—

The president of the network wrote letters to the international NGOs and other funding agencies and invited them to visit the network and meet the network members.

Action Aid provides them with two fellowships- for training and capacity building. Member organizations of Action Aid like PANI, Shambhu Nath Research Foundation, and FPAI also extended their support in different ways. Catholic Relief Service (CRS) provides financial help by bearing the cost of any training or workshop organized by the network. CRS also organized a capacity building workshop for the network members giving them information about HIV and AIDS, symptoms, CD4 test and CD4 count values and their meaning and other HIV tests, information and importance of GIPA and other issues related to HIV/AIDS. Family Planning Association of India (FPAI) provides financial help by bearing the cost of CD4 and other tests and medicines needed. Different U.N. Organizations like UNDP, UNICEF have extended their support by reimbursing the costs of different camps organized by the UPNP+ network like the awareness camp organized by the network in Allahabad in the Magh-Mela which was held in the month of January, 2006.

ADVOCACY

Media Advocacy--

The president, UPNP+ participated in a conference of Population Foundation of India (PFI) in October 2005 in Lucknow, which had 25-30 journalists as participants. He participated as a ***'positive speaker'*** in that conference. He established a good rapport with them and they acknowledged the work he was doing. They extended their help to the network by giving immense media support to the network and bringing them to the forefront of the society. There has been immense support from the print media especially- The Times of India, Hindustan Times, Indian Express, Dainik Jagaran and others who have presented an image of the network in such a way to the public that it has resulted in the formation of a positive attitude toward the PLWHA in the general population. The network felt that there was a need for the local media to be sensitized on the issue of HIV/AIDS. In general, the local media used words like "AIDS Rogi" or "HIV patient" to refer to PLWHA which presented an image of the HIV positive person as an ill person but in reports about the network and its members, the PLWHA were referred to as "HIV infected" or 'Person Living with HIV/AIDS' (PLWHA) which present an image of a HIV positive person as healthy person who is living with HIV and thus creates a positive image. This has all been a result of the effective media advocacy done by the members of UPNP+.

PPTCT Centre

The network works in close contact with the Prevention of Parent to Child transmission (PPTCT) centre in the medical colleges. Up till now, the network has been able to get three babies delivered successfully in the PPTCT centre in Allahabad. The network keeps a close watch on the supply and delivery of ARVs at the ARV centers of the state. Any complaint regarding the distribution of ARV from any part of the state is urgently attended to and due to the effective advocacy done by the network at the official level, the enquiry done by the network regarding the supply of ARV and the complaint made to the UPSACS is treated urgently by the UPSACS.

Local PLWHA Network Building

When the network started functioning as a group, some important guidelines were delineated by the board of the network as to how the network would function to achieve its goal. Some guidelines regarding network building which were and continue to be in the objectives of the group are--

- To disseminate correct information about HIV and AIDS in the general public to reduce the myths prevalent in the society regarding HIV/AIDS. .
- To link other PLWHA to the network who are unaware of the presence of a PLWHA group and can avail the facilities available at the network.
- It is the responsibility of every member to link at least one or two PLWHA to the network and make them a member of the network, giving them knowledge about HIV and AIDS.
- To strengthen the network and openly discuss on every issue in the group and share information with each other.

- Two volunteer PLWHA from every district are given the responsibility to increase the number of members in the network. They are also given the responsibility of attending all workshops being organized on the HIV/AIDS issue in their district and share the information with other members in the network. They are also directed to be in close contact with other members and keep their knowledge updated with others.

Apart from the above guidelines to the members, the network members have been able to link the PLWHA in their community and the area in which they live to the network by disseminating information about the work they are doing at the various hangouts they used to visit. They used to informally inform the people about HIV and its symptoms and people used to readily tell them about anyone they knew having the same symptoms and that person was approached by the network member. Thus new members were formed in this way. Recently, from January 2006, the network has started getting proper forms filled up by the new members with their written consent accepting the membership of the network. Earlier only verbal consent was taken of the members and they were registered and their records maintained.

Service delivery

The network offers support to the people coming to them in the form of counseling, getting their HIV tests done, CD4 count followed by facilitating the ARV treatment started from the ART centre, maintaining a follow-up of these people regarding their physical wellbeing and their emotional well-being. Once the individual approaching them becomes a member of the group, he receives basic information regarding HIV and AIDS and how to handle the day to day problems regarding it. He is also taught how to counsel others coming for help in an effective and empathic way. He is also informed about the different issues related to HIV and AIDS at the personal, regional and national level.

The new member is informed about the working of the group. He is motivated to share his experiences with the group and learn from other's experiences. Thus by sharing their experiences with each other, the members are motivated to form an enabling environment in which they can express themselves without fear and reduce their loneliness. The active network members are in close contact with the other 'active' members, especially with the office bearers, and thus their follow-up and dissemination of any new information is much easier to these members who are actively involved with the office bearers in establishing the network. The 'inactive' members are present only at important meetings or when they are needed by the network.

As members of the network hail from different districts of the state, the district level networks are being formed so that the management of the group is much easier and it is feasible for the members to approach the network office in their district or block for help. The district level networks have been formed in the key districts of Varanasi, Azamgarh, Etah and Allahabad. Maximum number of members are from these four districts as most of the board members, who are the most active members, are from these districts. They have been able to convince the government and non-government organizations about the working of the PLWHA network, as a part of their advocacy agenda, and thus it is now much easier for them to avail the medical as well as other services in these areas.

The network now also runs a Drop-in-Centre (DIC) in Allahabad sponsored by UPSACS. DICs are also being opened at the other district level network offices in Varanasi, Azamgarh, and Eta. The DIC has the facility of over-night stay for the PLWHA coming from adjoining areas to get themselves tested. The DIC has a doctor attending the centre (who is not a part of the DIC) every Saturday who treats for opportunistic infections and is 'specialized' in HIV treatment. The DIC also has the facility of getting the CD4 test done as well as the western blot test done from private laboratories.

Regular activities of the network--

When the network started functioning, the regular meetings of the members were held on every alternate Monday of the month at the office at the Andhawa bypass on the Allahabad-Varanasi highway, which is the Swarg office. The members used to come to attend the meetings from very far off places. The expenses of coming to the office for the meeting every week was too high for them and the network did not have enough money at that time to pay them the fare. To add on to this, the members had to come on every Thursday to consult the doctor coming to the network office. This caused double burden on the members. Those working would lose their wages on the days they came to the network office and it also caused physical strain on them. Thus the attendance of members started decreasing for the meetings. Keeping this in mind, the day of holding the meeting was shifted from every alternate Monday to every alternate Thursday of the week with effect from 6th July 2005. This reduced the double burden on the members as on the same day they could consult the doctor as well as attend the meeting and thus save their time and money.

In the meetings, the members were informed about the health status of other members especially those who were unable to attend the meetings because of being unwell and further plan of action was discussed about how to deal with the problems be it physical, emotional, financial, or official and collective decision is taken by the group regarding any problem encountered by the group or any of its members. A regular follow-up of the members was maintained either through telephonic contact or through personal contact. The group functions as one whole unit with each member in close contact with other members especially with the office bearers and the active members. Till date, the functioning of the group remains the same with regular meetings being held and regular follow- up of members being maintained of the members, mostly who are easily approachable and can be easily contacted.

Since the office of the network was on the highway, far away from the main city, it was decided by the members to have an office in the main city so that many more people could be informed about the presence of a PLWHA network in the city and they could be easily accessible to many more PLWHA who do not know where to go for help. Keeping this in mind, another office was opened in heart of the city, in February 2006 which is closer to all the VCTCs in the city as well as the government and other hospitals. The initial office of the network is also being maintained. The network now also runs a Drop-in- centre (DIC) for PLWHA, funded by the UPSACS, from the same office, in the city, which is leading to a gradual increase in the list of members of the network. Along with the counseling and O.I. treatment facility, now they also provide with CD4 test facility and overnight staying facility for those PLWHA who come from far off places to get their tests and treatment done in the city. The doctor visits the network office every Saturday so the day of bimonthly meeting of the members has been shifted from every alternate Thursday to every alternate Saturday.

Functional structure of UPNP+ as per the Society Bye-Laws

- The Board- there are ***eleven*** members in the board of UPNP+. The board members are elected from amongst the members of the network hailing from all parts of U.P. Any member who volunteers his/her name, his/her name has to be seconded by another member for any post. In case of loss of a board member due to any reason, the board elects another member by two thirds of the majority. There are no specific criteria for becoming a board member. The person has to be honest and willing to work for PLWHA.
- UPNP+ has a president, a vice president, a secretary, a joint secretary, a treasurer. The president is responsible for the overall functioning of the network. The vice president assists the president in his work and takes on his work in his absence. The secretary manages the day to day functioning of the network and keeps the president informed about it. The joint secretary assists the secretary in his work and takes on his work in the absence of the secretary. The treasurer manages the accounts and finance of the network. These functions were delineated in the bye-laws during the registration of the network. The real situation, however, is quite different.
- UPNP+ gives affiliation to district level networks and block level networks. At present, UPNP+ has given affiliation to four district level networks—Allahabad, Eta, Azamgarh, Varanasi districts and other block level networks are coming up. These district and block level networks are being formed under the guidance of UPNP+.
- UPNP+ gives membership to *only* the infected and not to the HIV affected people. Any person, who was HIV positive and approached them for support, was considered a member of their network but now membership forms are filled by the PLWHA whoever wishes to become a member of the network.

The Office bearers--:

The President-- the post of the president is being held by Mr. Naresh Yadav. He was unanimously appointed as the president of the network by the network members at the time of registration of the network. He is the most knowledgeable person about of HIV/AIDS in the network. He is well educated, and hails from a high economic class background. He has carried the responsibility of being the president well by involving himself in establishing the network to the fullest and in the activities of the network. The functioning of the network still rests, to a great extent on his shoulders.

The Vice-President-- Among the office bearers of UPNP+, the post of secretary was held by Mrs. Asma Bano for eight months but later the board members and the president felt that it was difficult for her to attend all the meetings held in different parts of the country and to be present at all occasions with the president as she has small children to look after and is also working as an AWW. Keeping this in mind, she was promoted to the post of vice-president and Mr. Rakesh Singh, who held the post of vice- president, was appointed as the secretary. Mrs. Asma Bano was unanimously appointed as the secretary and then as the vice-president keeping in mind 'the meaningful participation of women in the governing body of UPNP+'. She belongs to the Muslim community and also is capable of handling the post to which she has been appointed. She has also been instrumental in building up the network and linking women, especially those women who have lost their husbands to HIV/AIDS, to the network. She had earlier been in close contact with Swarg and working as AWW in the area, had been actively involved in the awareness campaigns organized by Swarg in that area.

The Secretary—this post is now being held by Mr. Rakesh Singh, who was earlier the vice-president of the network. He has been instrumental in building up the network and has been working hard with the president to establish the network. He had been working with Swarg when the concept of building a PLWHA network was introduced by the president to the members of Swarg. He has utilized his experience of working with Swarg and dealing with the issues in HIV/AIDS to the fullest in building the network at the local level. He comes from a middle economic class background and belongs to a reputed family in the area. Maximum numbers of members have been linked to the network by him.

The Joint Secretary- this designation is being held by Mr. Ram Pravesh Yadav. He comes from a middle class socio-economic background. He hails from the district of Azamgarh. He had been unanimously appointed as the joint-secretary. He has been interacting with the 'Lawyers' Collective'. He has a case pending with them which he had filed against his employers who had forced him to resign from his job due to his HIV sero-status. He had been attending the various meetings and seminars organized by the Lawyers' Collective and this exposure to the issues in the area of HIV/AIDS has given him a good understanding of these issues. At present, he is building up the district level network in Azamgarh. As he lives in Azamgarh, he is in contact with the other office bearers in Allahabad through e-mail and telephone and comes to Allahabad to participate in the important meetings or events of the network.

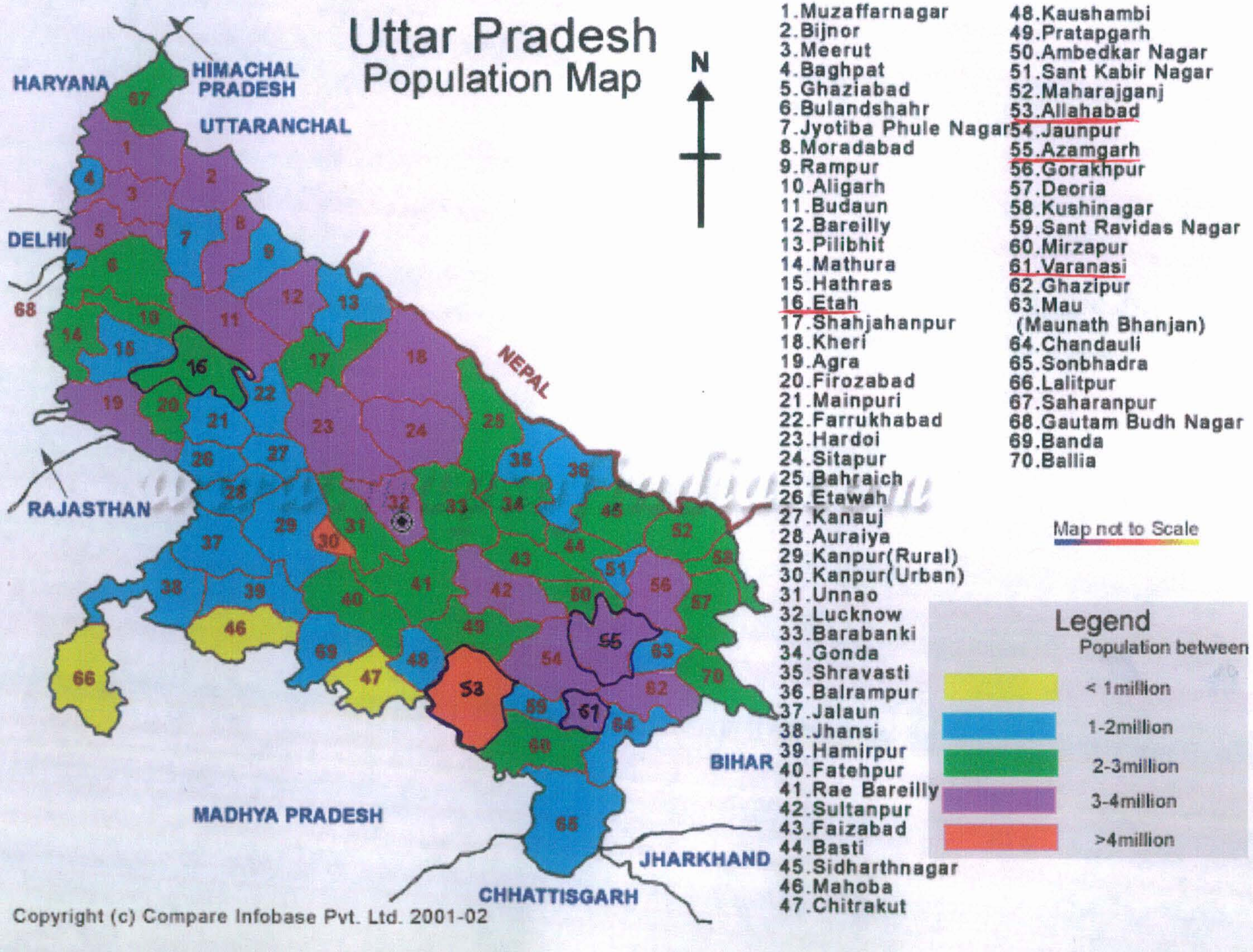
The Treasurer- Mr. Prem Chand holds the post of the treasurer in the network. He comes from a lower socio-economic category and had been appointed at this post on the recommendation of the project in-charge of Swarg. He had also been attending the office of Swarg, informally helping them out in the field identifying other HIV positive people. At present, he holds the post of the treasurer but is dysfunctional as he is incapable of managing the work of a treasurer. His education is only till class sixth and cannot manage the accounts and finances of the network. This part of the work is collectively managed by the president and the secretary. His name has also been given for the post of Out Reach Worker (ORW) at the DIC, Allahabad. He was in need of a job as his wife is HIV positive and was expecting a baby. She was in need of care and treatment. He looks after the office of the DIC.

The appointment of different members at different designations in the network is on the *"basis of their needs"* as the president feels they should be given a salary for the work they do to the best of their potential to efficiently run the network and increase its capacity. It is because of their hard work only that the network has been able to achieve what it has is such a short span of time. However, the members who are holding various positions in the network are those who are confident, out going, have prior experience of working with people, especially at the local level, and who have had exposure to the outer world, interacting with different organizations working in the field of HIV or health care. They have, thus been unanimously appointed at various positions as they were viewed as being capable of handling those positions.

At present, the district level networks of PLWHA have been formed in only four districts of U.P. as maximum number of member hail from these areas of U.P. and also the most active members of the network come from these areas. Currently, expansion of the network to other districts and blocks in U.P. is in progress.

CHAPTER THREE

Map of U.P. Showing the District Level Networks of U.P.NP+



Uttar Pradesh
Population Map

1.Muzaffarnagar
2.Bijnor
3.Meerut
4.Baghpat
5.Ghaziabad
6.Bulandshahr
7.Jyotiba Phule Nagar
8.Moradabad
9.Rampur
10.Aligarh
11.Budaun
12.Bareilly
13.Pilibhit
14.Mathura
15.Hathras
16.Etah
17.Shahjahanpur
18.Kheri
19.Agra
20.Firozabad
21.Mainpuri
22.Farrukhabad
23.Hardoi
24.Sitapur
25.Bahraich
26.Etawah
27.Kanauj
28.Auraiya
29.Kanpur(Rural)
30.Kanpur(Urban)
31.Unnao
32.Lucknow
33.Barabanki
34.Gonda
35.Shravasti
36.Balrampur
37.Jalaun
38.Jhansi
39.Hamirpur
40.Fatehpur
41.Rae Bareilly
42.Sultanpur
43.Faizabad
44.Basti
45.Sidharthnagar
46.Mahoba
47.Chitrakut
48.Kaushambi
49.Pratapgarh
50.Ambedkar Nagar
51.Sant Kabir Nagar
52.Maharajganj
53.Allahabad
54.Jaunpur
55.Azamgarh
56.Gorakhpur
57.Deoria
58.Kushinagar
59.Sant Ravidas Nagar
60.Mirzapur
61.Varanasi
62.Ghazipur
63.Mau
(Maunath Bhanjan)
64.Chandauli
65.Sonbhadra
66.Lalitpur
67.Saharanpur
68.Gautam Budh Nagar
69.Banda
70.Ballia

Legend
Population between

🟨 < 1million
🟦 1-2million
🟩 2-3million
🟪 3-4million
🟥 >4million

Chapter 3

Social Structure and Dynamics of the UPNP+ Network

At present the UPNP+ network comprises of 130 members. These consist of 25 concordant couples and almost an equal number (22) of widows whose husbands have either died of HIV infection or AIDS. It also includes a 28 male PLWHA whose wives have not been tested. These members have not got their wives tested, even after knowing their HIV status, and so their wives HIV status still remains unknown. Out of the 130 members, only 53 members are female while there are 77 male members.

Table no. 1

Categorization of 130 members of UPNP+

Category	Male	Female	Total
Concordant couples (husband & wife HIV positive)	25	25	50
Children	6	5	11
Unmarried Men	4	-	4
Men only tested (married men whose Wives have not been tested)	28	-	28
Widows	-	22	22
Widowers	3	-	3
Dead	11	1	12
Total	77	**53**	**130**

As seen in table no. 1, the female members are either wives of the HIV infected men who are also members of the network or are widows whose husbands have died either due to HIV infection or AIDS. All the children, except one male child, have parents who are members (Table no.3). In the category of members who are dead, there are 11 male and 1 female. The female in this category was the wife of a male member who now is in the widower category. While the widows in the study became members of the network after the death of their husbands who were either being treated by the doctor at Swarg and were in contact with Swarg or the network but not a member.

Table no. 2

Categorization of 130 members by economic class and age group

	Age group										
Economic Class	**0-10**		**10-20**		**20-30**		**30-40**		**40-50**		**Total**
	M	F	M	F	M	F	M	F	M	F	
High Class	1	3	-	-	3	7	8	5	-	-	27
Middle Class	-	2	-	-	11	10	17	5	1	1	47
Low Class	5	-	-	-	12	9	19	10	1	-	56
Total	6	5	-	-	26	26	44	20	2	1	130

In Table no. 2, we can see the categorization of 130 members of the network according to age group and economic class*. All the 130 members (taking each member as one unit) were classified into three broad categories of economic class --- high class, middle class and low class[*]. As we can see, out of the 130 members, 27 (21%) members fall in the high class category while 47(36%) in the middle class category. 56 (43%) members are in the lower economic class. It is also evident from the table no.2 that there are 44 males in the age-group of 30-40 years followed by 26 males in the age group of 20-30 years. The maximum number of females i.e. 26 are in the age group of 20-30 years followed by 20 females in the age-group of 30-40 years. This clearly shows that the females had become infected with HIV at a much earlier age in comparison to the males. The number of males in the middle and low economic class in the age-group of 20-30 and 30-40 years is higher in comparison to the females in this category as well as the members in the high economic class

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[*] Note- the members were classified according to economic class categories on the basis of the total household income. Households having a monthly income of –
>Rs.20,000= high income category
Rs.20,000-5000=middle income category
<Rs.5000= low income category

category. Thus the burden of the disease is borne by the 20-40 years age group which is the most productive age group. Also the members in the middle and low economic category are more in comparison to the high economic category members as reflected in the composition of members of the network.

The members of the network hail from different regions of the state, and belong to different castes and economic classes. The 130 members were grouped into households with men, women and children coming in one household being considered as one unit. Table no.3 shows the categorization of household according to economic class, caste and area of residence. The area of residence has been coded into four areas where the district level networks (DLNs) of the UPNP+ have been formed. Members in the areas closer to any of these four DLNs have been given the code of that area.

Table no. 3

Categorization of 83 households

Economic Class	Total Households	Caste			Area of Residence			
		High	OBC	Low	Allahabad	Azamgarh	Etah	Varanasi
High class	14	10	2	2	5	3	4	2
Middle class	34	14	19	1	18	10	2	4
Low class	35	10	14	11	21	10	-	4
Total	**83**	**34**	**35**	**14**	**44**	**23**	**6**	**10**

Out of the 83 households of UPNP+ network, 14 households are of high economic category members, 34 of middle class members and 35 of low economic category members. 44 households are in Allahabad followed by 23 households in Azamgarh. 10 households are in Varanasi and 6 households in Etah district. As seen in table no.3, 34 households are of high caste members, 35 households are of OBC members and only 14 households are of Low caste members. Middle class households are seen more in the high caste as well as OBC category. These households are based mostly in Allahabad and Azamgarh. In the low caste category, lower class households are seen more in comparison to the high and middle class category. Thus there is more representation of the high caste and OBC in the network, but who belong to the middle and lower economic class. The households are based more in Allahabad since this study was located here and it is the Head Office of the network. Maximum members are from Allahabad and its adjoining areas. There is representation of Azamgarh and Varanasi districts also as work has been done by the network members in these areas. Here also the middle and low class members are more in number in comparison to the high class.

The dynamics of the group were studied by the researcher being a part of the group, and volunteered as a HIV counselor, since she is a trained psychologist with a previous experience in HIV counseling. The researcher attended the network office in Allahabad regularly and participated in their day to day activities, and sometimes just observing the activities of the group and its members, interacting with them to understand the dynamics of the group within the group and the group's interaction with the outer world.

Internal dynamics of the group

When Mr. Naresh Yadav returned to Allahabad after attending the conference organized by the Lawyers' Collective in Delhi, he shared the idea of forming a group of PLWHA network the members and project in-charge of Swarg, he received a spontaneous and an enthusiastic response from them. They extended their fullest support to him in identifying and linking PLWHA to form a group, convincing them to form a group. Since Swarg had been working in the area for the past six years, they were in contact with a number of PLWHA in and around the area. They had also been feeling the need to unite the PLWHA so that they could collectively fight for their rights and easily avail the facilities, especially medical facilities needed by them. They readily agreed to help him form the network. Mr. Naresh Yadav started going to the office of Swarg regularly. There, he started counseling the people informally who used to come there for treatment of OIs or counseling for HIV. His counseling was more effective in comparison to the members of Swarg as he himself was HIV positive and disclosed his HIV status to those coming there, especially those who were diagnosed as HIV positive. These people could easily identify with him and he was able to infuse strength and courage in them and acted as a role model for them passing on the message that one can live a healthy and happy life even after being HIV positive and that HIV infection is not the end of life.

Soon, he was able to convince people to form a PLWHA network and the initial 11 members of the network formed the group. The 11 board members unanimously elected Mr. Naresh Yadav as their president. Since he was the most knowledgeable about HIV/AIDS amongst all the members, he was unanimously given the responsibility of guiding the group. He took up the responsibility and has guided and is still guiding the group till date. He is the most respected member of the group and keeps in touch with almost every member of the group personally. He believes in "participatory leadership", that is, he encourages all other members to participate actively in the activities of the group, considering him also as a member of the group and not as a leader. Any member of the group feels free to talk to him personally. He is approachable and accessible to any member of the group, be it a man or a woman.

Popularly known as 'Naresh Bhai', the president personally keeps track of all members of the group, especially of those who have recently taken the membership of the group. He gives due attention to all kinds of needs of the members, especially their treatment related needs. He is the key information provider for the group. He informs the group about every meeting he attends and explains to them about the issues raised in the meetings and shares his experiences with the group. He informs them about the recent developments, the issues and the technological advances in the area of HIV/AIDS.

Initially when the group was formed, only the president used to attend all the conferences and the meetings organized by other agencies. Soon, it became very difficult for him to be present at all places and also it was physically taxing for him. He felt the need for a second line of leadership. He started taking along one of the members of the group with him to the meetings so that they could get an experience as well as exposure to the outer world and learn how to effectively represent their group and their needs. He also makes sure that there is ample representation of women as participants and their issues in the meetings with others.

Apart from the president, the most important person in the network is the vice-president and now the secretary of the network Mr. Rakesh Singh. He is the most respected member of the group along with Mr. Naresh Yadav. He holds the group together as he keeps track of every member of the group and their specific needs and keeps informing the president about the various members and their needs. Mr. Rakesh Singh had been working with Swarg before the network was formed and so has knowledge about the issues related to HIV and how to handle them. He belongs to the same area where the office of UPNP+ was opened and so is fully aware of the area and the people.

Since he belongs to the same area, everyone in the area knows that he is HIV positive and is working as a social worker with Swarg for the HIV positive people. He holds a good reputation in the area; hence people trust him and approach him for help. He is the key person in the network as most of the members in Allahabad have come to the network through him. He holds a reputation of a sincere person who is devoted to work for the betterment of the state of PLWHA in the city. After the network had been formed, he and his wife have worked day and night to establish the network. His wife has been instrumental in mobilizing the women and linking them to the network. They have linked the network to the grass-root level—to those PLWHA who were beyond the reach of even the NGOs working in those areas and who were the most in need of help.

Apart from these two office bearers, the third key person in the network is Mrs. Asma Bano. She held the position of the secretary and recently has been promoted to the post of the Vice-President. She is a widow and has lost her husband to AIDS. She has been working as an Anganwadi worker (AWW) and thus is well acquainted with the issues related to women as well as HIV. Since she has been working in the area for quite some time, she has a personal relationship with the women in the area. She plays a major role in linking women to the network who have either lost their husband to HIV and AIDS or who along with their husbands, are HIV positive. She stands as a role model for the women in the group who have come out of their homes for the first time. She motivates them to be confident to express themselves and their needs at various levels of interaction with the outer world.

The other board members are also actively involved in establishing the network. Any member who attends any meeting or conference, shares his/her experiences with the other members in the regular meetings of the network. This helps other members to update their level of information. Due attention is given to the fact that every member present in the meeting understands what others are saying of the group since every member does not have the same level of understanding as others. Special attention is given to women and they are made to understand the issues. Thus their capacity building is done in this way so that they can deal with such issues and give their opinion on them when interacting with the outer world. Then they can represent the group and effectively communicate their needs to others.

The interaction among the men and women in the network is encouraged to be on an equal footing. The women are consulted in the internal matters of the group, especially in case of any other member of the group, but in case of official matters, women are mostly not involved. Even if they are consulted, they back off by saying that they do not understand these official matters and leave it to the men to take the decisions. Women who belong to the poorest economic category and are widows are taken special care of in relation to their medical needs and other needs like that of food and shelter. Even other members who belong to the low economic category are paid special attention to since they have nowhere to go except the network for help. The network tries to make arrangements for a source of income for these members by either helping them monetarily by personal contribution or by facilitating their getting jobs like that of house maids, watchman, peon etc.

Differences in behaviour due to the economic class difference among the members of the group were visible in the informal interactions of the members. Some members, especially the new members are boastful of their economic stability. They look upon others who are economically weak with sympathy. They are full of suggestions to improve the conditions of those in financial crisis but when their contribution is required, they back off. At one instance, when a couple, which falls in the high income category, were asked to participate in a project, they readily agreed but when they were told that they would be getting a certain amount of money, they said their daily income is much more than what they were being paid. Their behaviour was not liked by the other members as they said that some other members could have worked in their place who were in need of money.

Differences are also seen in the way the money earned through the network is spent by the members. Every member receives the same amount of money as TA/DA when they attend the meetings of international NGOs like Action Aid, CRS and others or when they work on some projects of these organisations. The members who are economically weak spend less than the amount given and spend the money on their treatment or save it for the future. The economically stable ones spend the money on luxury items like a fancy cell phone.

Subtle caste differences could also be seen amongst the members of the group. Though the members repeatedly said that they do not discriminate on the basis of caste, but whenever they introduced any member or informed the researcher about any member of the group, they used to instantly say to which caste the member belonged. The caste differences were not very clear among the males. However, one of the members of the network, who was initially a board member, and later backed out from the responsibility as he was not keeping well, gave an excuse for not coming to the office or participating in the activities of the network that, " I am a Brahmin.

People from all castes come to the office. I have to eat with them, sit with them and even if I have to take rest, I have to lie down on the same mattress on which others sit. All this will pollute my religion. I can't do this."

The caste difference was also apparent amongst the females. During an Awareness camp set up by the network in the month long Magh-Mela on the banks of Sangam, the union of river Ganga and Yamuna in Allahabad, the members of the network, were living together under one roof for the first time. The women, especially of the higher caste, used to cook the food. They did not allow members of the lower caste to even touch the utensils in which the food was being cooked or sit close to the "chullah" on which the food was being cooked. Mostly they served the food to everyone and maintained the cast hierarchy as far as possible. The lower caste women as well as men were not given a chance to serve food. The higher caste women or men used to serve food and wash their hands before and after serving food. This act of washing hands before and after touching food was objected by the lower caste women. They said, "What is the need of washing hands every time you touch food?" To this the higher caste women replied that it is a part of their norms as food is worshipped in their castes and hence has to be touched with clean hands. While eating also, the higher caste women sat together to eat with their eating plates kept a little aloof from the lower caste women. Some members, especially the women of different castes commented on the manner of eating and serving food of fellow women belonging to other castes.

Differences were also seen in the behaviour of the members whenever the family members of any member used to come to visit the network camp in the Magh-Mela. Family members of a higher caste member were made to sit on the chairs or in the tent which was well maintained and was used for official purposes, whereas, family members of the lower caste members were not given the same kind of 'special attention' and they usually sat on the ground or in the 'multipurpose' tent which was used for cooking food, as a store house and for taking rest by the members of the network and was not well maintained. Even while serving food, the family members of higher caste members were served food in 'steel plates' which are considered 'clean' by the high castes, whereas, the other members were served in plastic plates which were in every day use in the camp.

Higher level of intimacy was seen between the same caste members. They used to share their personal and family matters with each other and used to visit each others houses more often than other members. A certain level of hierarchy was maintained by the network members on the basis of caste, more importantly than by economic class. The high caste members were more respected than the low caste members. Even in the meetings, the high caste members used to sit together with the lower caste members sitting a bit far away from them. These caste differences were even more pronounced because of the fact that the high caste members were usually the educated members of the group.

Though every member was asked about his/her opinion regarding any decision, the lower caste members used to give their consent just by nodding their head even if they belonged to a stable economic category. They rarely gave suggestions even if it concerned them. On the contrary, the opinion of the higher caste members was obtained repeatedly on different issues and efforts were made to convince them on the viewpoints of the office bearers. Even when special attention was given to them regarding their viewpoints on the issues to take any decision, the high caste members used to often back out or be absent from the meetings or any programmes without any excuse, while the low caste members used to repeatedly inform the president or other office bearers why they were not able to participate in the programme or event. The decisions were mostly taken by the high class, high caste members on behalf of the lower caste, lower class members.

Though the president of the network claims that the members appointed at the various posts are not on the basis of education, caste, or economic class, yet the key positions in the network are held by the members who belong to the middle or higher economic category, are educated and have experience of the outer world. The decision making power regarding funding and expenses has been in the hands of only three or four board members who belong to the higher caste and higher economic class, are educated and have experience of the outer world, and who are *'male'*. All board members are informed about the issue and situation but generally they are told about the decision that is taken amongst these three-four members, including the president. The rest of the board members are convinced somehow as there is very little objection to what the president says. Whatever the president says is taken as an 'order' rather than a request or an issue to be discussed for a decision to be taken collectively by all the members present at that occasion. However, while making decisions, due consideration is given to the needs of not only the low class and caste members but also those members who need the support of the network be it financial, medical or social. Their need is treated as urgent and attended to especially when it is a need for treatment.

Perceptions about 'The Triangular Approach'

When the network had initially started working, the members of the network, even those who were the board members, were not conceptually clear as to what advocacy was and what communication was. When asked about what advocacy was, they replied, *"advocacy means telling other people about our needs"*. One of the most active members of the network, when asked to define advocacy replied, "It means giving information about HIV/AIDS to people, especially to those who have no knowledge about it and who live in villages as well as to those who are at higher positions, holding various offices." They still believe that advocacy means communicating their needs and problems to other people which includes the common man of a village, of a city as well as those people who are higher in the hierarchy of caste, class and education. It was only when the members were repeatedly asked about what they meant by advocacy and how they did it, during the interactions with the media, that they felt the need to be trained in advocacy. Till date only one or two members have been trained in advocacy but the training was in English so they could not comprehend what was being told. Thus they are still not clear what the correct meaning of advocacy is. However, the president's understanding of advocacy has evolved overtime with increasing interactions with other organisations and people. He believes that advocacy should result in the PLWHAs getting access to the services, especially, medical services and other services needed by them to lead a normal and healthy life.

When the members, and especially the president, was asked what they understood by *'network building'*, the president replied, "at present we are not focussing on network building, as the INP+ has specified in its triangular approach, but we are in a stage of 'networking', i.e., linking PLWHA to the network". When the researcher further enquired about the districts and block level networks which are coming up, the president replied, "These district and block level networks are also a part of networking and not network building. Network building is a later stage and will be done once these (district level network) DLNs are formed." The other members also agreed with each other that network building was linking the PLWHA to the network and thus strengthening it. On being asked whether the 'networking' included 'care and support' component, the members as well as the president emphatically replied that it does not include 'care and support'.

The members were also asked what they understood by *'service delivery'*. They replied that whatever services they provided to the PLWHA like treatment and testing facility and Drop-in-Centre (DIC) came under service delivery. When the researcher probed further asking whether it included care and support, the members replied that care and support and service delivery both include the same activities. Contrary to this, the president again said, "Only advocacy included care and support because advocacy is done to make the health services available and accessible to the PLWHA."

Information given to the members

In the informal group discussions amongst the members, they used to often talk about their physical state. They compared their state of health before the network was formed and after they became a part of the network. They discussed their experiences with each other and gained insights into other's diverse experiences and learnt from each other how to handle those situations in future more effectively. They talked about how the network has eased their lives by giving them information about HIV and how to deal with the opportunistic infections, ARV treatment, information about nutrition, necessity of use of condoms, spousal relationships etc.

Women members of the network are paid most attention to with respect to information regarding Urinary tract Infection (UTI), Sexually transmitted diseases (STD), use of condoms. Since most of the male members of the network are literate, they are able to read the booklets distributed to them by the office and if they have any clarifications to make, they openly discuss it with the other male members. While in the case of women, most of them are illiterate or even if they are literate enough to read, they rarely read the IEC materials given to them.

Generally the women do not express any discomfort or problem they are experiencing, be it physical or emotional. They hesitate in telling the problem openly and often try to hide the real situation and hence their problems often remain unsolved. Most of the women in the network have been infected of HIV through their husbands. The network, as a group, believes that women should be specifically given knowledge about how to save themselves from being infected and further, if infected, how to deal with the infection, take specific precautions and comply to the treatment regimen in order to keep themselves and their family healthy and safe.

There were two cases of condom failure leading to pregnancy in two concordant couples. One couple was able to get the foetus aborted, which was a *collective decision of the (active) network members*, while in the case of the other couple, it was too late to get the abortion done so the pregnancy had to be continued. The network members realized the importance of effective communication of knowledge and its practice in real life. In these two cases, the husbands were blamed for their carelessness for which their wives had to suffer. After these incidents, the whole network felt the need to empower women to speak up for their decisions and not just be passive followers of their husband's decisions.

Dynamics of interaction with the outer world

After being registered on 7th April 2004 as UPWPLHA under the Society's Act, the members of the network, especially the president, were continuously involved in networking and gathering support on behalf of the UPNP+ network with the UPSACS, the other NGOs working in the state, the media and other resource organisations. He was successful in establishing a good rapport with the people from different organisations working in the area of HIV/AIDS. However, the UPSACS officials were difficult to convince on the issue of networking of HIV positive persons.

The president of UPNP+ was invited in the official meetings, seminars and conferences organised by the other NGOs and other organisations working in this area to represent the positive people but the UPSACS, in their meeting with the different NGOs and other organisations working on HIV/AIDS did not invite the UPNP+ president. The UPNP+ president came to know about the meeting from members of other organisations working in the area of HIV/AIDS who were invited in that meeting which was on the 'State Project Implementation Planning' (SPIP). The UPNP+ president when to the UPSACS office and demanded that he should be included in the meeting as he represented the 'positive people' whose interests have to be taken into consideration when planning a state project. At last after much argument he was allowed to attend the meeting but in the 'State Project Implementation Planning' (SPIP) report, there was no mention of networks of PLWHA.

After this incident, the UPNP+ president approached the 'Project Director' of UPSACS and met him personally to convince him about the work he was doing and that he already had support from other organisations working on issues of HIV/AIDS in the state as well as in the country. At last, he was able to convince the Project Director of UPSACS. He was invited in the meeting on 'National AIDS Control Program', third phase (NACPIII), on 20th June 2005, in which the other participants were from 'Centre for Disease Control' (CDC), NACP and UPSACS. There the UPNP+ President demanded the facility of viral load testing to be available in U.P. He also demanded that doctors should be trained on the issues of HIV testing and treatment and all NGOs and other organisations working in the area of HIV/AIDS should work together to fight the disease.

In the month of July 2005, a meeting was organised by the UPNP+ in Allahabad, in which about twenty-five PLWHA from all over U.P. participated. The meeting was also attended by representatives from Family Planning Association of India (FPAI), Naz Foundation of India, and Swarg and who had been instrumental in building up the network. The main objective of this meeting was to provide complete knowledge of HIV and AIDS to the members and inform them about the necessity of using a condom and to motivate them to use condoms with their partners to stop the transmission of infection. Information was also given about proper use of condom and sexually transmitted infection (STI). PLWHA were also informed about the efforts being made by the network to make the facilities easily available to them. This was the first big meeting of the network. It was a closed door meeting and only members of the network and those working along with it were allowed to attend it. The president himself financed this meeting.

In August 2005, a press conference was organised jointly by UPNP+ and Indian Network of Positive People (INP+) in Lucknow. In the press conference, Mr. Manoj Pardesi from INP+ gave information about HIV and AIDS and how one can live a healthy and happy life even after being HIV positive. Mr. Manoj Pardesi and Mr.

Naresh Yadav both spoke as positive speakers and shared their experiences with the media. The following day, a press conference was organised by UNICEF in which Mr. Manoj Pardesi from INP+, Mr. Naresh Yadav from UPNP+, Dr. Nirmal from UNICEF, Dr. Jaya Sridhar from Inter News Network, Dr.S.P.Goyal, Project Director, Dr.Yogesh Chandra, Assistant Project Director, UPSACS participated. Information about ARV treatment for pregnant PLWHA mothers and their children was discussed. Diet and nutrition of the pregnant PLHA mothers and their neonates was also discussed. Consensus on the following issues were reached which were needed to be worked upon—

1) Need to work with the PLWHA
2) Reduce the fear; come forward
3) Awareness about transmission
4) Safe sex
5) Stages of AIDS
6) HIV is incurable but prevention and control is possible
7) Behaviour change

The Project Director of UPSACS acknowledged that six states are most affected by HIV/AIDS. In comparison to them, U.P. is less affected but it is under observation. No statistics are available on the impact of HIV in urban and rural areas of U.P. and thus there is a need to work in this area. Regular consultations with the media are also important as media is an effective tool in bringing issues like poverty and unemployment, hunger and starvation, to the forefront in the society which leads to development of welfare programmes for the people. They also requested the media to be sensitive towards the PLWHA and use non-discriminatory language while reporting about them. This was also supported by Mr. Manoj Pardesi from INP+. Dr. Nirmal from UNICEF said that the meeting would initiate a dialogue between the organisations working in the field of HIV/AIDS and the media in U.P. to put a check on the disease and in turn prove to be an effective tool in controlling the spread of the disease. Dr. Jaya Sridhar acknowledged that regional newspapers play a big role in generating awareness in the general public. She also said that the U.P. state government did not present the health plan of the state in a proper way and at present about 51 lakh 34 thousand people are estimated to be HIV positive in U.P.

In September, 2005, a meeting was organised by UPSACS in which 10 PLWHA from UPNP+ were invited by UPSACS to Lucknow. There, the Project Director (P.D.) of UPSACS, Mr. S.P.Goyal and Mrs. Mukta Sharma, Incharge, Care and Support, met the PLWHA. They were asked to differentiate between HIV and AIDS and share their knowledge and experiences with them. The PLWHA explained to them that they were HIV positive and had not reached the stage of AIDS and that they were healthy. They also informed them that it was important for them to have good nutritious diet in order to remain healthy and prolong their life. The P.D. assured that information about HIV would be given at all levels from district level like to the Chief medical Officer (CMO), District Magistrate (D.M.), Superintendent of Police, to the block and village level like Anganwadi centres, PHCs and CHCs. He also said that a 'card' will be issued to every PLWHA by the D.M.'s office having a code number on it. This card could be used by the PLWHA for easy access to treatment. He also said that HIV positive people have every right to live in the society and command an equal status which should be given to them and it should be made sure that they are not discriminated and their dignity is not lowered especially by the non HIV positive people.

Some PLWHA narrated the discriminatory behaviour they had experienced in their areas. One of them said that if people around them come to know that a HIV positive person is sitting next to them they look upon them with suspicion and hatred and move to another place to sit. Another PLWHA said that they feared if they move out of their village and the policemen come to know somehow that they are HIV positive, they will put them in jail. The PLWHA expressed how they are and to what extent they are experiencing stigma and discrimination. They said that due to lack of knowledge there is too much of stigma attached to the disease and so to lower it in the society awareness about the disease is the only solution. Another member of the UPNP+ network who is also a representative of Naz foundation said that special focus should be on awareness about HIV disease, its treatment and employment of the PLWHA.

The PLWHA demanded that—

- PLWHA should be brought into the mainstream of the society
- There should be an open discussion on the issue of HIV and AIDS with the government and the PLWHA
- ART centres should be opened in all the medical colleges of the state.
- India has a vast population so government of India should work in collaboration with the NGOs working in the country on the issue of HIV and AIDS to implement the GIPA Policy in India.

In October, 2005, in the INP+ workshop at Chennai, five PLWHA members, two females and three male members from the UPNP+ network participated. In the workshop the members learned how to form a new network, what is advocacy and how it is done. They also learned about other PLWHA networks in the south and their working. Stress was also given to the necessity of good counselling to be done of the persons who come in contact with the network members and the need to form district level networks. They also attended the sessions on 'Mother to Child Transmission' MTCT which included treatment regimen for the mother as well as the child, 'Septran' as an effective medicine for the HIV positive children, nutrition for mother and child, and breast feeding. They also learned about new treatment regimens and new HIV antibody testing methods through which HIV antibodies could be detected by any body fluid like saliva, urine and vaginal fluid.

In November 2005, a three day capacity building workshop was organised by Catholic Relief Services (CRS) for the members of UPNP+ in Lucknow. The participants were told to prepare a list of issues on which they wanted information and discussion. These were—

- Information about medicine, treatment
- Information about employment
- Information about from where support can be obtained

- Health related information
- How to help each other or form a group
- Issue of children orphaned by HIV and AIDS
- Information about HIV counselling
- Information about human rights, law and justice
- Information about proper nutrition.

In the workshop they were given information about HIV and AIDS. They were also informed about the various HIV tests like rapid ELISA tests, CD4-CD8 count and their various cut-off values and implications, Western Blot and PCR tests and how the values and results of each test determine the ARV treatment regimen. They were also told about GIPA and its importance and implications, and importance of 'peer educators' in the area of HIV/AIDS. In the workshop, the members were made to think about – what is UPNP+, why is it needed and what is its aim? They were also made to ponder upon the objectives of UPNP+. After the workshop, the members were taken to Shanti Niketan Hospital in the Suburbs of Lucknow where they learnt how to manage the new HIV positive cases approaching them.

In the same month, about 20 PLWHA from UPNP+ participated in the workshop by Action Aid called 'Stepping Stones' which was focussed on behaviour change strategies for the PLWHA. The content of the training of 'master trainers' included information about the human body, difference between a male and a female body, information about STI, reproductive tract infection (RTI), HIV, qualities of a good human being, being a good listener, sexual relations, understanding the emotions and feelings of spouse or sexual partner, proper expression of emotions, use of condom, masturbation, oral, anal and vaginal sex, consent of the sexual partner and love. Two members of UPNP+ have been receiving scholarship from Action Aid and have been selected for 'leadership training'. One of them is the wife of the president of the network and the other is the Joint Secretary of the network.

On 4th December, 2005, an event was organised jointly by all NGOs working on the issue of HIV and AIDS in the city of Allahabad. 15 UPNP+ members participated in the programme representing the HIV positive persons in Allahabad. This was the first time that HIV positive persons had made a public appearance as 'HIV positives' in the city. The State health minister, the District Magistrate (D.M), the Chief Medical Officer (C.M.O) and others were present in the programme. Although the UPNP+ members were able to make a presence in this event, they were looked upon with suspicion rather than being supported by the other organisations and the government officials. Even the media interpreted and reported about the stories of the PLWHA blaming them for their behaviour which led to the disease.

A seminar was organised by the Lawyers Association working on Human Rights in the city of Allahabad in December 2005. In this seminar, for the first time 20 PLWHA from the city came out as positive speakers and discussed their issues with others in the light of other issues like 'Right to Food' and 'Employment Guarantee Scheme'. The president of UPNP+ participated as a speaker along with Mr. Suman Jana from FPAI to speak on the issue of stigma and discrimination of PLWHAs and proper implementation of various government schemes for better accessibility and availability of services to the poor and marginalized of which PLWHAs form a part. In the seminar, the PLWHA occupied the seats in the last row of the seminar hall. They interacted amongst themselves but avoided talking to other people. Even if someone tried talking to them, they either did not reply or their only reply was, "I am HIV positive". They became a subject of amusement for the other participants. Their behaviour clearly showed that they were not comfortable with their identity as a PLWHA in the general public.

Besides Swarg, UPNP+ now attempts to works in collaboration with the other NGOs working in the city but it still does not have their full support. It works with –

- Lok Sewa Smriti Sansthan
- Bapu Gramudhyog
- Arthik Anusandhan

- Jan Kalyan Maha Samiti
- Action for women and Rural Development
- Gramin Sewa Sansthan.

They make a token presence whenever invited to any function or meeting organised by UPNP+ and do not actively seek any collaboration or give any support on their own.

Awareness camp in the Magh Mela

The UPNP+ members had put up an awareness camp in the month long Magh-Mela which is held every year in the month of January- February on the banks of Sangam, the fusion of rivers Ganga and Yamuna at Allahabad in Uttar Pradesh. Thousands of people come every day to take the holy dip at Sangam. The awareness camp by UPNP+ started on 14th January and ended on 14th February.

The objectives of the camp were— Dissemination of information about HIV and AIDS by the PLWHA in such a big congregation of people on the issue of HIV and AIDS. Attempting to reduce the stigma, discrimination and myths prevalent about HIV and AIDS in the society. To bring the PLWHA into the mainstream of the society and to develop a positive attitude on the issue of HIV/AIDS in the general society.

In the awareness camp, 25 male and 15 female members from different districts of U.P. like Allahabad, Eta, Azamgarh, Varanasi, and Kushinagar participated. In the mela, the UPNP+ members went around wearing an apron with positive messages about HIV written on them. They also distributed pamphlets and booklets on HIV/AIDS with the contact numbers and address of UPNP+ written on them. The members distributed the IEC materials to the general public and imparted knowledge about HIV/AIDS. They went to the different camps of government offices like police, fire station, Northern-Central railways, Public Works Department (PWD), shops, exhibitions and also to the camps of the 'Sadhus'. They received a very good response from the general public as well as the people in various camps they visited. A person in the mela remarked, "*Manav rahega tabhi dharm rahega*", that is, religion can exist only when man is alive and hence awareness about HIV/AIDS becomes very important in present time.

The most unexpected response was from the Sadhus and other religious camps of various 'maths' or different schools of thought in the Hindu religion. The Sadhus' were quite eager to know about HIV and its treatment and prevention. One Sadhvi said that one should talk about the tradition and culture of India, about Ram and Sita instead of talking about sexual health and condoms. They congratulated the network members for the 'good' work they were doing and promised to extend their full support to the network to free the world of HIV/AIDS. Through this awareness camp, the network was able to gain acceptance and lower the stigma or fear of stigma in the general public. The network was able to add fifteen new members from this awareness camp.

This awareness camp was a big achievement for the network as soon its impact could be seen. Every day around five-ten people from the general public used to come to the camp to get information about HIV/AIDS and its treatment and where could they go for help. Through this camp, the network could reach those people also who are very difficult to approach. In the Magh- Mela, the general population which comes to take the holy dip at Sangam is the rural population with a comparatively lesser urban population and there is a need for awareness of HIV/AIDS in the rural areas. Another big advantage of this camp was that the women, especially the rural women could be given information about HIV. In the mela, the women hesitated in talking about HIV and even in taking the pamphlets that were being distributed. They were given information about HIV/AIDS by the women members of the network. Generally the women remain ignorant of the disease and become passive recipients of the HIV infection from their husbands. Thus the network was able to approach this vulnerable section of the population who is most in need of information to save themselves and their family of HIV/AIDS.

Another big achievement of the network was that in the exhibition put up by Northern-Central Railway in the Magh-Mela, a very scary sketch of a skull with blood all over and a statement written below, "AIDS is a dreadful disease" was put up on a very big glow sign board at the entrance gate. The UPNP+ network members were able to get the board removed from there and it was replaced by a board with a 'neutral' message about HIV/AIDS.

Where network made its presence felt

The network members visit the Anganwadi centres in their respective areas and give information about HIV and AIDS. In one case when one of the members of the network who is also working as an Anganwadi Sahayika (helper), was stopped from distributing eatables in the Anganwadi centre when her HIV status became known to other people working there, the network members on getting the information of the incident immediately reached there and gave information to all the people there about HIV and AIDS and thus were able to change the stigmatizing and discriminating environment into a healthy environment.

In another case, a child was thrown out of the school when the teacher came to know that his father had died due to AIDS and his mother was HIV positive. The mother of the child is a member of the network. The primary school is located in the same area in which the network office is situated. When the members of the network came to know about this incident, they reached the school and gave information about HIV/AIDS to the school teachers. After giving answers to all the queries that the teachers had, the UPNP+ members were able to convince them that others would not be infected by HIV through the child. The child was admitted back into the school. Follow up of the child was also done to ascertain that the child is well adjusted in the school and is not discriminated or taunted by the other students or teachers. After this incident, the network felt the need to work with the schools. The UPNP+ members have been able to sensitize the schools in the area and have been able to put the children back to school whose parents had been found to be HIV positive and due to this their children were thrown out of the schools.

In another case, a PLWHA came to the network office suffering from a host of O.Is. He needed hospitalisation. He was admitted in a well known hospital in the city the same evening he came to the network office. The next morning he was thrown out of the hospital as soon as the staff came to know that he was HIV positive. His condition was worsening. On the recommendation of Dr. Amitabh Upadhyay, he was again admitted in a nursing home near the office. Here again, by evening, the attending doctor and the owner of the nursing home not only charged extra money for keeping the PLWHA in the hospital for only four hours but also told the relatives and the members of the network to take him away as he could no longer keep the 'patient' in his nursing home. After much argument the PLWHA was brought back to the office and then sent back home with the medicines. After two days the PLWHA died. Though the network was not able to save the PLWHA, this incident made the members realize that they have to fight against the stigma and discrimination against them and especially sensitize the health service providers on this issue.

What the health care providers say....

1. The UPSACS—despite many meetings with the UPSACS, the network till date has not been recognised by the UPSACS as a PLWHA network working in the state. The reason given by the UPSACS is that they do not consider the networks office bearers and board members to be elected representatives of the network. According t them, they would only consider it as a true PLWHA network, as per the NACO guidelines, when proper elections will be held and the office bearers would be the truly elected representatives of the network. The UPSACS have supplied the network *only* with the IEC material as the network mostly involves the media in making any demand to the UPSACS which is resented by the UPSACS.

2. The VCTCs --- there are two VCTC centres in the city of Allahabad. When the researcher visited these centres at the start of her field visit, to enquire about the network, the counsellors at these centres expressed their ignorance about the presence of any such 'positive peoples' network in the city. When they were asked whether a network of PLWHA will be successful in catering to the needs of the HIV positive persons, the counsellors of one VCTC replied that it would be effective. They said, "We at the VCTC centres can only provide them with counselling and testing facility. In our city (Allahabad), apart from the treatment for O.I. no other treatment facility is available. The hospitals in the city do not even admit the HIV positive people. The situation is worse for the poor people who are HIV positive or have AIDS. They cannot afford the private treatment and the government hospitals do not treat them. They have nowhere to go. Even if we suggest them to go to Varanasi to get their CD4 done so that they can be put on ART, they cannot bear the expenses of going to Varanasi and paying Rs.500 for the registration for the test and the ART. These 'patients' often do not return to the VCTC neither do they reach the ART centre. They leave themselves to fate and return to their homes or resort to other options like ayurvedic treatments, 'jhad phuk baba', spiritual healers, 'tantriks' and others". They acknowledged that if a network of HIV positive people is formed, it would not only provide strength and confidence to the PLWHA but also facilitate the access to treatment and care. They would also be able to fight for their rights as a group and be able to lower the stigma and discrimination which they experience almost every day. By the end of the field visit of the researcher, which was after three months, this VCTC had extended its support to the network which was in a much stable position by then. They now refer 'generally' those cases to the network who are unable to go to Varanasi for CD4 and ART, or those PLWHA who are experiencing problems related to stigma and discrimination due to HIV/AIDS.

   On the contrary, the counsellor at the other VCTC maintained that formation of a PLWHA network was just a method to get a project from the international

NGOs as any project in the field of HIV/AIDS means good amount of funds. The male counsellor said, "These are all tricks to earn money. No one bothers about the HIV positive people. I have been working as a counsellor in this VCTC for the past six years. I have seen so many NGOs come and go. They only work for themselves...for money. Once they get the money they won't even think whether the PLWHA is being treated, whether he has food to eat, how is his family coping with his illness, the economic and emotional burden, what stigma and discrimination is he facing in the community in which he lives?" When he was asked whether he would refer the PLWHA to the network he replied, "first of all I will enquire about it. When I am sure that they are not misusing the PLWHA and sincerely want to work for them, then only I will refer the PLWHA to them." Till date no PLWHA has been referred to the network from this VCTC. The network members, even after repeated meetings with this VCTC counsellor, have not been able to build a trustful relationship with them.

3. The treating doctor--- the 'only' treating doctor for the network is Dr. Amitabh Upadhyay. He had been working with Swarg for the past five years. He has been instrumental in the formation of the network. When approached by the researcher, he replied that he ***does not*** have the knowledge of any HIV positive network being formed in the city. He said that his work is to treat the patients with HIV or AIDS. When asked about Swarg, he said that it was a Truckers' intervention project and he worked with them and received a salary. When asked whether he would treat the HIV positive people 'free of cost' or charge a lesser amount of fee if the PLWHA were referred to him from the network, he said, ".....certainly not! I have my family; I have to think about them also. Even when I was working with Swarg, I used to give away the medicines which I received as physician's samples to my patients to treat the O.Is. I used to often arrange the expensive medicines and never charged anything from them. Even now my consultation fee for HIV positive 'patients' is only Rs.100 in which the they can consult me for a maximum of three times

in a period of one month. What can I do more? After all, "ghoda ghaas se dosti karega to khayega kya?"

At present Dr. Upadhyay visits the network office every Saturday. He is not on salary but charges his consultation fee of Rs.100 from the 'patients'. He prescribes the ARV treatment to his patients for only twenty days and so has to be consulted after every twenty days. He treats the PLWHA for the side effects of the ARV treatment whether prescribed by him or obtained from other sources. He is easily approachable and dependable and people prefer to go to him rather than going all the way to Varanasi for it. Since most of the network members have been treated by him when they were not on ART from Varanasi, they trust him and even he is very responsive to them and their health problems. He knows most of the members personally and is a big source of encouragement for them.

4. The CMO and the nodal officer (HIV/AIDS) --- when the researcher met the CMO and the nodal officer on the AIDS Day programme organised jointly by all organisations and NGOs working in the city on HIV/AIDS, she enquired about the general health services, the state of HIV disease in the city and any new initiative taken by the UPSACS in this regard. They replied that the UPSACS do not send us any statistics or report of the prevalence of HIV/AIDS in the city or even in the state, "We have not received any document in this regard. Either the VCTCs know about the statistics or the UPSACS". When they were asked whether they knew about any network of HIV positive people which is being formed in the city and would it be helpful in any way to the PLWHA? They replied, "We have just seen some of the members of that network in the programme. It is a good concept to form a network. It should work if they themselves are dedicated towards it. We will see what we can do. We need orders from the UPSACS". Till date no support has been given by the CMO or the Nodal officer to the network. Even when the awareness camp in the magh-mela was organised by the network, they did

not support the network in any way, neither in recommending them to get the place allotted in the mela area, nor supplying them with IEC or any other material or even helping them financially. It was all arranged by the president of the network himself out of his own pocket. Later the cost of the mela camp was reimbursed partly by UPSACS and partly by UNICEF. The network has received the money from UNICEF but the money send to them
by the UPSACS is still pending at the CMO's office.

5. **Other NGOs --- the other NGOs in the city which are working on the issue of** HIV/AIDS still do not fully support the network. They do acknowledge the work being done by the network. One NGO which is working on a truckers' intervention project in the city but on the Allahabad- Kanpur highway and were also trying to build up a network of HIV positive people in the city said, "Mr. Naresh Yadav is doing a good work. It is much easier for him to form a network of PLWHA as he himself is HIV positive. The information given by him will be more effective than if it is given by us to the HIV positive person. Hence he will be successful in his mission". Another project co-ordinator of a NGO said, "These are all tricks to earn money. Once they are able to link adequate number of PLWHA, they will be in a good bargaining position and funds will flow in. But it is quite likely that once they are established and have power in their hands, they will forget about the PLWHA and their welfare. This is what has happened with the people in INP+. Now they are busy only in attending big meetings and sitting in their air-conditioned rooms. They have forgotten about the PLWHA and their welfare. Just wait and watch".

Swarg 'the truckers' intervention Project'

Swarg has been the back bone of UPNP+. The foundation of the PLWHA network was laid down by Swarg. It had been working in the area for the past six years and felt a pressing need to unite the PLWHA so that they can collectively fight for their rights and avail the medical facilities and deal with the stigma and discrimination they were encountering in their day to day life. It was the project in-charge of Swarg who persuaded Mr. Naresh Yadav to attend the conference of Lawyers' Collective in Delhi. Swarg has been helping the network members in establishing the network. Maximum number of members of the network have been linked to the network by Swarg as they were in contact with the PLWHA in the area and adjoining areas. Even most of the office bearers and board members of UPNP+ have been in contact or unofficially had been working with Swarg. The project in-charge of Swarg has been a continuous source of support and encouragement to the network but now the role of Swarg is not being acknowledged by the network. The project in-charge of Swarg, Mr.Anil Yadavendu has apprehensions about the future of the network as he fears that the network has drifted from its goal of catering to the needs of the PLWHA for which it was formed but now the 'active' network members including the president is more involved in taking up projects and handling too much of responsibilities conferred onto him by the INP+. He also remarked that these active members are more involved in taking up projects of national and international NGOs and earning money rather than thinking about the rest of the 'most needy' PLWHA in the network and arranging for their livelihood and treatment.

Problems faced by the PLWHA

The PLWHA expressed their problems which they face while interacting with the outer world. Since majority of the PLWHA are from lower socio-economic strata of the society, very few are well educated or have experience of interacting with the outer world. Their problems were—

1) When the members attend any meeting, seminar or conference of national or international NGOs, INP+ or even the government, they complain that the speakers speak in 'English' which is incomprehensible for them as they do not know this language. One of the members who had attended the

INP+ conference in Chennai told the researcher that he could not understand even a single word in the daily sessions. When he requested the organisers to arrange for an interpreter who could translate the presentations in Hindi, the organiser replied, "I cannot do this for one or two people". He even told the member, " if you are not able to understand what the speakers are saying here then go back and ask your president" to which the member replied, ".....if I had to ask my president then why did I come all the way to Chennai". Later the member repented that it was the first meeting from which he gained nothing.

2) The members also expressed having problems in documenting and maintaining records of the meetings and events, especially in English. They are in the process of learning to document and maintain records. Till date the UPNP+ does not have its own brochure, pamphlet or booklet. They distribute the IEC material provided by the UPSACS with the UPNP+ stamp on it.

3) They also articulated that they are not chosen for jobs or projects offered by different organisations and NGOs as they do not fulfil the educational requirements. Most of the jobs or projects require at least a post graduate or a graduate degree and very few PLWHA posses these qualifications and even if they do they are already engaged in some or the other project of job. Hence very few options are available for those PLWHA who are uneducated or are educated but not graduate.

4) The network members also told the researcher that they were unable to work in their own area in which they live. The most active members of the network said that they have no problem in imparting knowledge about HIV/AIDS to other people, sharing their experiences with them as a 'positive speaker' in different areas but in their own home town or area in which they live, they avoid being known as HIV positive or working on this issue. Some members reported that they fear that people will start commenting and taunting them and their family members. They also said that, "people will stare at us and look at us with suspicion and hatred. This kind of behaviour will be unbearable for us. We feel so helpless in our area, our locality and

> sometimes even while working in our city. Most of us still do not have the courage to face our relatives if we meet them in any of the meetings or events within the city and be identified as a HIV positive person. Often in these situations we avoid meeting them and leave the place as soon as possible".

To conclude, it can be seen that there is a predominance of middle class and low class members in the composition of the network, especially in the age group of 20-40 years (table no.2). The high caste members are more in all the three economic categories, the OBC members also represent themselves in the middle and low income category (table no. 3). The internal dynamics of the network reflect the role of the caste in the daily interactions. The president and the Secretary, the key persons in the network are from high class and middle class OBC category. They are considered to be from "unchi jati" by themselves and others and thus hold a status of respect. The third key person is a Muslim who is the only active Muslim and holds the post of vice president due to her experience of working with women in the Anganwadi centre and Swarg. It is also seen that the decision making power lies with the high caste or OBC category members who hold the key positions and their decisions are accepted by others without question. The women in the network are 53 as compared to men who are 77 in number in the membership of the network (table no.1). As it is seen the women do not play a role in the decision making process of the network. They accept the decisions of the 'male' members even if the decision is about them, often by just nodding their heads.

Though the network members have attended many meetings and workshops, the members still feel they need to be trained more and receive more knowledge about HIV/AIDS as the common problem they encountered was the problem of language. They could not comprehend what was being said in the meetings as in most of the meetings and conferences, the speakers speak in English. The members themselves realized that they are not clear about the concepts and their meaning which they are using in their daily interactions while working with the network. While interacting with the outer world, the network has received a mixed response from the help providers. In the city, the network has some support from one of the two government VCTC and some other NGOs. It has still to build a level of trust in the eyes of the CMO, UPSACS and other key help providers. The network, at present, is in the process of building itself and a level of trust in the eyes of these key help providers, while it simultaneously develops links with the national and international network and support agencies.

CHAPTER FOUR

Chapter 4

Quality of Life of Positive People: Impact of HIV Status and of the Network

This chapter looks into the accounts of the regular and active members of the 'Allahabad Network of Positive People', a district level unit of the 'U.P. Network of Positive People' (UPNP+). Through these accounts of the network members narrating their experiences, the researcher has tried to explore the impact of knowledge of HIV status after they were diagnosed HIV sero-positive. An attempt was made to look into the differences in the experiences of the network members belonging to different castes, economic categories and gender and thus to see the impact of social structure and position. The researcher also tried to see how the network has been able to bring about a change in the lives of its members. The experiences of the members have been analysed on different dimensions emerging out of the review of existing literature– quality of life (physical, emotional, social) stigma (internalized and external), discrimination, confidentiality and disclosure, , level of information, social support (instrumental, informational emotional, economic), and women specific issues (status in the house, having a baby, sexual relations, contraception).

Profile of the twenty-two network members

Detailed case studies were prepared of 22 members who were the most active and regular members of the network. These include the office bearers of UPNP+ namely, the president, the vice-president, the secretary, the joint secretary and the treasurer. Apart from these five members, amongst the rest of the members whose narrative accounts have been taken, most of the members have been instrumental in building up the network and have been the founder members of UPNP+. They have been classified into economic class categories[1]-- high class, middle class, low class as in Table no.4 below— it shows that these regular and active members have a

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[1] Economic category on the basis of total household income— >Rs.20,000 per month= high class, Rs. 20,000—Rs.5000= middle class,
< Rs.5000 per month= low class.

proportionately lower representation of the low economic category which is 36.4% as compared to 43.1% in the whole network. Representation of the middle class is 41% in the regular and active members as compared to 36.1% in the whole network while the higher economic category has 23% of its representation in the regular and active members as compared to only 21% of the high income category members in the whole network.

Table no.4

Categorization of the 22 members

Category of Members	**High Class**	**Middle Class**	**Low Class**
Concordant couples (both husband and wife are HIV+)	2 (HC)*	2 (HC)	1 (LC)**
Unmarried men	0	2 (HC)	0
Men whose wives have not been tested	1 (HC)	3 (2 HC + 1 LC)	1 (HC)
Widows	0	0	5 (2 HC +1 Muslim + 3LC)
Total	5	9	8

*HC= High caste

**LC= Low caste

Of the concordant couples, two couples fall into each of the high and middle class categories while one couple falls into the lower economic category. The unmarried male members fall in the middle class category and three male married members whose wives have not been tested fall in the middle class category while one each in the high class and low class income category. As the wives of these five members have not been tested, their sero-status is unknown and thus they are not the members of the network at present. All the widow members whose narratives have been taken fall in the low economic group, indicating either an earlier death of the men in this class, or a fall in economic status of the women due to the expenditure on husband's illness and loss of his income.

In Table no.5, which shows the socio-demographic and treatment profile the members of the network, it is seen that the members falling into the higher economic category are well educated, holding a graduate and post-graduate degree while majority of the members in the middle and lower economic categories have education ranging from class 6th to class 12th. The couples in the higher class belong to the higher castes; the couples in the middle class belong to the 'Other Backward Caste' (OBC) category while the couple in the lower economic class belongs to the OBC and lower caste. Majority of the couples in the study live in joint families, however, the family size given in the table is for their nuclear units only. The couples in the above table no.5 having a family size of two indicate that they had been recently married and their family formation had not started and HIV infection for them meant an end to their desire of having children.

The couples with the family size of 4 indicate that they have two children each. These couples reported that they had adopted a permanent method of contraception before being diagnosed HIV positive. This has meant that they are less motivated to use condoms, while those couples with a family size of three indicate that they have one child and therefore use condoms more consciously. All children of the network members who have been taken for case study are HIV sero-negative and thus they are not the registered members of the network and have not been interviewed.

It is also evident from table no.5 that the occupations of the members vary according to their economic category. The higher class members are well educated and are involved in occupations running their own business or a boutique. The members falling into the middle class economic category are involved in occupations like owner of a small shop, farming and running a small hotel, driver, salesman etc. Looking at the lower income category, the occupations are that of a "hamali" or a cart puller, Anganwadi Worker (AWW), agricultural labour, housemaid etc.

Table no.5 also shows whether the members are on Anti-retroviral treatment or not and if they are then from when have they started it. It is seen that the members in the

Table No. 5

Demographic and treatment profile

Eco. Class	Code Name	Sex	Age	Marit. Status	Caste	Edu	Occupation	House.H Income	Fami Size	DLN	Yr. of HIV test	CD4 count	ART startd	treatment Pub/Pri	Status in Network
High	A	M	32	M	2	PG	Business	1 Lakh	2 jt.	1	2003	532	2003	pri	**President**
	B	F	28	M	2	PG	Business	1Lakh	2 jt.	1	2003	546	2003	pri	Member
	C	M	37	M	1	PG	Business	1Lakh	4 jt.	1	2004	-	nil	pri	Member
	D	F	33	M	1	UG	Boutique	1Lakh	4 jt.	1	2004	-	nil	pri	Member
	E	M	33	M	1	PG	Busn+Farm	1.5 Lakh	3	3	2001	-	2001	pri	**B** Member
Middle	F	M	36	M	2	UG	Shop + Farm	20,000	4 jt.	1	2002	300	2004	pri	**Secretary**
	G	F	30	M	2	8th	Housewife	20,000	4 jt.	1	2002	482		NA	Member
	H	M	34	M	2	7th	Tailor	15,000	2 jt.	2	2000	-	2004	pub.	**J. Sec**
	I	M	40	M	2	8th	Homeguard	20,000	6 jt.	1	2001	38	2005	pub.	Member
	J	M	28	M	2	8th	Salesman	10,000	4 jt.	1	2003	360	2005	pri	Member
	K	M	27	UM	1	9th	Driver	15,000	1 jt.	4	2003	-	2005	pub.	Member
	L	M	20	UM	1	B.E.	Student	20,000	1 jt.	1	2005	275	2005	pri	Member
	M	M	25	M	2	10th	Hotel Owner	10,000	2	1	2004	160	2004	pri	Member
	N	F	22	M	2	8th	Housewife	10,000	2	1	2004	376	2005	pri	Member
Low	O	M	30	M	1	10th	Labourer	3,000	3 jt.	1	2003	53	2004	pub	Member
	P	M	28	M	3	6th	Hamali	4,000	3 jt.	1	2004	307	nil	pub	**Treasurer**
	Q	F	25	M	3	8th	AWH	4,000	3 jt.	1	2004	162	2005	pub	Member
	R	F	32	W	1	10th	AWW	2,500	5	1	2002	313	nil	NA	**V.President**
	S	F	38	W	2	nil	Housemaid	800	2	1	2003	632	nil	NA	Member
	T	F	35	W	2	nil	Agri Labour	500	6	1	2004	210	nil	NA	Member
	U	F	30	W	1	8th	Beedi worker	2000	4	1	2004	338	nil	NA	Member
	V	F	35	W	3	nil	Agri Labour	2500	5	1	2000	155	2005	pub	**B** Member

PG- Post Graduate
UG- Under Graduate
AWW- Anganwadi worker
AWH- Anganwadi helper
PRI- Private Health Care
PUB- Public Health Care
DLN- District Level Network

higher income group had started their ARV treatment soon after being diagnosed HIV positive. Their treatment was started by a private doctor they were consulting and they bought the medicines from the market. The ARV treatment of the members in the middle class category was started one or two years after the diagnosis. In these cases also the treatment was started by buying the medicines from the market. The government hospitals were approached only when they could not afford the cost of treatment. While in the case members which falls into the lower economic category, the ARV treatment of members was started by the network from the government ART Centre, BHU Varanasi.

Thus the affordability as well as accessibility to the medical services is determined by the economic condition of the person. As seen here, the persons who could afford the treatment costs availed the private medical services as long as they could bear the costs, whereas those who could not afford had left themselves to destiny and after becoming the members of the network were entirely dependent on the network to decide their fate as they had no other option, with the same period of infectivity as that of the members of the higher and middle class categories.

Analysis of the narratives according to the issues in the area of HIV/AIDS in the context of economic class differences

Many studies have been documented up till now in the area of HIV/AIDS which have narrated the experiences of the PLWHA of either middle economic class or the lower economic class. In this study an attempt was made to see the differences in the experiences of the high economic class, the middle class and the low class PLWHA. As shown in table no.4, five members in this study fall in the high income group while there are nine members in the middle class and eight members in the low economic category. Experiences of the members in different classes differ from those falling into other economic classes on various dimensions like stigma, discrimination, level of information, confidentiality and disclosure, quality of life, social support, and issues related to women. The level of involvement and the benefits derived from the network also differ for different members falling into different categories of caste, class and gender.

As seen in table no.4, four members each, fall into the high income category and the middle income category with two members falling into the low income category of the concordant couples. The experiences of these members differ on various aspects.

After being diagnosed HIV sero-positive, the first reaction of the members differed greatly due to the mode of transmission. In the case of concordant couples in the high class, the situations which led to the HIV test were different.
"Suddenly in the month of June, I experienced rapid weight loss. Along with it I also started having loose watery diarrhea and high fever. I consulted a private doctor and he advised me to go for HIV test. I went for the test since I was very confident that I would not be having the disease and the test is only to rule out the possibility of HIV."

A, 32year old married man. (High class, OBC)

"I was very confident that he would be HIV negative and more than me he looked very calm and relaxed. After two days he went to take the HIV report with his friend. When he came back, he was very quiet. I kept on asking him but he didn't say a word. At night he told me that he had got the report and he was HIV positive. I was shocked to hear this! I didn't know how to react. I never expected this. I knew that HIV was incurable and one who gets HIV dies very soon. My husband who was always full of energy suddenly looked so helpless. He started crying and I could not control myself either."

B, wife of A, 28 year old (high class, OBC)

In the above case of the concordant couple (A-B), the diagnosis of HIV was unexpected. Due to this, the reactions of the couple were intense. Since they were newly married and were just planning their future life, this diagnosis suddenly thwarted their future plans. A feeling of helplessness and hopelessness had seeped

Table No. 6

Impact of HIV Status																		
Eco. Class		**High Class**			**Middle Class**							**Low Class**						
		A-B	**C-D**	**E**	**F-G**	**H**	**I**	**J**	**K**	**L**	**M-N**	**O**	**P-Q**	**R**	**S** **V**	**T**		**U**
Physical	symptoms	Fever, wt loss, vomiting	Prolonged illness	Fever Wt. loss	Nil	Nil	diarrhea Low	herpes	diarrhea	Fever Wt.loss	Diarrha, Vomiting fever	T.B	Stomach ache, weakness, fever	Nil	Nil	Nil	Low	Low
Emotional		Helplessness, hopelessness	relief	—	Fear of dying	Fear of dying		Fear of losing respect	Nil	Nil	Fear of death	Fear of death	Fear of death	Nil	Nil	Nil	Nil	Nil
Social																		
Stigma	Internalized	High	Low	High	High	Low	Low	High	Low	Low	Low	High	Low	Low	Low	Low	High	low
	Real	low	high	Low	High	high	High	High	High	Low	High	low	v.high	Low	v.high	v.high	Low	high
Disclosure by self		Ltd.disc.	Totally open	Ltd.disc.	Ltd.disc.	Ltd.disc.	Ltd.disc.	Ltd.disc.	doctor	Ltd.disc.	hospital	Hosp.	hospital	No.disc.	doctor	doctor	Friend	Doctor
Confidentiality	Maintained Breached	maintained		-	B .by sister	B.by ESI hosp	maintained	Hospital	hospital	maintained	hospital	-	hospital	-	B. by villagers	B. by villagers	-	-
Discrimination	Hospital	low	low	low	low	-	high	v.high	low	-	v.high	low	v.high	low	high	high	Low	High
	Workplace	low	low	low	low	v.high	low	low	low	-	-	-	- high	low	low	low	Low	low
	Community	low	high	low	low	med	low	low	low	low	low	low	high	low	v.high	v.high	-	High
	Family	low	low	low	med	-	low	low	low	low	high	low	Low-high	low	low	low	Low	-

Table No. 7 - Impact of Joining the Network

		High Class			Middle Class							Low Class						
		A-B	C-D	E	F-G	H	I	J	K	L	M-N	O	P-Q	R	S	T	U	V
QOL	**Physical**	improved	improved	improved	improved	improved	improved	improved	improved	improved	improved	declined	improved	same	improved	declined	improved	improved
	Social	improved	same	improved	improved	improved	same	declined	improved	same	improved	declined	improved	same	improved	improved	Improved	improved
	Emotional	improved	Improved	improved	improved	improved	improved	declined	improved	improved	improved	improved	improved	same	improved	improved	Improved	improved
Social Support	**Economic**	family	family	family	family	family	family	family	family	family	family	family	Network + family	Network+self	self	family	family	family
	Emotional	family	family	family	Family+network	network	net work	Family+network	Family+network	Family+friends	Family+network	Family+network	network	network	network	network	net Work	network
	Informational	INP+	network	internet	Swarg+network	network	net work	net work	VCTC+network	network	network	network	network	network	network	network	net Work	network
	Instrumental	self	self	self	Swarg+network	network	net work	net work	family+network	family+network	network	network	network	network	network	network	net work	network
Women Specific Issues	**Status in the House**	same	same	-	same	-	-	-	-	-	low	-	low	same	low	same	Same same	
	Decided to Have a baby	no	no	-	N.A.	-	-	-	-	-	undecided	-	pregnant	N.A.	N.A.	N.A.	N.A.	N.A
	Sexual Relation	same	strained	-	same	-	-	-	-	-	same	-	same	N.A.	N.A.	N.A.	N.A. NA	
	Contraception	condom	condom	-	Tubectomy+condom	-	-	-	-	-	condom	-	condom	N.A.	N.A.	N.A.	N.A.	NA

into their lives. The diagnosis seemed to them as a death sentence. They felt that their lives had ended before starting.

In case of another couple in the same category, the HIV diagnosis brought great relief to them as they came to know the reason behind all the misery.

"He was still not feeling well even after one month of hospitalization. We told the doctor many times about it but he always said that my husband was weak so he had fever. He never paid heed to what we said. At last, he was discharged from the hospital. At home, he started having severe headache and fever. He was becoming weaker day by day. My family took him to every doctor they knew, within the city or in different cities. But none could relieve him of his pains. Meanwhile, he suffered from relapsed tuberculosis three times. His health was deteriorating. There was a time when he couldn't sleep. He did not sleep for days. He used to feel cold and chilly in summer too. He had almost lost his senses. He couldn't recognize anyone. No doctor could diagnose him correctly. This was the only reason which was killing him. Neither he, nor anyone else knew what had happened to him. It was very difficult for me to see him in this state. I was tired of taking care of him. One day I prayed to God, "Take him away; at least he will be relieved of his pains. He has suffered enough."
C, 37 and wife D, 33years (high class, high caste)

There was hesitation on the part of the doctor treating, especially in low prevalence areas of HIV like Allahabad, the members of the high class to suggest them to get the HIV test done. Knowing the members social status, even if other people and even the doctor suspected the disease, they hesitated in informing them or suggesting them to go for the HIV test.

> "I took him to our family doctor. I told him that I wanted my husband to be tested for HIV also as this was the only test left to be done. The doctor said that he was also thinking about it but hesitated to say this as he had known us for years. He got him tested for HIV in a leading private pathology lab in the city. He was found to be HIV sero-positive. I got him tested two more times at different

> pathology labs. They confirmed the earlier report. This was a great relief for us. At last we came to know what the problem was."
>
> C and D, 37, 33 years (high class, high caste)

The HIV diagnosis was a death sentence for one couple who had not expected it whereas, it was a great relief for the other couple whose disease could not be diagnosed even after long episodes of illness. The suggestion of getting the HIV test done by the doctor differed in the two situation because in the case of A and B, their test was done in Mumbai, which has a high prevalence of HIV and the general level of knowledge about HIV/AIDS is much higher in this region. So the HIV test was spontaneous suggestion by the doctor, "just to rule out the possibility of HIV" and the test was taken by the couple as a routine test for diagnosis. Whereas in the case of C and D, the doctor hesitated in suggesting them to go for an HIV test as their test was done in Allahabad, which is a low prevalence area and the general level of knowledge about HIV is very low. Due to this, HIV is highly stigmatized in this region. Even for suggesting a HIV test, the doctors have to think many times, and even more in cases where they know the person individually at personal level. Another reason for hesitating to suggest for HIV test may be that since the doctor and others identified with these members, they did not expect them to be infected with HIV.

In the middle class category, while the members were asymptomatic, the accidentally came to know about their HIV status.

> "My sister fell down from the first floor of my house. She fractured her hand. She was admitted to the hospital. She was there for 18 days. She required blood transfusion. All of us had our blood tested. My blood was not found fit for transfusion. I was called in the laboratory. The lab technician there told me that I was HIV positive. I was shocked to hear this. I didn't know what to do. I couldn't sleep, I couldn't eat. I didn't tell this to anyone. I didn't know what to say"
>
> F, 36 years, married man (middle class, OBC).

> "My wife was expecting our first child. I was very happy. I took her for the routine medical check-up in June 2004, when she was in her sixth month of her pregnancy. There, her blood tests were done, including the HIV test without our knowledge or any form of counseling. There she was declared HIV seropositive. At that time we knew very little about HIV. I took it very normally. She was again tested for HIV in her ninth month of pregnancy, in a different hospital. The doctor there told us about it and said, "None of the hospitals here will admit her as it is a dreadful disease". He told me to get myself tested too as he was convinced that I would also be having the disease. I got myself tested and declared HIV seropositive too. I was shattered. I didn't know what to do. I was the youngest one in the family. Everyone loved me. I knew I was going to die soon. My wife would also die. What would happen to my child? This was all a result of my deeds"
>
> M, 25 years, married man (middle class, OBC)

While in these two cases, the members discovered their HIV sero-status by chance, they attributed the cause of infection to themselves rather than their wives and did not hesitate in accepting it. Their initial reaction was also that of shock followed by helplessness and hopelessness, but they received support from their wives and the family members which reduced their fear and helplessness to a great extent.

> "At home, my health had started deteriorating. I started having watery stools that wouldn't stop at any cost. I suffered from fever also. I couldn't digest anything. Whatever I ate, I use to vomit. I became weak day by day. My father took me to different doctors but none could relieve me of my ailments. They treated me only for my opportunistic infections. I felt I would die any moment. It was horrifying experience for me. My problems kept on increasing. I was almost bedridden. I wanted to live. The whole family was sad. My

> wife did everything for me. She was there by my side always. She never complained of anything. My father and brother use to sit beside me, talk to me, and enquire about my health"
>
> M, 25 years, married man (middle class, OBC)

In contrast to the above cases, the concordant couple in the lower economic category can to know about their HIV status when the husband was suffering from a host of OIs.

> "This is a punishment of my wrong doings. My innocent wife is also suffering because of me. I have lost one child to HIV. He was only one and a half year old. My daughter is six year old. She does not have the disease. I thank God for it. Every one in my family knows about our disease"
>
> P, 28 years, married man (low class, low caste)

Here, the husband was blamed by the family members for transmitting the disease to his wife and the child. The wife was supported by her mother-in-law in this case as she said that the daughter-in-law was with her all the time and it was her son who was living in Bombay, so the infection has come from her son to the family. While in the case of M, the mother-in-law was adamant on getting rid of the wife N, as she believed that she was the cause of all miseries.

> "My mother was after my wife. She didn't want her to stay with me as she thought she was the cause of all misfortunes. She was determined to send her back to her house. My wife was the only one who took care of me without any complaint. I thought if she goes away, who will look after me?"
>
> M, 25 years, married man (middle class, OBC)

Though the family members were supportive economically in fifteen cases, and emotionally in nine cases (Table no.6) the fear of contracting the infection, in some cases led to some family members leaving the house.

> "My brother's wife never came near me or enquired about my health. She feared that she might get infected. She, along with her children and my brother, left the house"
>
> M, 25 years, married man (middle class, OBC)

Stigma

The social sanctions suffered by people afflicted with the disease fit well under the broader rubric of social stigmatization where stigma refers to a visible mark, such as a brand used to disgrace, shame, condemn, or ostracize. In this study, the participants experienced stigma, though in varying degrees. The level of the real stigma which they encountered varied in accordance which their socio- economic status and caste.

> "I was admitted to a very famous hospital in the city. I was taken to the ICU and all tests related to fever were done. I did not tell the doctor that I had HIV. I feared that he would throw be out of the hospital and this is what happened later. The tests showed that I was HIV positive. Everyone, from the nurse to the ward boy started looking at me with judgmental attitudes. They asked me again and again how I got the disease"
>
> J, 28 year, married man (middle class, OBC)

> "We were open about our HIV status. Every one, including our family members, relatives and friends knew that we were HIV positive. They also knew that my husband got the disease because of the blood transfusion. Though few believed it, very few people showed any kind of hesitation in talking to us. A few people did stop coming to our house and avoided meeting us. We felt bad about their behaviour. But after some days, they themselves started talking to us, suggesting doctors and hospitals to get our treatment done".
>
> C, 37 years, married man (high class, high caste)

While the members falling into the high class income category either did not experience stigma, or they experienced it at very few instances, the degree of which also reduced over time.

The experiences of members in the middle and lower economic category were profound.

> "He was admitted in a private hospital in the city. The doctor saw the reports and gave him the medicine but discharged him from the hospital saying that they did not admit HIV patients or else no one would come to their hospital. He was brought to a tea shop nearby on a stretcher where he was laid down till we arranged for some vehicle. I was astonished to see the shopkeeper shout, "Take him away or nobody will come to my shop. You will ruin my business. Take him away immediately from here". He lay on the road in the scorching heat of the sun. We brought him home."
>
> S, 38 year old widow (low class, low caste).

> "It was a normal day. As usual, I was distributing eatables in the Anganwadi centre when a woman from my neighborhood came and told her friend not to take the eatable from me. I had no clue why she was saying so. She shouted at me and said, "You and your husband have AIDS, you will infect others also". After this no one even talked to me. I was sent back home. I felt humiliated."
>
> Q, 25 year old wife (low class, low caste).

The stigma experienced by the members of the lower economic category was much greater than the members of the higher economic category because the belonged to the already marginalised group of low class and low caste and thus they experienced 'double or layered stigma'. Diagnosis of HIV or generally known as 'AIDS' only added to their miseries.

Internalized Stigma

People who attributed the cause of the infection to themselves experienced greater psychological distress and dysphoria while those who attributed the infection to chance or another person experienced less distress. Though the higher socio-economic category members encountered minimal amount of stigma, they experienced very high level of internalized stigma, whereas only three members in the middle class category experienced internalized stigma. Internalized stigma in case of the lower socio-economic category members was nil.

> "My mind was not at peace. All sorts of questions were coming to my mind and I was busy finding their answers. I stopped going out for work. I locked myself in the house for many days. I was scared going out. I feared that everyone would come to know that I have AIDS. I knew they would look at me with suspicion, pass remarks at me. I did not have the courage to face them."
>
> A, 32 year married man (high class, OBC).

> "I was afraid to face my wife and everyone at home. I thought, 'what would they think of me? They would consider me as a man of bad character, what would my sister think of me? I am the eldest brother, I have always been a man of strong character, and everyone respects me. I will loose all the respect and love of the family. What will my friends think if they come to know? What will my children think about me when they grow up, when they will come to know that their father died due to AIDS?"
>
> F, 36 year old married man (middle class, OBC)

As seen in the above two cases in which the members are more concerned about their reputation in the family and the society, and they fear that once their family and friends come to know of their HIV status, they would loose the respect and reputation they had and people will look at them with suspicion, as a man of bad character. The intensity of internalized stigma was so high in the members of the higher and middle economic category that they took every possible step to maintain their anonymity.

> "When I had to get my re-testing done, to confirm my test report, I took the Lab.Technician to a public park and under a tree in a distant corner of the park so that very few people can see us. I gave by blood for the test behind that tree to ensure that I am visible to very few people, if at all. As soon as my work was complete, I fled."
> J, 28, married man (middle class, OBC).

> "Whenever I had to meet the doctor, I was tensed. I had to meet him in his clinic, which I detested. I waited for long hours in his clinic for all his patients to go. I used to request the doctor to strictly instruct his staff not to send any patient, nor come inside while I was in his cabin. The doctor was very supportive. He understood my situation well. He always encouraged me."
> A, 32 married man (high class, OBC)

The intensity of the internalized stigma was so high for the upper and middle class members that it persisted for many months. Even when they are now active members of a PLWHA network, the fear of being identified as a PLWHA in their own city is evident in subtle ways.

While interacting with the researcher, the members belonging to the higher class and higher castes, either avoided talking to her by saying, "aur logon ka interview lejiye, hamari aapki baat to hoti rahegi", or even when they interacted, they generally framed their answers in minimal possible words. These members also avoided their wives meeting the researcher. These members and their wives were the last ones to be interviewed by the researcher. The researcher had to interview them many times in order to form a coherent picture of their situation.

Discrimination

Though none of the members belonging to high class experienced any form of discrimination, the members of the middle class and low class experienced much discrimination due to their HIV status. Discrimination occurred in different ways, in different forms. The most common forms of discrimination were seen at workplace, at hospitals, in the community and in the family.

> "In the hospital, no one came to clean neither my room nor the toilet. Everyone feared that they would get the disease from me. The doctors gave me the injections wearing double pair of gloves and treated me as if I was an untouchable. The next morning they discharged me from the hospital saying that they were helpless; they could not keep me in the hospital. They had to think about the other patients too. We offered them extra money also but they did not admit me again."
>
> J,28 years, married man (middle class, OBC)

In this case, the PLWHA was thrown out of the hospital due to his HIV status. Even though the member was ready to offer extra money, the hospital did not admit him again. However, the discrimination experienced by those who belong to the lower class, is much greater than the middle class members.

> "He was admitted in a private hospital in the city. The doctor saw the reports and gave him the medicine but discharged him from the hospital saying that they did not admit HIV patients or else no one would come to their hospital.
>
> S, 38 years, widow (low class, low caste)

People who have HIV and work in service- providing occupations are especially vulnerable to discrimination. Employers are no different from the general public and often hold irrational beliefs that HIV positive employees will threaten the health of customers and clients. Even employers who know that HIV is not transmitted on the job may realistically fear that the public will not understand and their business could be adversely affected if it became known that they had an HIV positive employee. Discrimination at workplace was reported by one member of the network. The member was forced to resign from his job as his HIV status had been disclosed by one of his colleagues to the other colleagues and the boss.

> "....some workers in the ESI hospital leaked the information. The whole company and even the manager of the company came to know about it. No one said anything directly to me. My manager used to often say, "You are not well, you should leave the job." Sometimes he use to say "I am helpless I have to expel you from the job. It is better that you resign." I did not resign. Everyday I used to go to work but they didn't let me enter the gate. They made me sit at the gate for hours. For two whole days they made me sit at the gate. Everyone passed by making nasty remarks at me. I was insulted and ill-treated. At last, I resigned. I went to the LIC office to get my Life insurance money. I just showed them my HIV test report. They looked at me as if I was a demon. They were so scared of me. Within four days my insurance money was in my bank account. After this I did not try to find a new job"
>
> H, 34 year old married man (middle class, OBC)

Fear of contracting the disease from a PLWHA was the main source of discrimination at workplace, as in the above case, and even in the family, and in the hospital. The other members did not report of any discrimination at workplace as they left their jobs and came back home as soon as they came to know about their HIV status. No member reported of looking out for jobs after their diagnosis, even when they were asymptomatic, until they became a member of the network.

Discrimination in the community was experienced mainly by the members of low class and low caste. Diagnosis and subsequent death of a family member due to HIV/AIDS gave a base to the stigma and discrimination related to HIV/AIDS in the community confirming their belief that having "AIDS" means misery and death.

> "At home, he was very ill. Everyone in the village came to know that we had AIDS. No one said anything directly to us but they made suggestive remarks. After some days my husband died. There was no one else at home except my children. I was crying but nobody came to my house. His dead body was lying there on the cot but no one came to put it in the ground. The children were small. They helped me to put him on the ground. Not a single woman from the village came to console me. After many hours, some men from the village came to the door of the house and told my son to do the cleaning of the dead body. He was too young to do that so my daughter did all the cleaning and other things. The villagers said, "He was a Hindu. His last rites have to be performed". After much discussion four people agreed to lift his dead body and took him to the cremation ground"
>
> S, 38 year old widow (low class, low caste)

> "After his death, life had become very tough for me. In the village, people used to avoid talking to me. The talked amongst themselves about me and my husband and made all sorts of judgmental remarks about him. They feared that we could spread the disease to them."
>
> T, 35 year old widow (low class, low caste)

The above two cases were members of low class as well as low caste. However, the experience of a member, who, although falls into the lower economic category, belongs to a higher caste, is very different from the rest.

> "I belong to a Brahmin family with majority of Brahmin families in the village. My family holds a good reputation. There was a general concern about my health in the village. People used to come to meet me and would suggest all kinds of remedies they knew. We also did not hide from anybody that I had AIDS, there was no question of hiding as no one knew anything about it, neither did we. There was a rumor in the village that R.S. who lived in the nearby village had

> also contracted AIDS. He was also a man of good repute and belonged to a good family. This news, that I had the same disease which R.S. has, spread like fire in the village. They started comparing my state with his state. They said that whatever happened to him should also happen to me! He seemed very healthy, so my state would also improve. I would not die because of the disease"
>
> O, 30 years, married man (low class, high caste).

Discrimination within the family was generally not seen in many households. However, three members reported of experiencing discriminatory behaviour in the family. No form of discrimination was experienced by the members belonging to high class in this study; however, the members falling into the middle and low income category experienced discriminatory behaviour at home.

> "At home, no one spoke to me. They did not let me work in the kitchen. They separated our utensils".
>
> G, 30 years, married woman (middle class, OBC)

None of the members belonging to higher class or lower class reported experiencing discriminatory behaviour at home. The family members were supportive in most of the cases except one or two members in some families.

> ……. "My husband started having high fever. He was diagnosed as having malaria and was admitted in a hospital. His brothers who also lived in Mumbai came to know that both of us were HIV positive. They supported us in every way be it financially or emotionally. They never showed any kind of hesitation in being with us or taking care of us. They have supported us all through. Up till now, my in-laws do not know about our disease. Even my family does not know about our disease. We have told them that we are working with an

> NGO which is working for HIV positive people, but they do not know that we ourselves are HIV positive."
>
> B, wife of A, 28 year old (high class, OBC)

Apart from the brothers, the parents still do not know about their disease. The brothers supported them without showing any sign of hesitation. Family members support was seen in both cases of the above concordant couples. Even in the cases of members falling into other economic categories of middle class and low class, the family support and especially the support of the wife was present in all cases.

> "I used to soil the bed often. My wife used to clean up everything. My mother was so afraid of the disease that she never came near me. She used to stand at the door of my room and enquire about my health. Nobody touched my clothes or washed me. My wife did everything for me. She was there by my side always. She never complained of anything. My father and brother use to sit beside me, talk to me, and enquire about my health."
>
> M, 25 years, married man (middle class, high caste)

Though the family support, in the form of financial and emotional support, was present in almost all cases, the support of the family in lower economic class category was also determined by the household income.

> "I earned about Rs.3500/month. Now, I have no source of income. Whatever I had earned and saved has been spent on my and my wife's treatment. We both are HIV positive. Until now, my brothers were supporting the family, but now, due to our illness, one had left home with his family when we were diagnosed, the other left the house recently as his wife did not want him to bear the burden of all of us. My parents are too old and my wife is eight months pregnant. From where do I arrange for the treatment and delivery of my wife as well as food for the family?"
>
> P, 28 years, married man (low caste, low class)

Women are the prime care takers of their infected husbands. Being HIV positive themselves and in need of care, they are thought to bear the responsibility of taking care of their husbands as well as of the family by others in the family and even by their own husbands.

The reaction to the diagnosis in the two cases of concordant couples in the high class differed due to the mode of transmission, the acceptance of the diagnosis by the family and the wife also differed in these cases. The responses of the wives greatly differed in the two cases.

> "At home, we told everyone that we had HIV. We live in a joint family. No one in the family showed any kind of discriminatory behaviour toward us. On the contrary, they were very supportive. They took good care of us. This was probably because everyone knew that my husband got the disease because of the blood transfusion and not due to any other cause. As far as I was concerned, I never felt any kind of anger or disappointment that I am positive because of him. I am satisfied to see him healthy and happy now. I am his wife, I have to live with him and take care of him for the whole of my life."
>
> D, wife of C, 33 and 37 years (high class, high caste).

In this case, the wife reports that they were not discriminated at home neither did she feel anger towards her husband because everyone including her knew that the cause was the blood transfusion, whereas in the other case of A and B the situation was very different.

> "...I asked him all sorts of questions to which he had no answer. I suspected him of going to other women. I trusted him more than myself. I loved him and had never thought that he could go to other

> woman. I felt cheated. This feeling increased my anger towards him.
> I just kept crying……."
>
> B, wife of A, 28 years (high class, high caste).

Here, the wife had feelings of anger and hatred towards the husband after knowing about the disease. She suspected him of infidelity as she did not get a clear answer from her husband about how he got the infection.

For women who know that they are infected, what dominates virtually every minute of the day are two primary emotions, that of anger and guilt. Anger towards the person who infected them, usually their husband, and guilt because they have infected one or more of their children.

> "He started having fever again. I took him to the government hospital in the city. They declared that he had T.B. His treatment was started but the headache didn't go at any cost. He was discharged from the hospital and send to the district T.B. Hospital. There he was first tested for HIV. He was found positive. The doctor told him that he was HIV positive and to my great surprise, he said that he knew that he was positive. I was taken aback. The doctor told me to get myself tested too. I was also found to be positive. I confronted my husband. I was angry at him. He had cheated on me. He married me knowing that he had AIDS and would die soon. I was the only daughter of my family. My first husband had died only after two years of our marriage. I did not want to marry again but I was young. My family forced me to marry again and this was the result. What worse could have happened than this? I started crying. What else could I do? Then my husband told me that his first wife had AIDS and T.B. and she died because of these diseases. He had married me because he had a small son who needed a mother to look after him."
>
> S, 38 year old widow (low class, low caste).

Although it is almost invariably the husband who is the vector of HIV infection for wives, a married woman who is found to be infected with HIV is often expelled from the family unit especially after the death of her husband due to HIV. The husband, if his wife dies first due to the disease, seeks a new wife, often a younger woman who is believed to be uninfected and therefore safe, and who, in turn, is exposed to the infection.

Once married, women are usually expected to remain faithful to their husbands but are unable to compel fidelity in return. Women have little alternative but to accept the risk that sexual intercourse with their husband entails. They usually have little or no means of support for themselves and their children other than by remaining within the marriage. Even if condoms are available to them, most women are not able to ensure that their husbands use them.

> "......Our sexual life has been normal since then. We use condoms but I am very scared. I know condoms are not very safe. Sometimes my husband does not want to use condoms. This becomes a problem for me and at present this is my biggest concern."
>
> D, wife of C, 33 years (high class, high caste).

Men do not use condoms and most women do not have the ability to protect themselves in this way. As it is well known now, that condoms are not hundred percent safe, two cases of condom failure occurred in the network with two concordant couples leading to pregnancy in both cases. In the case of M and N, who belong to the middle class category, the child could be aborted as immediate action was taken by the network as soon as it came to the knowledge of the network members. However, in the case of P and Q, who belong to the lower economic category, the child could not be aborted as the couple could not take a decision regarding it and when they were not able to handle the situation, they informed the network. By then it was too late to get the child aborted and the pregnancy had to be carried to full term. In these cases, the husbands were blamed by the family as well as the network members for their carelessness. Despite that, Q, wife of P, is treated badly in the house. She is in need of greater care as she is pregnant with herself being HIV positive and on ARV treatment.

The impact of the HIV epidemic on women is not confined to their own risk of being infected with HIV. As primary carers, women bear the burden of caring for the sick, of holding the family unit together in the face of sickness and death and of coping with the trauma of the dying. They must forego productive activities or employment opportunities in order to fulfill their duties as caregivers. The psychological burdens and responsibilities carried by women in these circumstances are great and are exacerbated where the women herself is infected with HIV and experiences anxiety about her own health and the future care of her children.

Women are also in a markedly disadvantaged position with respect to confidentiality. The majority of HIV- infected women discover their HIV status during their pregnancy or when one of their children becomes sick with AIDS. At this point, any confidentiality protection for women disappears as local knowledge about the child's illness leads to open assumption about the HIV status of the mother. The woman is frequently held responsible for having transmitted HIV to her children, even though it is mostly the husband who introduced HIV to the family.

> "My wife was expecting our first child. I was very happy. I took her for the routine medical check-up in June 2004, when she was in her sixth month of her pregnancy. There, her blood tests were done, including the HIV test without our knowledge or any form of counseling. There she was declared HIV seropositive. At that time we knew very little about HIV. I took it very normally. She was again tested for HIV in her ninth month of pregnancy, in a different hospital. The doctor there told us about it and said, "None of the hospitals here will admit her as it is a dreadful disease". I did not tell my wife anything about it. I took her to the best hospitals in the city but they turned us away as soon as they saw the HIV report. At last, on someone's suggestion that no private hospital would admit her

> except the Government hospitals, we went to Civil Hospital, Thane. They admitted my wife. She was taken to ward no. 4. As soon as she reached there, the nurse shouted, "who brought her here, she is HIV positive. Take her away from here"........ "My wife was about to deliver the child. In the labour room, the nurses told her, "You and your husband are going to die soon. Both of you have AIDS". The hospital demanded a pair of scissors, gloves, bale of cotton, and other instruments needed to deliver the child, to be brought by us. The new born child was very weak. It had loose, watery stools, and died after one month."
>
> M, 25 years, husband of N (Middle class, OBC)

Plight of the widows

Situation of women in the case of widows is even worse. All the 5 members in this category, as seen in table no. 1.1, have female headed households, whether they themselves are the head of their houses after the death of their husbands or are living with their mother or mother-in-laws. These five women have lost their husbands to AIDS and they themselves are HIV positive. Female headedness, however, in these cases, is more in terms of the assumption of the earner role and of economic responsibility rather than an increase in her decision making powers. The economic burden on these households of the disease and subsequent death of the husbands has pushed these household from a more stable middle economic category to the lower economic category.

> "When my husband was alive and worked, he used to send about one thousand per month, but now after his death, I can barely manage. My small piece (one bigah) of land has already been mortgaged when my husband had fallen ill. I work on others fields and earn small amount of money. I have stopped sending my children to school. I have no means to pay the fees. At present I have to repay a loan of Rs.16 thousand, which I had taken from the bank for his treatment when he was alive. I have also taken a loan of Rs.9

> thousand from the villagers and some amount from my relatives. The loans are increasing day by day. Where do I pay it from? When these children grow up, they will repay it. The villagers want me to desert the house and go away so that they can gain hold on my house and my land. What do I do?"
>
> T, 35 year old widow (low class, low caste).

> "......Life is tough. I do not have a BPL card but I do get the widow pension after every six month which is Rs.750. For one and a half months work, I get five kilos of wheat per day. Life was better when he was alive. He had good earning from the shop. We were happy. All of us lived together in Bombay."
>
> S, 38 year old widow (low class, low caste).

The most severe forms of stigma and discrimination were also experienced by these women. Stigma at the village and community level in case of these women occurred at a time when they were most in need of support from them.

> "We brought his body home. In the village, every one came to know that my husband had AIDS. No one came to my house or even to console me. No one even gave any thing to my children to eat as nothing could be cooked in the house. No villager came forward to carry the dead body. My brothers did everything. Women are not supposed to go to the ghat with the dead body but I went. I was there when the last rites were being performed. Even my daughters had gone to the ghat. Except my family, there was no one else with us. They all feared that they would get the disease, even from the dead body".
>
> T, 35 year old widow (low class, low caste).

The stigma in these cases did not end with the death of the 'severely ill' husbands but it extended to the rest of the family members, even without knowing whether they were HIV positive or not.

> "After his death life had slowly started to return to normal. I decided to work and went in search for it. People behaved in a very strange manner when they saw me coming. They used to change their path after seeing me. They gossiped about me and my husband, they passed suggestive remarks with judgmental attitudes. No one talked to me in the village. Life became very tough."
>
> S, 38 year old widow (low class, low caste).

The economic impact of the disease was severely felt by the widows. All their savings have already been spend on the disease. They are in debt and have no support to fall back upon. The stigma and discrimination experienced by these women is much greater than in other cases. To add on to this, they are not educated and have small children to look after. They are not able to get any job as the information of their disease travels faster than them. One of the members in this category explained the reason for not being regular at the meeting of the network by saying, "I have a teenage daughter. I can't leave her alone in the house. I have to think of her safety also." Another member whose daughter is getting married in the month of May, when asked whether she has informed her daughter about the disease and its precaution, replied, "My brothers have arranged her marriage. I have not talked to her about the disease. She is old enough to understand things. Her in-laws do not know about my disease." When asked by the researcher that being a member of the network and being well informed, is it not her responsibility to inform her daughter about the disease and other related issues, she replied, "What can I tell her, she has to adjust according to her in-laws and her husband. Ab jo batana hai who hi log batayenge, hamare batane se kya hota hai." Her daughter is getting married to a fruit vendor who works in Mumbai (just like her father), and she is ready to enter into a life and re-live her mother's life. Her mother, having gone through the miseries, still does not feel the need to talk to her daughter about it. She realizes that even if her daughter has knowledge about the disease and its prevention, it would not change her life in any way. Talking about sexuality and the role and responsibilities associated with it is still a taboo in the Indian society.

Men whose wives have not been tested

As seen in table no.4, five male members have not got their wives tested for HIV. Out of these, one member each, falls in the higher and lower economic category, with three members falling in the middle income category.

The member in the high economic category has not disclosed his HIV status to his wife and so getting her tested means disclosing his status first and then convincing her to get tested. He claims to be taking proper precautions since the time he was found to be HIV positive but even after being an active member of the network does not feel the need to get his wife tested.

The member in the low economic category gave the reason for not getting his wife tested by saying that he has not been able to get himself properly treated and is unable to maintain regular treatment. If his wife also gets diagnosed as having HIV, his problems will increase further. Since this member belongs to a high caste, the family members do not allow the wife to go out or even talk to the network members. The wife is ignorant about the disease which her husband is suffering from.

Out of the members in the middle income category, one member has not disclosed his HIV status in the house. He has informed his family that he has blood cancer. He told the researcher that he is looking for the right moment to tell his wife about it and get her tested for HIV. Another member who was newly married when he was diagnosed as having HIV had told his wife about his diagnosis. Within a few days, his wife left him and went back to her house before he could convince her to get tested. The member does not know whether his wife got herself tested or not later. The third member in this category claims to be taking proper precautions since the time of his diagnosis but does not feel the need to get his wife tested. He says, "When I am taking precautions, why should I get her tested. I know nothing will happen to her. She looks very healthy. If she had the disease, she would have been ill like me"

As seen here, the members do not feel the need to get their wives tested for HIV as they place their health on priority than their wife's health and also take their health status to be an indicator for their wife's health. Some members, on the other hand, have not been able to disclose their HIV status to their wives and their family, and have been trying to lead a normal life, just waiting for the right moment to disclose their sero-status. However, the members claim to be taking proper precautions with their wives, ensuring not to transmit the infection to them.

The ayurvedic treatment

Three members, whose narratives have been taken, reported having taken *'ayurvedic treatment'* for HIV which claimed of curing HIV/AIDS.

> "Fifteen days after my being tested, I started taking an ayurvedic medicine from 'Fair Pharma', Arunakullam, Kochi. The firm claimed to cure the disease completely. I took the medicine for two and a half years. It cost me about three thousand per month..... I believed that the medicine I was taking would cure be one day but the fear that I could die any moment, I may be found dead the next morning, always bothered me.... I did not get any relief from the medicine I was taking but the belief that it would cure me some day made me continue it. After joining the network I came to know about HIV and its treatment and that it cannot be cured. I am working with the network to ensure that other people are not fooled like me as I was for three years by the ayurvedic medicine company. I spent almost all my savings to buy those medicines which were useless. If I had invested that amount I would have utilized it for my family and myself today."
>
> J, 28 years, married man (middle class, OBC)

As seen here, the member spent almost all his savings to buy the medicine which, according to him, was a waste as it did not give him any relief. On the contrary, some members reported of ayurvedic treatment being more effective than the ARV treatment in curing the OIs and improving their health.

> "I did not have any problem for one year. After one year, I started having loose motions. It used to re-occur after few days. I had become very weak. I started taking ayurvedic medicine. I took it for one year spending one thousand rupees per month on it. It did not give me any relief. I came back to the village in 2003. I came to know about Swarg through a friend. The doctor there started my T.B. and HIV treatment. The treatment I was taking was costing too much. The Swarg members told me that I had to buy the medicines as they had no provision of giving medicines for T.B. and HIV. I stopped going there. I took the medicines as long as I could afford. Then I stopped taking all medicines. In June, I fell ill. I had high fever. No medicine worked. I felt I would die any moment. Then I took a medicine from the Ayurvedic Dawakhana which worked."
>
> I, 40 years, married man (middle class, OBC)

Another important reason for opting for ayurvedic treatment was the side effects of the ARV treatment. Many members reported of experiencing side effects. The members were given assurance by the treating doctors that the side effects would go within few days but the members were not able to cope with them. Even after trying out different combinations of drugs, most of the members repeatedly reported of drug reaction in their body. Another reason was the change in the treatment regimen from what the doctor at the network office prescribed and what the members received from the ART centre. Apart from this, the ARV treatment regimen did not go with the T.B. treatment regimen so most of the members resorted to either discontinuing both the treatments or to some other form of treatment like ayurvedic or even 'jhad phuk' or spiritual healers. The regularity of the members to the meetings and activities of the network was also determined by this factor as their main interest in the network was due to the availability of treatment.

The problem of single (unmarried) men

In this study, two unmarried men were interviewed who are the members of the network. One of them, K, is a Rajput by caste and is 27 year old. He is educated till class 9th and was a bodyguard and driver of a factory owner in Bombay. He belongs to a good family and falls into the middle class economic category. He came to know about his HIV sero-positive status when he fell ill with diarrhea, weight loss and weakness.

The other member L is only 20 year old and is a Brahmin by caste. He belongs to a good, reputed middle class family. He is studying engineering in Allahabad. He was transfused blood during his operation of nose and after three months he was found HIV positive as he was not keeping well since his operation. Both the members received immense support from their family members. In case of L., he was supported the most by his friends. They were always by his side and accompanied him everywhere. He has started attending his classes and his friends have helped him in his studies and he has been able to clear his second year exams with 65% marks.

In both of these cases, the ARV treatment was started as soon as they were diagnosed HIV positive and the treatment did not suit them so it had to be stopped.

> "My health was deteriorating. I was bedridden for almost six months. My brother took me to Gaya with him. There, I was taken to a doctor who started my ARV treatment. He gave me the medicine for Rs.750 for fifteen days. I took it for only two-three days. I got rashes all over my body. I started feeling giddy and fainted. I was unconscious for full twenty four hours. I was rushed to the hospital where fifty to sixty thousand rupees were spent on me. I feel I was pulled back from the jaws of death. I was very scared."
>
> K, 27 years, unmarried male (middle class, high caste)

The treatment was started by buying the medicines from the chemist shop and later their treatment was started from the government ART centre. They came to the network when they heard that some PLWHA organization is working in the city.

The problem which these members are facing at present is that their parents want them to get married. In the case of K. the parents know that he is HIV positive but do not understand its implication.

> "My parents had fixed my marriage. Since I had fallen ill before any kind of ceremony could be performed, we broke the marriage. Every one at home came to know that I had AIDS and I would die within six months, but since they have no knowledge about it, they do not know the implications of being HIV positive. Now, more than fourteen months have passed. They now believe that I do not have AIDS as if I had AIDS, I would have died by now."
>
> K, 27 years, unmarried male (middle class, high caste)

K is in dilemma whether to tell his parents about the disease or not. His parents are too old and want him to get married as soon as possible. He fears that if he tells them, they would not be able to bear the shock. If he doesn't tell them, they would get him married. He is looking for a HIV positive lady whom he can marry before his parents are able to find a girl for him.

Role of the network in the life of its members

The network has been newly formed and at the time of data collection, the network had not even completed a year of its formation. However, the network members who have been interviewed are the most active and regular members who have been instrumental in its formation.

Though all the members reported receiving emotional support from their family and the network, the informational support was provided only from the network. Once the respondents had become a part of the network, their level of information has increased many folds. The members now are confident and can fight for their rights. The network has been able to instigate a new hope to live and has brought a change in the way they perceived themselves and the society.

> "After joining this network, our lives have changed completely. UPNP+ has given us a new hope and a new shine of confidence to our eyes. My husband is the vice-president of the network. I am very happy for him. I see him involved in his work day and night. I am glad, he now has a purpose in life and I am with him in his mission. He has regained his respect in the community. He goes to different places and represents the network. Both of us are proud to be a part of the network and work to identify and help those people who are suffering from HIV and do not know what to do or where to go for treatment or support. We give them an environment where they can feel free to share their worries with us and we try our best to help them. As far as I am concerned, I would just like to educate my children in an English medium school and make them capable enough to stand on their own feet and never feel that their parents or their lives were different from others."
>
> G, 30 years, married woman (middle class, OBC).

Needs and expectations from the network

The expectations of the members from the network and from their new life differ for members falling into different categories of economic class and gender. The network offers instrumental support to its members especially in taking them to the ART centre i.e. from Allahabad to Varanasi, getting their HIV tests done and ARV treatment started. The (active) network members also monitor each others health and make sure that they are regular with the treatment and the tests. The members from the low class are benefited the most from the network in this regard. At present the prime concern of the network members (the active members) is treatment of its other, *needy* members who cannot afford the treatment and its extended costs.

Another pressing need of its members is the need for a livelihood. The network has got the charge of opening 'Drop-in-centres' (DIC) in U.P. the DIC is sponsored by the UPSACS and is being opened at the offices of the upcoming district level networks of UPNP+. The network members work on different posts in the DIC. The network is in the process of arranging for jobs for the rest of its (active) members. The office bearers and the founder members of the network recognize the need of its members and they know that if they are not able to fulfill the two most important felt needs of its members, which is the need for treatment of HIV and employment, they will lose the members, thus the main focus of the network is to fulfill these two needs.

The network members also reported improvement in their quality of life after they joined the network. They reported improved health and emotional wellbeing. They also reported of an increase in their social status being identified as a member of the network and also *'working as a social worker with the HIV positive people'*. It should be noted here that the members, especially those belonging to higher or middle class and higher caste, are still not comfortable with the identity of a PLWHA and a member of a PLWHA network. They are more comfortable calling themselves *'social workers'* who are working with the HIV positive people. At the same time, some of the members, who belong to the higher economic category, told the researcher during the informal conversations that they wanted the government to allot them 'special quotas' or a kind of reservation in different jobs and services like those for the minority groups or for the physically challenged. Some other members reported that by becoming a member of this network they wanted to fight for the rights of the PLWHA.

> "The sense of belongingness which I have for this group is because they are always by my side. I feel responsible towards the group and will do everything for the members of the group and their rights. I would work with the group to bring those people who are like us to this group so that they also have correct information about the disease and can make their life better. I will help them to come out of

> the fear of HIV disease and fight for their rights, to have an equal status and to be treated as normal human beings in the society."
>
> M, 25 years, married man (middle class, OBC)

When the researcher raised the issues regarding the contradiction in the perception of the role of the members and their needs and aspirations, the members were unable to get a clear vision on what they wanted from the network. However, they did recognize that their prime concern at present was ARV treatment and treatment of OIs for its members and along with this the most pressing need was a source of livelihood for those members who were economically unstable.

Stigma, discrimination and identity as a PLWHA

To sum up, it can be seen here that the lower economic class, which mostly includes the lower caste members also, is hit the hardest by the disease followed by the middle class. The lower class members had to bear the most severe forms of stigma and discrimination and had minimum amount of social support and information about the disease and its treatment. The middle class could bear the burden of the disease at the financial and social level to an extent but with the depletion of their resources with the progression of the disease, they also felt the need for a support group which could cater to their increasing need for treatment and support, be it financial, emotional or instrumental. In contrast, the high class members showed reluctance in accepting their identity as a PLWHA and being open about their HIV status. None of the members experienced stigma or discrimination because of being HIV positive. However, they reported very high level of internalized stigma and bothered much about their reputation in the family and community in which they moved.

The members in high class category did not report much change in their quality of life after becoming a member of the network, though their social reputation had improved much being identified as a *'social worker'*, working for the HIV positive people. The quality of life of the middle class members and the low class members had improved since the time they became a member of the network, in comparison to the time when they had been diagnosed with HIV and had no such PLWHA network to support them, but the improvement is only in terms of treatment and social support (table no.6, 7). These members have not been able to attain the same level of normalcy in their life as it was before they were diagnosed HIV positive. The economic impact of the disease has disrupted their normal life and they have not been able to stabilize economically since then.

Level of knowledge

The level of knowledge of the higher class members was the highest followed by the middle class members and was lowest for the low class members. Accordingly, the benefits derived from the network was highest for the high class members as they were the most educated ones, well informed and experienced in dealing with the outer world. Their involvement in the activities of the network is based on their need for social status and meaningful engagement whereas in the case of the members of the lower class, it is their pressing need for treatment and livelihood which brought them to the network. The members from the high and middle class occupy the job positions offered by other organizations for their projects and derive a good stipend from these organizations, while the members in the low class do not have a job or very few of them have been adjusted into jobs like that of a peon, house maids etc. The financial assistance offered to them by the network, often by contribution, is very less in comparison to the salary drawn by the financially stable members. Thus the benefits derived from the network are greatest for the high class members, at the economic and social level, while the neediest section, the lower class members still are waiting to lead a normal, stable life and look upon the network to fulfill their needs

CHAPTER FIVE

Conclusion

This study was aimed to explore a PLWHA network and its structure, objectives and functioning processes. Attempt was also made to study the impact of joining the network on the lives of its members and hence to examine the efficacy of the network in addressing the needs of the PLWHA in the context of their differing social backgrounds. The adoption of qualitative research methodology allowed for a holistic and contextual understanding of the experiences of the network members. The data was utilized to understand the experiences of the members at the individual level, the spousal dyad and at the level of the network. It has been found from the review of literature on HIV and AIDS that though the incidence and prevalence of HIV and AIDS cuts across all sections of the society, research focuses disproportionately on the experience of lower and middle income group.

Since the experiences of individuals are known to differ, depending on their life situations, inquiries covering middle class and upper class individuals affected by HIV and AIDS are essential in order to understand their requirements. This study has attempted to explore the experiences of the individuals belonging to higher, middle and lower economic category. It has also tried to study the dynamics of interactions among the members of the network belonging to different economic categories as well as different caste categories and how the caste and economic class composition is reflected in the structure of the network and its functioning.

It is seen that composition of the network reflects a predominance of middle and low economic category members, especially in the age group of 20-40 years (Table no.2). The high caste members are almost equally distributed in all the three economic categories, while the OBC members present themselves in the middle and low income category (Table no.3). Caste plays an important role in the daily interactions of the members in the network. The organizational structure of the network also reflects that three key positions, that of the president, the secretary and the joint secretary are occupied by members who belong to the high and middle class OBC category. The two other positions of the vice-president and the treasurer that have minimal role in the organisation's decision-making, are held, one by a Muslim widow and the other by a member from the low caste. Both these members are from the low economic category. Apart from the treasurer, the other office holders have had a previous exposure to issues in HIV and AIDS and are educated. Thus they are considered to be capable of handling the posts. However, there is an under representation of women in the functioning body of the network. This may be due to the fact that the women, amongst the regular and active members, are not willing to take up the responsibility and majority of them are not educated (Table no. 5). At present, there are four women and seven men who constitute the board of the network keeping in mind 'the meaningful participation of women in the governing body of UPNP+'. Women, those who are the board members, do not play an active role in decision making process of the network. Their presence is often a token one. As cited in this study, even when women are consulted to make any decision, they agree to the recommendation of other members just by 'nodding' their heads.

The network members also felt the need to be trained further on different issues related to HIV and AIDS and the trainings to be in their regional language so that they can gain knowledge and be more capable of handling different situations while working to establish the network. While interacting with the outer world also, the network has received a mixed response from the help providers. It is working towards building a trustful relationship with those who can provide the maximum help.

Quality of life- Impact of HIV status

The experiences of the members show that the lower economic class, which mostly includes the low caste members, is hit the hardest by the disease. They have minimum amount of information about the disease and have experienced the most severe forms of stigma and discrimination. They had left themselves to fate until they became a member of the network which could take care of their emotional, financial and medical needs. The middle class members had to suffer stigma and discrimination at many instances but they could bear the burden of the disease at the financial and social level to an extent. However, with the depletion of their resources with the progression of their disease, they felt the need for a support group. The members from the high class did not experience much change in the personal and the social level. Their stable economic and social status enabled them to handle the diagnosis of HIV with much less negative impact than on the others.

The members in the high class reported experiencing high levels of internalized stigma with very low levels of real stigma in their daily life. Only two members in the middle class reported high levels of internalized stigma while seven other members experienced it at very low levels. The members in the low economic class reported experiencing no or very low levels of internalized stigma. The real or the 'enacted' stigma was high for the middle and low economic category members. The emotional response of the majority of members was fear of death, hopelessness and helplessness. The widows, however, did not report any clear emotional response. This may be due to the fact that they had lost their husbands to the disease and blunting of emotions may have occurred.

Women and especially widows, in this study, were found to be most in need of support, be it financial, instrumental or emotional. As it is seen in the study, all five widows are in the low economic category. Prior to the diagnosis of the HIV infection to their husbands, their household income placed them at the lower end of the middle class category. The HIV infection not only lowered the family income but also lead to the loss of the sole earner of the family. These members are entirely dependent on the network to fulfil their needs providing them social support.

The health care system-

Ten out of twenty-two members reported experiencing discrimination and breach of confidentiality and disclosure in the health care setting. However, these ten members belong to the middle and low income category while the members in the high income category did not report of any such experience. The interface of health care system with HIV and AIDS occurs in three major domains: disclosure, discrimination and support. The health care is the first place where HIV diagnosis is known (D'Cruz, 2002). All the five members in the high economic category reported accessing private treatment while the members in the low-income category reported accessing the public health care. The members in the middle-income group showed a mixed response with five members accessing private health care and three public health care system. This shows that the poor still resort to the public services for more of their secondary and tertiary level care than do the better off.

The network, as a group, is attempting to cater to maximum possible needs of its members. The group felt the need for proper health care delivery system. They felt the need for more VCTCs, CD4 and other testing and treatment facilities to be given in every city so that monitoring, treatment and management of the HIV cases could be done.

The impact of joining the network-

The quality of life of the middle and lower economic category members has improved since the time they became the members of the network in comparison to the time when they were diagnosed as HIV positive and no PLWHA network was present to support them (Table no.6&7). However, 3 of the 5 members in the high economic category experienced gain in social status as compared to their social status before diagnosis of HIV. 3 members out of 9 members in the middle class also reported gain in their social status after joining the network, being recognized as 'social workers'. However, the improvement in quality of life for the members of low and middle class members was more in terms of easy access to proper treatment and medical facilities relieving them of their physical symptoms and reducing the extended cost of treatment. The main source of instrumental support and information and about HIV disease and other related issues has been the network, as reported by the members (Table no.7).

The network, being a form of coping mechanism for the people infected with HIV, has been able to give its members an environment in which they can openly express themselves without the fear of being discriminated or stigmatized. Interpreting the meaning of being HIV-infected is a continual process of assessing one's probability of progression, of rendering medical information intelligible. Being HIV-positive is not so much a stigmatizing condition, as one of "existential crisis", that is, it requires greater anticipation and manipulation of others' response to self. The network has given them an opportunity to share their feelings and fears with others like them which is critical in shaping their "personal and social identity" and giving them a sense of self. As Goffman notes, "in-group" alignments teach the individual to begin to conceptualize his predicament as normal, as shared by others, and to see this alignment as more "natural" than any form of alignment to "normals".[1] It not only gives them a "safe space" but the space itself generates new social relations and a new language in which to communicate. The result is a reconstruction of a new social identity.

The network has utilized the opportunities existing in its socio-cultural milieu like the Magh-Mela to disseminate information about HIV and AIDS through the PLWHA in such a big congregation of people. They attempted to reduce the stigma, discrimination and myths prevalent in the society about HIV and AIDS. It was also an effort to bring the PLWHA to the mainstream of the society and to develop a positive attitude on the issue of HIV and AIDS in the general public. Through this effort, the network was able to reach to those people of rural areas who were very difficult to approach. They could also reach to rural women and inform them about the disease and its prevention. Thus the network was able to approach that vulnerable section of population which is most in need of information to save themselves and their families from the disease.

The network has been able to build a level of trust and credibility in the eyes of the national and international organizations and funding agencies and has started receiving funds and projects from these organizations. It has still to build a level of trust in the eyes of the UPSACS and other NGOs in the city to work in tandem to reduce stigma and discrimination and bring the PLWHA into the mainstream of the

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[1] Goffman, 1963 in 'Against Death', Ariss, 1997

society. However, the network felt the need to be trained thoroughly in advocacy, HIV counseling and have correct and adequate information about the treatment regimens and other issues in HIV. They reported that the trainings they received for capacity building were in English which they could not comprehend. Thus they recommended the facility of either translators to be provided or the trainings to be given in regional language.

The way forward—

The organization has reached a certain level where one by sixth of the members are clearly benefited by the network due to varying degrees of their involvement, socio-economic status and gender.

The organization has also reached a certain level of visibility and credibility with the support organizations. This puts them at the cross-roads whether the organization will grow and use its support for improving the conditions of larger and larger number of PLWHAs or remain limited to greater and greater gains for a small number, will depend upon the current conditions and how the dynamics of the organization unfolds in the coming months and years.

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Appendix

CONSENT FORM

I.,.................................., state that I have been informed about the study being conducted on UPNP+ (UPWPLHA).

I hereby give my consent to interview me for the same.

Date

Name-

BASELINE DATA SCHEDULE

1. NAME-
2. AGE-
3. GENDER-
4. SEXUAL ORIENTATION-
5. MARITAL STATUS-
6. ADDRESS (present &earlier)-

7. CASTE-
8. OCCUPATION-
9. INCOME (Present & what used to be earlier)-
10. FAMILY SIZE-
11. MIGRANT/NON MIGRANT-
12. EDUCATIONAL STATUS-
13. PERIOD OF INFECTIVITY-
14. PRESENTING SYMPTOMS-
15. No. and type of medical institutions visited (public/private)-
16. Whether on ART or not and from where-
17. DURATION OF HAVING BEEN ON ART-
18. FINANCIAL STATUS-

Checklist of issues to be explored

1. Preparedness of the physicians in treating PLWHA, knowledge of the medical aspects of HIV and AIDS.
2. Supportive/unsupportive and hierarchical relationships between patient and health care providers.
3. Experience of social isolation, judgmental attitudes, severed relationships, denial of support and care.
4. Experience of PLWHA in government and private hospitals etc. in relation to admission, operations, physical isolation in wards, informed consent, partner notification, mandatory testing, restricted access to facilities e.g. toilets, food, utensils etc., refusal to touch or lift the dead body.
5. Experience of discrimination, stigma and denial at workplace—removal from job, forced resignation, social distancing, labelling and name calling etc.
6. Level of Internalized HIV stigma (IHS) and its severity in different groups especially those recently diagnosed and those earlier diagnosed, being a part of the network or not a part of the network.
7. Level of information available and through whom, level of IHS specific to level of stigma prevalent in the area, difference in sexual relationships due to high or low IHS.
8. Issues related to disclosure—how easy or difficult it was to disclose the HIV status and to whom?
9. Is there progression overtime from higher IHS to lower IHS level as the duration of having being diagnosed increases?
10. High IHS group was more likely than low IHS group to ever attend an HIV support group. (they knew fewer people with HIV).
11. Source of social support—whether friends and social networks more important (if they are?) than family to seek support, barriers to social support—its effect on physical and mental health (acceptance, intimacy, disclosure, availability, protection of family from oneself etc.)

12. People who do not attend support groups—their characteristics, what about their informational, emotional and instrumental needs.
13. How has support group helped them to meet their emotional, informational, and instrumental needs? Has being a part of the support group helped them- how and in what way? How does it feel to be identified as a group member of a particular group (PLWHA) at other places?
14. PLWHA's perception of its roles, activities, health problems and how they have dealt with within the group or network.
15. PLWHA's perception of the government services and its effects on accessibility as being a part of the network.
16. PLWHA's perception of the other network members and especially the leaders. Level of interaction with the leaders, their way of handling people and role in the dynamics of the network
17. How are PLWHAs identified in the community, how are they made a member of the network?
18. How has network helped them in role retention, role reversal and lowering of family burden of the PLWHAs (class differences).
19. Do PLWHAs 'drop-out' from the network? Why? What leads them to drop out?
20. Extent to which the network has been able to change the attitude of the system as a whole-including medical, toward the PLWHA.
21. How is advocacy done and confidentiality maintained in the network?
22. Information about other local group and people, as well as other state level and national level organisations helping this group, in what way? Information about supply of ARVs, funding other instrumental support, advocacy, medical treatment etc.