

People with HIV: Stigma, Coping and Support Systems An Insider's Perspective



प्रयास

आरोग्य, ऊर्जा, शिक्षण आणि पालकत्व
या विषयांतील विशेष प्रयत्न

People with HIV: Stigma, Coping and Support Systems
An insider's perspective

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आपल्या आयुष्याची चित्तरकथा
कुठल्या कुणाला सांगणं फार अवघड असतं.
कितीही ठरवलं तरी
पुनर्अनुभवांपासून सुटताच येत नाही.
तरीही तुम्ही मागे हटला नाहीत.
हे कधी विसरता येणार नाही.

*"Rendering your life story to an outsider is not easy.
It did mean engaging in revisiting the painful past.
Still you did not step back.
We can never forget this."*

**People with HIV:
Stigma, Coping and Support Systems**
An Insider's Perspective

Dr. Shrinivas Darak
Dr. Sanjeevani Kulkarni

2005

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– Prayas Health Group

Abbreviations Used

AIDS - Acquired immunodeficiency syndrome

ART - Anti-retroviral treatment

HCP - Health- care provider

HIV - Human immunodeficiency virus

PLWHA - People living with HIV/AIDS

TB - Tuberculosis

SW - Sex worker

NGO - Non-governmental organization

Foreword

HIV/AIDS has replaced leprosy as the metaphor for stigma. HIV/AIDS-related stigma pervades much of the discourse on HIV/AIDS and has a negative impact on those who are positive, their families, their communities, and the society at large. The near universal nature and the high intensity of stigma attached to HIV/AIDS may be attributed to its intimate connection with two subjects that are taboo (stigmatised) in most societies and certainly in South Asia – sexual behaviour and death. Apart from having a direct impact on those infected or affected by HIV, stigma leads to denial of the severity and extent of HIV/AIDS, which results in a lack of concerted and coordinated planning and action to meet the challenge of the disease. Stigma impedes preventive efforts as open and non-judgmental communication about sexual matters is proscribed, availability and accessibility of preventive measures is restricted, and care and support is inadequate.

This study, *“People with HIV: Stigma, Coping and Support Systems: An Insider’s Perspective,”* conducted by Prayas is one of a series of research projects supported by the NIMHANS Small Grants Programme for Research on Sexuality and Sexual Behaviour with funding from the Ford Foundation (970-0375).

The Prayas team has admirably fulfilled all the goals of the NIMHANS Small Grants Programme: They have addressed a pressing issue in a sensitive way; they have broached thorny ethical issues, and provided service as well as carrying out research. They have innovated and developed appropriate research methodology - the disclosure graph. Further the research has immediate practical application at the service level and informs public policy.

This study stands out in that it examines underlying factors such as gender and social status that modulate stigma. The study examines the key role that stigma plays in defining events in the life of people with HIV – from the moment that they find out their positive status, and continuing on to decisions and dilemmas around disclosure, perceived and enacted stigma, restructuring of their pattern of living in order to minimise stigma, changes in relationships, access to health care, interaction with health care staff, where stigma and discrimination may be encountered for the first time, coping mechanisms and support systems. The power of social structural factors such as gender and economic security in modulating the extent to which stigma is produced and reproduced is patent from this study. The well educated, the well off have access to health care and expensive medication and thus the means to maintain confidentiality and privacy, control disclosure and maintain social status.

The rapidly changing HIV/AIDS epidemiology is causing some reduction of HIV/AIDS-related stigma and discrimination. There is an increased prevalence in ‘the general population’, mother-to-child transmission is on the rise and there is an increase in cases of people with symptoms of HIV/AIDS. The institution of voluntary counselling and testing centres, the emerging strategies to prevent mother-to-child transmission, and availability and access to antiretroviral drugs also have their effect on stigmatisation. An important issue from both the point view of people living with HIV/AIDS (PLWHA) and from the public health perspective is the impact of accessibility to effective and affordable treatment on reducing HIV-related stigma. The Prayas study explores social and other support networks and the influence of these on care and stigma perception and coping.

This book will be of considerable interest to health professionals, policy makers, social scientist, and researchers and to all those interested in and concerned about the human condition.

– Jayashree Ramakrishna
Coordinator, NIMHANS Small Grants Programme
for Research on Sexuality and Sexual Behaviour
Department of Health Education,
National Institute of Mental Health & Neuro Sciences, Bangalore

The NIMHANS Small Grants Programme aimed to encourage rigorous yet sensitive research on sexuality and sexual behaviour that is trans/multidisciplinary in nature, cognizant of the context, involves marginalized groups and addresses priority concerns that are relevant for programme and policy development. A major objective was to develop innovative methods to capture sensitive, complex, diverse and hidden information, while ensuring rigor, validity and adherence to ethical standards. It aimed to promote opportunities for development of research skills by providing ongoing technical assistance and facilitating networking to share ideas and skills. In the funding cycle that extended from 1998-2003, eleven studies were funded. Six projects centred on young people, three on school-going youth and three on out-of-school youth. Two focused on women, one on traditional sex workers (*devadasi*) and another on women who consume alcohol. One examined LGBT (lesbian, gay, bisexual and transgender) journeys. Two focused on HIV/AIDS related issues. The NIMHANS Small Grants Programme for Research on Sexuality and Sexual Behaviour is bringing out a series of monographs to make these studies accessible.

A Review by Dr. Shallini Bharat

Tata Institute of Social Sciences (TISS), Mumbai

The study “People with HIV: Stigma, Coping and Support Systems – An Insider’s Perspective” is a useful and welcome addition to the burgeoning literature on Stigma and discrimination in the field of HIV/AIDS. A difficult and complex investigation, due not only to the sensitive nature of the problem but also due to the interlinked issues of ethics and human rights, the study assumes importance and contributes to existing knowledge on the subject. The study explores the nature and forms of HIV/AIDS related stigma and discrimination, the impact on the quality of life and health status of the infected people, and the ‘strategies’ used to cope with stigma and discrimination. The methodology of the study complements the nature and complexity of the investigation. The development of a quantitative measure of stigma is an additional feature of this investigation.

The study employs a conceptual framework that attempts to link stigma as a phenomenon on one hand, to ‘support systems’ and ‘methods of coping’ on the other, mediated by the process of ‘disclosure’. The framework, though useful, seems oversimplified on several counts. First, the concept of stigma is reduced to the typology of ‘enacted’ and ‘felt’ stigma - a typology most commonly used but not exhaustive and comprehensive. Available qualitative explorations thus far, have made it possible to unravel stigma as ‘ascribed’ and ‘achieved’ and ‘symbolic’ and ‘instrumental’ stigma. At another level it has been found useful to distinguish between covert and overt stigma. With regard to support systems and coping, it is difficult to consider the former in isolation of the latter or as separate boxes. Support systems in many ways are part of the ‘engagement’ coping strategy. One way of coping for example, is by ‘engaging’ with the problem through the active use of some social support/network system – professional or relational. The conceptualisation of ‘coping’ as ‘engagement’ and ‘disengagement’ is useful but it is important to explicate how actions such as suicide/suicidal ideation among PLHA may be treated. A noticeable omission when discussing support systems is that of ‘self help groups’, for example “PLHA support groups” in the context of HIV/AIDS epidemic.

‘Disclosure’ is an important mediating process but other useful mediators are the family (supportive or non-supportive), sex (male/female), cause of infection (perceived or actual that labels those infected as ‘guilty or ‘innocent’), stage of infection (early or late wherein physical manifestation of the disease may be a marker for stigma), and few more among others. Disclosure may be treated as a minimum necessary condition to experiencing stigma and discrimination but marker diseases may subvert its significance – a point that has relevance for management of opportunistic infections among PLHA.

From a methodological point of view, the selection of respondents from a health clinic poses special problems regarding generalisability. Additionally, exposure of the clinic attendees to the counselling process may have already influenced their coping strategy and support seeking behaviour, and thereby their experience of stigma and discrimination. While it is acknowledged that most studies on PLHA are carried out with clinic based samples, the findings must be discussed with these limitations in mind. In the present study, data reported in Table 4 may help to explore the impact of counseling exposure on stigma experience and coping methods employed.

The findings related to disclosure are very interesting and important from the point of informing counseling services. However, it is important to analyse how disclosure and further dissemination of status were influenced by counseling/ongoing counseling. And how disclosures in turn influenced coping (or did not influence). It would have also been important to explore into the dynamics of disclosure – for example how past family relationships/with spouse, in-laws, and gender norms influence disclosure process – i.e. disclosure to whom, when, why and what.

Stigma related findings lend additional support to what is already known from earlier researches in the country - the gender dimension of AIDS stigma and stigma experienced at health settings etc, for example. This section also needs to explore stigma that results from ‘ignorance’ and lack

of complete and correct information. On Page 40, for example, there is mention of 'fear of acquisition of infection' as a reason for discrimination. On Page 41, similarly the perception about imminent and early death-explains stigmatising attitude. These findings have programmatic implications in designing awareness programs and need to be conveyed to the planners.

Both the sections on coping and support systems present several useful insights that should help in designing interventions. The role of men in supporting their wives is a particularly important piece of evidence. What is missing from the study is the role of positive people's network as support system in coping and health seeking.

The development of a stigma scale is a useful contribution to the field and must be tested in the field for reliability and validity.

The findings of the study present useful insights into the dynamics of AIDS stigma and its manifestation in discriminatory practices across a spectrum of settings. Additionally, they validate the findings of studies conducted on this theme by several other researchers in the country (Bharat, 1999/2001; UNIFEM, 2000; ILO 2003; INP +, 1999/2000; APN +, 2002), a point that has not been discussed or even mentioned in the report. A significant contribution of this study is that it confirms the pervasiveness of AIDS stigma reported in previous researches from different locations in the country (Mumbai, Bangalore, Delhi, Manipur, Chennai, and now Pune) and across time span (from the 1998 study by Bharat to the present one in 2003 – arguably a very short time span but nevertheless important to keep in mind when tracking the issue in forthcoming studies). This has implications for both policy and program development on stigma reduction efforts in the country.

A Review by Dr. Sanjay Mehendale

Senior Deputy Director
National AIDS Research Institute (NARI), Pune

I read with interest the report prepared by the Health Group of Prayas on “People with HIV: Stigma, Coping and Support Systems”. This is a very elaborate and nicely compiled report that could immensely benefit researchers in the area of socio-behavioral research and also the care providers.

Although the study is primarily focused on persons visiting a private HIV clinic, it has brought out important findings that have a broad and general appeal and application. The report is appropriately sequenced into sections maintaining good flow of reading. The findings presented in the areas of disclosure, stigma, coping and support systems are detailed and elaborate.

The chapter on Disclosure outlines the complexities involved in the first disclosure of the HIV positive status and differential patterns in disclosure by gender. The issue of disclosure to the spouse has been duly emphasized as this is expected to have long-term repercussions on the family support structure. Additional analysis of data in women might provide some more information.

Description of Stigma, in the context of fear of how people would react to the knowledge of HIV status and their experiences of stigmatization and discrimination provides many insights on this so far under-researched area in the field of HIV/AIDS. Stigma and discrimination by the health care providers can have serious consequences especially in the Indian context with a high burden of HIV disease and associated morbidity. The model of image of HIV positive person in the society needs to be modified to include factors like sexually transmitted diseases and other co-morbidities.

The observations related to coping and listing of disengagement and engagement strategies can be utilized in designing appropriate educational material as a part of the intervention packet to be provided to HIV infected individuals. The chapter on Support Systems can be expanded to include additional data and observations.

I would like to congratulate the health team of Prayas for working on this difficult area of stigma, discrimination and coping and providing invaluable data. I expect that the group will succeed in following this study by more focused and specific studies that could provide clues for development of practical and feasible intervention strategies.

A Review by Dr. Ram Gambhir

Associate Professor
Department of Anthropology
University of Pune, Pune

The global and national estimates of HIV-AIDS prevalence clearly suggest that it is a major public health problem. In India, in the initial phase of the epidemic, the focus was on the prevention of transmission through public awareness and behaviour change. However, in the process these prevention efforts took a biased and moralistic stand. This coupled with the existing sexual and moral norms in the community created an image of HIV-AIDS, which is negative, scary and highly stigmatising. This scenario is not only detrimental to PLHA but also to the ongoing prevention efforts as it influences people's information and health seeking behaviour.

The study "People with HIV: Stigma, Coping and Support Systems –An Insiders' Perspective" by PRAYAS assumes critical importance in this context. It focuses upon social stigma associated with HIV/AIDS as perceived by PLHA and its consequences for health seeking. It also considers stigma as a stressor in the life of PLHA and explores various mechanisms by which they cope with.

The issue of stigma as seen by PLHAs' is explored at three levels – self, society and health care providers. The study shows that the stigma emerging from these three source various in nature and intensity. Thus there exists variation in stigma and discrimination, demonstrated by persons of different social categories (friends, close and distant relatives) probably reflecting their own fears and concerns, which are the real source for social stigma and social distance.

The study describes engagement and disengagement coping strategies. I think that the results can be better conceptualised and raised from the level of mere description. The concept of 'restructuring' is used to explain coping at the psychological level. It would be interesting to extend it to include the behavioural aspects of patients. Similarly variations in patterns of disclosure and support patterns on account of gender differences are mentioned but a more comprehensive and cohesive discussion on gender, stigma and coping is possible.

The study begins with and derives its rationale from theoretical conceptual model, which broadly explain sources of stigma and its effects on coping and support system in the context of HIV. As a logical extension, the study should conclude with the empirical conceptual model, which would describe the actual dynamics of stigma and associated aspects.

At a more theoretical level the study attempts to develop stigma scale. However knowing that social stigma is cross-culturally variable and context bound, the scale should be explicitly relevant to Indian situation and should be of practical value.

The present study is a capacity building research exercise. It provides insights into various issues surrounding HIV-related stigma from the perspective of PLHA. Given its potential the study may be viewed as an initial exploration into the issues of HIV/AIDS related social stigma and possibility of arriving at stigma scale. This experience should serve as a guide for a more elaborate and rigorous study.

Background

The dimensions of the worldwide pandemic of HIV/AIDS are now well known. The gravity of the situation, even in India, has also been acknowledged with more than 5.1 million people already estimated to be living with HIV in the country (NACO estimation by the end of 2003) and with an addition of a minimum of 300,000 new infections per year. The tasks necessary to contain this wildfire spread of the disease are also more or less clear. It has also been recognized that the debate over whether the resources should be spent more on prevention or on the care of infected individuals is now probably resolved, with realization that both prevention and care are intricately related to each other and are, in fact, inseparable.

This study was conducted at a private clinic which provides care and treatment to PLWHA but which is not a part of the PRAYAS activities; however the counselling support to all the PLWHA and their families is provided by the free counselling centre run by PRAYAS, which works in close association with the private clinic.

The study was inspired by the work already done by the PRAYAS Health Group over last 10 years. Reflections of the spread of the epidemic were observed in the evolving patterns of cases seen by us. Changes were being observed in the gender distribution, the socio-economic backgrounds and social situation. The men and women being counselled by us narrated their life stories and provided insights that helped our work. However the observations, though deeply moving, remained anecdotal or intuitional. We needed to document the facts and try to analyse them systematically to support our hypotheses.

What did these people say? Many confessed that they might have thought of committing suicide had they not met the counsellor at that time. Their concerns not only emerged out of fear and ignorance about the disease which was evident when we talked to them, but also had much to do with the fear of stigma, the fear of being discriminated against. The impact on the daily lives of PLWHA was transparently evident. People had numerous questions. There was the fear of facing society. Unfortunately these fears were not 'myths'. The society did discriminate against PLWHA.

Stigmatisation and discrimination are not new to Indian society. Many sociologists emphasize that our society is driven by stigma- such as stigma based on religion, caste, gender, sexual preference and

orientation, profession, as well as disease. HIV/AIDS is a complex issue that has emerged only recently. It encompasses several of these factors together. In addition are the aspects of incurability and prolonged morbidity that makes the situation darker.

Men detected positive found it extremely difficult to disclose the fact to their wives. Much courage had to be summoned up before they could do so. This disclosure was crucial. Making it created so much tension not only because of the imminent death associated with the diagnosis, but more so because it was a disclosure about the immoral behaviour, betrayal, promiscuity, etc. That was an aspect both found more difficult to handle.

People are afraid to get tested; they are reluctant to get their partners tested. They are worried about the results. Will they be able to face the reality if the results turn out to be positive? There were also the concerns about additional resources required if another person in the family were also tested positive. Maximum reluctance was observed regarding the screening of the children, even in situations where there were sufficient resources. To face the brutal fact and the consequent guilt was beyond the parents' capacity in many cases.

On the other hand there were persons who were facing life with HIV confidently and comfortably. They were taking care of themselves, working hard, and trying to spend life with as much happiness as possible. We remember a young domestic worker; she herself is infected with HIV and lost her husband recently. Both her daughters are also infected. But she is taking life in her stride. What has helped her to come to this state? How is she coping so well with the stress?

Our experiences at the counseling centre inspired us to look at the issues of stigma. What were the exact stigmas? What was its nature for an individual? How did people cope with their situations? What were their support systems? What could have been their support systems? We wanted to analyse all this on the basis of a conceptual framework and then to look at the conclusions in such a way that would further help us improve our counseling, both in the methodology as well as the content and provide a better support to PLWHA.

We also felt that such an analysis would contribute to a better understanding of the lives of PLWHA and improve prevention, care and support strategies.

*When the history of AIDS and our time is written,
the inextricable links between health and social stigma,
discrimination, human rights, and dignity
may be recognized as our most important contribution.*

– Jonathan Mann

Introduction

More than two decades into the HIV/AIDS epidemic, the stigma and discrimination against people living with or affected by HIV/AIDS continues unabated. Fear of acquiring the infection, perceived morbidity and mortality associated with the disease, and community notions about sexual morality contribute to a large extent to the persistence of stigma and pose a significant challenge to implementing prevention and care programs for HIV/AIDS. Thus stigma increases the vulnerability of people to HIV and worsens the impact of infection on PLWHA (Nyblade, Pande *et al.* 2001)

Jonathan Mann, former head of WHO's Global Programme on AIDS identified stigma as a 'third epidemic' early in the history of HIV (the first being the hidden but accelerating spread of HIV and the second the visible rise of AIDS cases).

"It is now clear that vulnerability to becoming infected with HIV derives directly from stigma and discrimination (and more broadly, violation of human rights and dignity) occurring within each society. Thus we have learned that to uproot the HIV/AIDS epidemic, as well as to protect and promote health more generally, human rights and dignity must be advanced.

– Jonathan Mann

Stigmatising a particular behaviour, character or disease is not a new phenomenon. Diseases such as leprosy, tuberculosis, mental disorders, vitiligo are other examples of diseases that stigmatise persons suffering from them. Though in all stigmatising conditions, a person suffering from the disease is devalued by society, the context and forms of devaluation and its psychosocial consequences are different for different diseases. People with tuberculosis may be isolated for the fear of acquiring the infection but will not be blamed for their disease as in leprosy where having the disease is linked with 'sin' and sufferers are held responsible for their disease. Persons with diseases like vitiligo are devalued because of the obvious visibility of the disease. In the present era, AIDS is probably the most important disease to be stigmatised, which must be because of its association with death, incurability, high morbidity and undoubtedly with morality.

HIV/AIDS is one of the few diseases that touch multiple aspects of human life. The most important of these is sexuality, which is intimate, hidden and

the most unexplored area of human interaction. The epidemic shed light on the ground realities of sexual behaviours and sexual networking in any community. These are usually contrary to the existing societal norms resulting in denial and non-acceptance of the disease in this community. The nature of this disease, absence to a large extent of societal support and the stigma attached pose many challenges for PLWHA in coping with the disease.

While providing care and support to PLWHA, the most important thing is to explore these matters from the perspective of people living with HIV/AIDS. In this way, one can explore the ways to minimize the impact of stigma on their lives and help them to adopt better coping strategies through counseling so that they can lead lives that are more positive and meaningful.

This study is such an enquiry and the main objectives of the study were to understand –

- Dimensions, context, levels and forms of stigmatisation from the perspective of people living with HIV/AIDS,
- Diffusion of information of a person's HIV status and the apparent reasons for that,
- Different support systems for PLWHA,
- Various strategies adopted by PLWHA for coping with the disease,
- Stigmatisation in the health care system; its forms, context and consequences.

Conceptual Framework

The conceptual framework for this study was based on our review of the literature on stigma, and also that on coping and support systems. Many of the studies reviewed were not focused on HIV/AIDS. These studies were mainly in relation to mental disorders. The recent past has seen an increased number of studies on stigma globally and also in India, but there are hardly any studies to understand the interrelation of stigma, support systems and coping.

The history of stigma research suggests that this concept of stigma gained currency in social science research first through the work of Erving Goffman. He defined it as "an attribute that is deeply discrediting" and that reduces the bearer "from a whole and usual person to a tainted, discounted one" (Goffman 1963). Goffman applied the (negative) term "stigma" to any condition, attribute, trait, or

behaviour that symbolically marked off the bearer as “culturally unacceptable” or inferior with consequent feelings of shame, guilt and disgrace. Subsequently many scholars have looked at it from various perspectives and suggested different dimensions of the concept. Schneider and Conrad (1981) and Dell (1986) have argued that for stigma to exist and operate, targeted individuals must accept the devaluation. Katz considered the process of social interaction in his conceptualisation of stigma. He says that the issue of isolation and rejection and subsequent prejudice and discrimination, stems from the fact that we often try to avoid interaction with the individuals whose bodily and psychological characteristics deviate from our group norms.

While studying HIV/AIDS related stigma, social scientists have differentiated the types of reactions to people with HIV. The first type, labelled as ‘**instrumental stigma**’, is derived mainly from fear of AIDS as communicable and lethal and thus there is a desire to protect oneself from it. The second type referred to as ‘**symbolic stigma**’ is based on the metaphorical social meanings attached to AIDS, the people who contract it and the ways in which it is transmitted. It results from the use of AIDS as a vehicle for expressing hostility towards other groups that were already stigmatised before the epidemic began (Herek 2001).

British sociologist Graham Scambler (1989) conceptualised stigma from the perspective of people

living with HIV/AIDS. Recognizing the fact that the overt acts of discrimination are not necessary for stigma to affect its target and many stigmatised individuals regulate their own behaviours to avoid others’ hostility and abuse, he differentiated between **enacted stigma** (overt acts of discrimination) and **felt stigma** (a stigmatised person’s internal sense of shame and fear of persecution) (Scambler 1989). Since we were looking at stigma from the perspective of PLWHA, we used the same classifications of stigma in this study. (Fig. 1)

Another dimension of stigma studies, which recently generated interest among scholars, is the conceptualisation of stigma and discrimination as a stressor in the life of a stigmatised person (Allison 1998; Anderson, Clark & Williams 1999; Miller & Major 2000). One advantage of putting stigma squarely in the domain of stress and coping is that it invites consideration of the many ways in which stigma can affect a stigmatised person, such as its psychological, social and biological effects (Clark *et al.* 1999). People with HIV/AIDS have a vast array of responses to different stressors affecting them due to their HIV infection and consequent devalued social status. They are not simply the victims or passive recipients of people’s prejudices and discrimination. Rather they actively respond to the stresses by using their personal and social resources. In other words they try to cope with the situation. “Coping” as defined by Catherine *et al.* is “the act of taking specific efforts, both behavioural and psychological, to master,

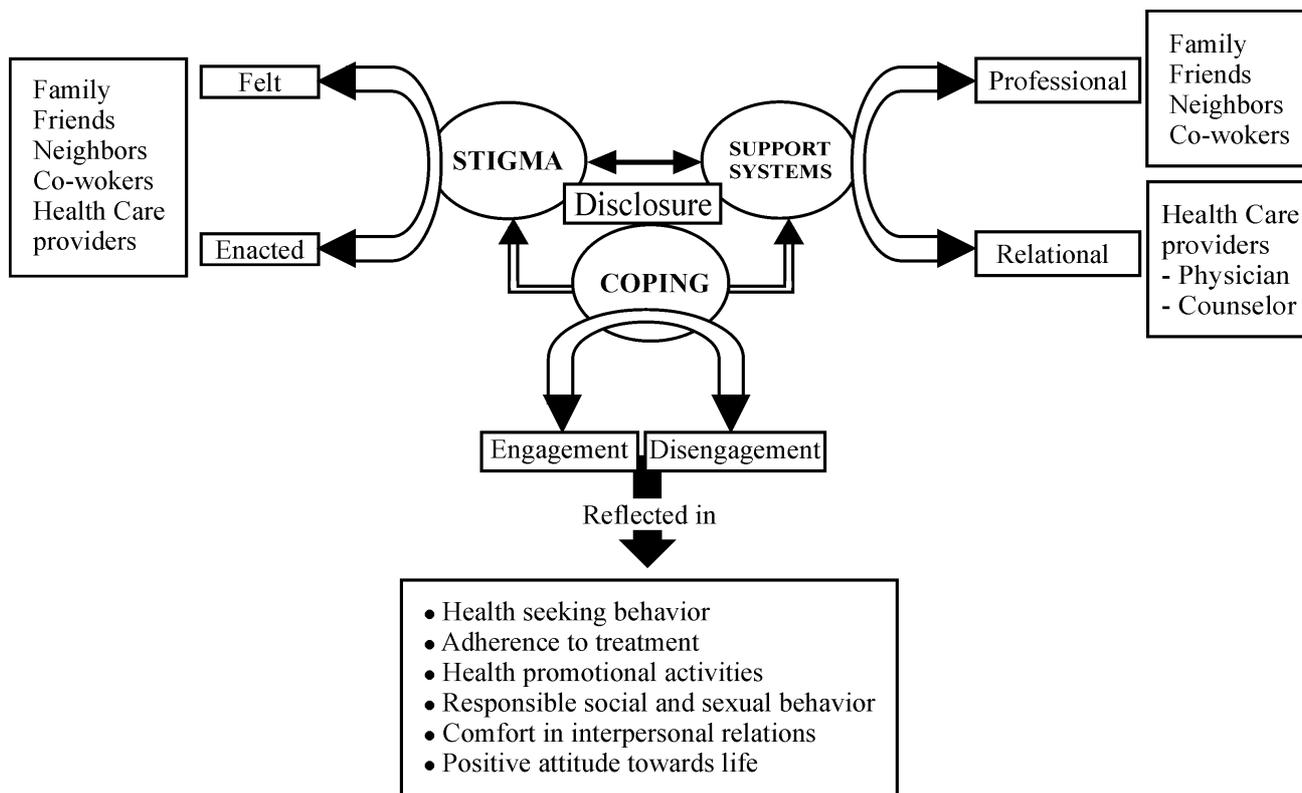


Fig. 1: Conceptual framework for understanding interrelations of stigma, coping and support systems in case of PLWHA

tolerate, reduce or minimize a stressful event.” (Catherine et al 2000) The term “coping” is reserved to ‘conscious volitional efforts’ (Compass *et al.* 2000). Such efforts can be made by engaging with the stress or a problem which is termed-**engagement coping** or can be made by diverting the attention away from it-**disengagement coping**. Though coping actions are classified into distinct categories, it is important to note that stress responses are dynamic, multifaceted and interdependent. Positive or negative feedback from one response may alter the next response and a person may use multiple coping strategies simultaneously to cope with the stressful situation (Miller & Kaiser 2001).

As has been mentioned above, people make use of various personal and social resources while responding to stress. The role of individuals from their social network is an important factor influencing their coping. Many studies have been made to understand how people mobilize their social support network while coping with a chronic illness. In case of HIV, the way in which PLWHA mobilize their support network becomes complex mainly because of the stigma attached to the disease. Therefore under such

circumstances it is worthwhile exploring what constitutes the support systems for PLWHA. In this study we intend to look at support systems under two broad headings based on the people from whom the support is drawn. First is the **professional support system** which includes the support PLWHA get from health care providers and second is the **relational support systems**, which includes the support from members of social networks such as relatives and friends.

From the point of view of the conceptual framework (Fig. 1) stigma, coping and support systems are intertwined and interdependent concepts. It is also important to note that disclosure of HIV status to significant others is greatly influenced by stigma and has direct linkages with seeking support and coping with HIV infection. Stigma affects the support systems for PLWHA, which in turn affects their coping with the disease and thus affecting the outcome in terms of physical, social and psychological health. In this report we have analysed this data along with various demographic and social factors influencing stigma, coping and support systems and presented the results from the perspective of people living with HIV/AIDS.

Methodology

This study was conducted by selecting a sample of patients attending a private HIV clinic in Pune, Maharashtra, India. So it would be pertinent to know more about this set up.

About the Clinic

This is a private dermatology and STI clinic started in 1985 and is located in the heart of Pune city. The first HIV patient was seen in 1989. The doctor was interested and involved in HIV related awareness activities even before he saw this patient at the clinic. As the epidemic grew, the number of HIV positive people visiting the clinic continued to increase. The doctor along with his other colleagues established an NGO, PRAYAS in 1994.

At present this clinic is functioning as a specialized care centre for people living with HIV/AIDS. Approximately 60 to 90 new HIV positive persons attend this clinic every month. PRAYAS, an NGO, provides free counseling services to these people infected with HIV and their kinsfolk affected by HIV.

Being mainly a referral centre, the individual's first HIV testing and disclosure of their report hardly ever occurs at this clinic. Most cases are screened and detected HIV positive somewhere else. Most often other health care providers refer them to this clinic. Further care in terms of treatment of opportunistic infection and antiretroviral treatment is provided at the clinic. Since the doctor is attached to four hospitals in the city, institutional care can be arranged for those patients who need it. The clinic gets its clientele from in and around Pune city as well as from other parts of Maharashtra State. This is probably because few doctors provide treatment for HIV infection. Patients taking treatment from this clinic have also referred several cases.

The gender distribution of the patients attending the clinic shows that there are 66% men and 34% women (analysis of data in the year 2002). However, it is now being observed that the percentage of women attending this clinic is gradually increasing. Patients are largely from middle to higher socio-economic strata. There are very few people from very low socio-economic strata.

Generally patients consult the physician first and are then referred to the counsellor if they wish and give their consent. However, it is not mandatory for the patients to see the physician in order to use the

counseling service. The counsellor is available daily in the morning as well as in the evening. Routinely all the new cases attending the clinic are referred to the counsellor and the further appointments with the counsellors are given based on the needs of individual patients. Many patients require frequent sessions with the counsellor during the initial period after diagnosis or during any crisis situation such as death of a partner or child. Generally all patients take a session with the counsellor before they decide to go on antiretroviral treatment. Adherence counseling is also a major component of counseling and is strongly advocated at the clinic.

Selection of Informants

The project was sanctioned and started in November 2001. After the preparatory phase, we started enrolling patients for the study from January 2002 (Fig. 2).

- Generally only those PLWHA who started visiting the clinic after May 2000 were included in the study.
- PLWHA were enrolled only when the counsellor was reasonably confident that they could bear the stress of the interviews. This took at least a couple of sessions with the counsellor before they were comfortable enough.
- Persons below the age of 18 years were not enrolled in the study as there were problems regarding the validity of their consents.

Patients who sought treatment and counseling were selected by purposive sampling method. Before enrolling them in the study, they were informed about the nature and objectives of the study and then were asked for their willingness to participate in it. It was found that out of 111 patient 79 showed a willingness to participate in the study and 32 were unwilling to do so for various reasons. The main reason was that participation would mean disclosure of their status to the interviewer and they were unwilling to do that. Others could not participate because of the scarcity of time. Since they travelled long distances to reach the clinic, they could not wait for a long time to see the physician, the counsellor and then the interviewer. There were no specific exclusion criteria apart from the individual's unwillingness.

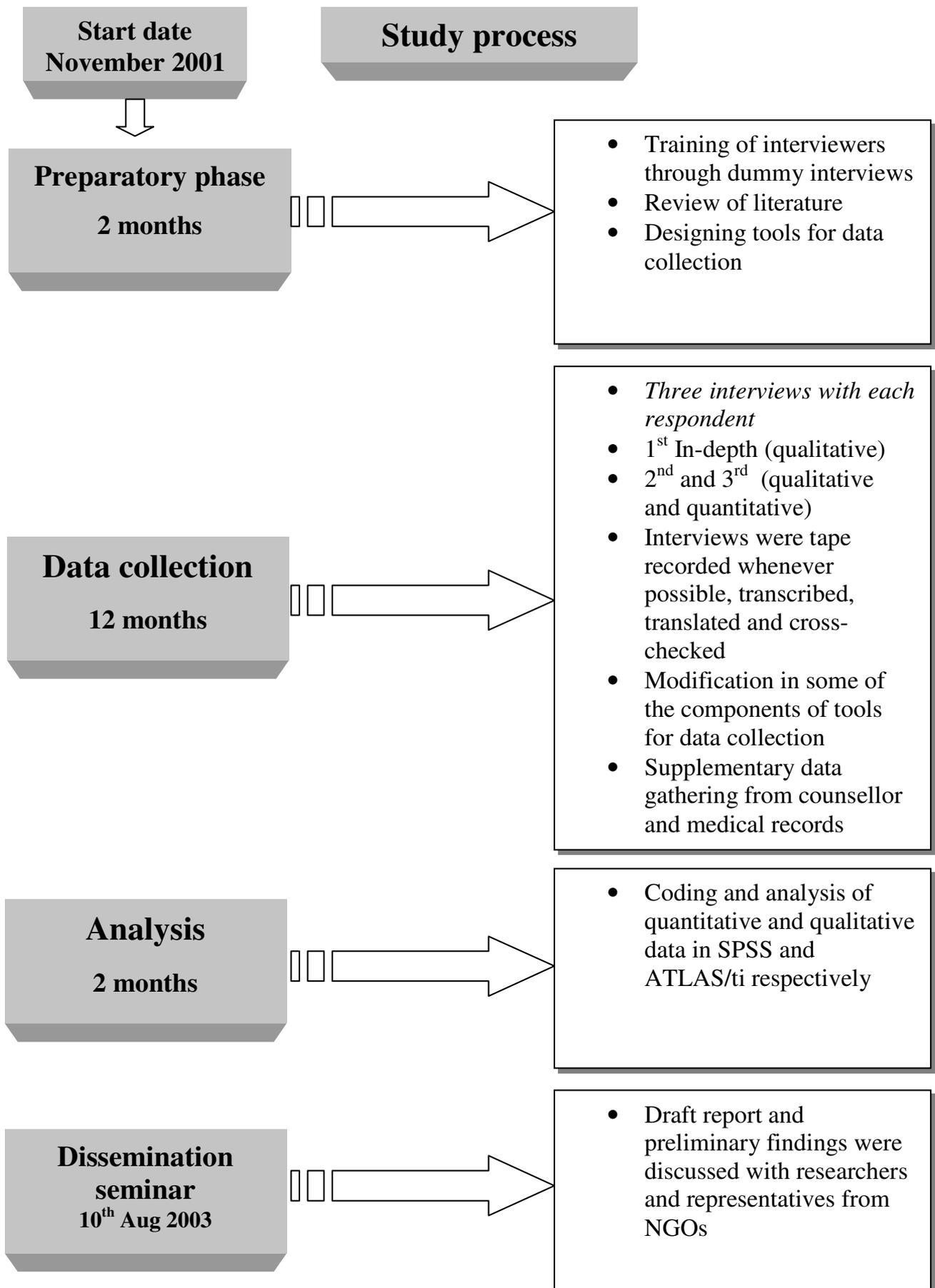


Fig. 2: Study process

Research Design

The research design was mainly qualitative and exploratory in nature however we also used some quantitative tools for data collection.

Process and Tools for Data Collection

The research team consisted of the counsellor, the physician and the two interviewers. The counsellor introduced PLWHA to the interviewers. The interviewers then obtained an informed written consent (see annexure 1). Patients were interviewed by an interviewer of their own gender. Three sequential interviews were planned with each patient with a gap of at least one month between two interviews. For their convenience, these interviews were scheduled with the follow up visits at the clinic. Forty-seven of seventy-nine respondents completed all the three interviews. The first interview was unstructured, in-depth and qualitative in nature. In this interview data were collected with the help of the 'interview guidelines (see annexure 2). In the second interview, along with collecting the qualitative data we used another tool to collect quantitative data related to disclosure of HIV status. These data were collected in the form of a graph and we have named the tool 'disclosure graph' (see annexure 3). The third interview was entirely quantitative in nature during which we requested the participants to respond to a structured questionnaire, which was developed in the form of a stigma scale (see annexure 4). Preliminary analysis suggests that with a larger sample the scale could be further validated.

Data Analysis

Qualitative data – In-depth interviews were conducted mainly in Marathi with some in Hindi and one in English. These were transcribed and then translated into English, keeping significant verbatim quotes in the original language. The translations were checked by the counsellor to see that there were no distortions of the facts. Individual cases were entered into the computer using MS WORD, and analysed by coding into ATLAS/ti (a software for analysing qualitative data).

Quantitative data – regarding the demographic variables, disclosure graphs and stigma scale were analysed by using SPSS.

Ethical Issues

PRAYAS strongly believes and strictly follows the ethical norms while conducting any research.

We assured complete confidentiality to all our respondents. A fully informed written consent, including consent to use data from the counsellor's notes as well as from their medical records was obtained from each respondent. Respondents were assured that they could quit participating in the study any time and that would have no implications as far as providing care and support to them at the clinic was concerned.

During the process of interviewing, many respondents experienced varying degrees of stress. In such cases, they were given compassionate support.

Profile of the Respondents

Demographic Background

The study was conducted in the period between November 2001 to February 2003. The sample for this study consisted of 79 PLWHA, 50 men and 29 women. Men were from different age group whereas most women were below 30 years of age. The majority of men and women were living as married. There were 7 women who were separated from their husbands, out of these, six women had separated after they were diagnosed as HIV positive. The majority of the respondents were from an urban area but not all were from Pune City. Almost 30% of them had to travel a distance of more than 100 kms to reach the clinic. (Table 1)

Socio-Economic Background

Education and occupation of the respondents is given in Table 2. It was difficult to evaluate their economic status based only on a limited and fixed set of parameters because of the complexity in terms of their place of residence and the kind of resources they used for livelihood. In this research, we used a different methodology to assess the socio-economic status of

the respondents. Counsellor, medical consultant and two interviewers independently evaluated the economic status and after their discussion, respondents were allotted a category. The main points considered during this evaluation were - income of the individual or in cases of housewives, income of the husband, the total income of the family, material resources available for the person, and affordability of antiretroviral treatment. To construct a socio-economic scale (SES) we also ascribed scores to education and occupation. These were added to the scores given to the economic status and a three-point scale was constructed. Based on this scale, it was observed that most of the respondents belonged to the medium to high socio-economic strata.

HIV Related Background

Men had been tested for HIV mainly because they were symptomatic and were in the advanced stage of the disease when they reached the clinic. Women were tested either because their husbands were HIV positive or during their pregnancy and were by and large in an early stage of the disease (Table 3).

Table 1: Demographic background

		Men	Women	Total
Age	Below 25 yrs	2	11	13
	26-30 yrs	11	9	20
	31-35 yrs	20	7	27
	Above 36 yrs	17	2	19
	Total	50	29	79
Marital status	Unmarried	5	0	5
	Married	40	19	59
	Separated	0	7	7
	Divorced	2	0	02
	Widowed	3	3	6
	Total	50	29	79
Residence	Urban	40	24	64
	Rural	10	5	15
	Total	50	29	79

Table 2: Socio-economic background

		Men	Women	Total
Education	Primary schooling	7	3	10
	Secondary & Higher Sec.	26	13	39
	Graduate and PG	17	13	30
	Total	50	29	79
Occupation	Unskilled work	18	0	18
	Professional work	11	6	17
	Business	11	0	11
	Currently not working	10	0	10
	Housewives	NA	23	23
	Total	50	29	79
SES	Low	9	3	12
	Medium	24	14	38
	High	17	12	29
	Total	50	29	79

Table 3: HIV related background

		Men	Women	Total
Reasons for testing	Symptoms	43	6	49
	Spouse tested positive	5	12	17
	ANC	NA	8	8
	Other	2	3	5
	Total	50	29	79
HIV status of spouse	Negative	17	5	22
	Positive	19	22	41
	Not tested	6	1	7
	Not known	3	1	4
	NA*	5	0	5
	Total	50	29	79
Clinical stage	Early HIV	5	15	20
	Moderately advanced	13	9	22
	Advanced	32	5	37
	Total	50	29	79
ART	Taking ART	44	12	56

* NA represents unmarried persons.

The clinical staging was done based on CDC AIDS surveillance case definition (Clinical categories A, B and C) supported whenever possible with CD4/CD8 counts.

Table 4: Time gap for reaching the clinic and duration for accessing care

		Men	Women	Total
Referral	In the same month of diagnosis	25	10	35
	1-6 month after diagnosis	17	10	27
	> 6 months after diagnosis	8	9	17
	Total	50	29	79
Coming to this clinic	For less than 6 months	28	16	44
	7 months to 1 year	6	7	13
	More than 1 year	16	6	22
	Total	50	29	79

Table 5: Probable mode of acquiring the infection

Men		Women	
Sex workers	22	Husband	17
Casual sex	14	Boyfriend	2
Wife	4	1st husband	4
Don't know	9	Don't know	2
Other	1	Other	4

* Casual sex was defined as sex with someone neither in sex work nor in stable relationship.

The patients coming to the clinic were mainly referred from other health care facilities after they were diagnosed as HIV positive. The above table (Table 4) shows the time gap before reaching the clinic after their diagnosis and the duration for which they have been coming to the clinic.

Patients who were referred to the clinic in the same month of their diagnosis had little interaction with other health care providers apart from the referring physician and then at this clinic. Others who reached the clinic after a prolonged gap did have experience of accessing care from various health care providers.

Probable Mode of Acquiring the Infection

Table 5 shows the probable sources of acquiring the infection as reported by the respondents during their

open ended in depth interviews. Twenty-two men said that they contracted the infection by having sex with a sex worker in a designated 'red light area'. Thirteen men said that they got the infection through a relationship, either serious or casual, with a woman who was not a sex worker. One person in this study said that he got the infection through sexual relations with a man. Nine men said that they did not know how they got the infection. They did not give any history of high-risk sexual behaviour or blood transfusion. Women mostly got the infection from their husbands. There were three women in this sample who acquired the infection through blood transfusion and one acquired it through occupational exposure. She was working in a laboratory as a technician.

The Findings

The findings of this study are presented under four major themes

1. **Disclosure of HIV status** – Disclosure is a linking theme in most of the narratives. Since there are striking gender difference in the patterns and process of disclosure, we present a gender-based comparison of our disclosure related data in this chapter. Data are presented under following subheadings
 - a. Learning about HIV positive status: First disclosure
 - b. Further diffusion of information
 - c. Disclosure to spouse
2. **Stigma** – In this chapter, the findings related to stigma are discussed under the following subheadings:
 - a. Fear of stigmatisation
 - b. Enacted stigma -actual experiences of stigmatisation at various levels such as natal family, in-laws etc.
 - c. Stigmatisation and discrimination in health facilities.
 - d. Consequences of fear and/or experiences of stigmatisation
 - e. Perceptions of PLWHA about stereotype of HIV positive individual in the community.
3. **Coping** – This chapter presents various coping strategies adopted by PLWHA while dealing with various stressors produced because of their HIV infection. The coping strategies are discussed under the following subheadings
 - a. Disengagement coping strategies
 - b. Engagement coping strategies
4. **Support systems** – In this chapter we discuss the support systems for PLWHA under two broad heading:
 - a. Relational support
 - b. Professional support

The composition of these systems and the kind of support they provide to PLWHA are also explored in this chapter.

*A disease named AIDS
Has neutralized our diversity
And compressed our differences
Into the single moment
Common to us all
The moment of disclosure.*

– Anonymous

1 Disclosure

The shock of learning about one's HIV positive sero-status persists for a long time and there is also the immediate worry about disclosing the status to the immediate family and other people in the social network. On the one hand it can help PLWHA in mobilizing their social network for obtaining support but at the same time it can be a means for experiencing stigma. Thus, knowledge about the patterns and process of disclosure becomes important while studying stigma and support systems.

Goffman in his book, "Notes of management of spoiled identity", succinctly summarized the stress of disclosure for a stigmatised person especially when the stigma is not apparently visible.

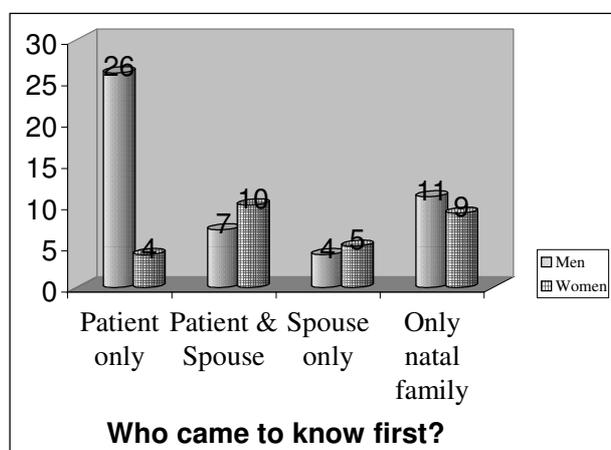
"When his 'different'ness is not immediately apparent, and is not known beforehand (or at least known by him to be known to the others), when in fact he is a discreditable, not a discredited, person, then the issue is not that of managing tension generated during social contacts but rather that of managing information about his failing. To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case to whom, how, when and where." (Goffman, 1963)

In this study we have tried to collect the information by asking questions about disclosure by whom, to whom, how and when. Data were collected in the form of graphs (see annexure 3), analysis of which revealed different patterns.

1.1 Learning about HIV Positive Status: First Disclosure

Before going in to the details of the information disseminated from one person to another, it will be pertinent to see to whom the HIV positive status of an individual was revealed first. In this sample of 79 people, a majority of men were diagnosed because they had approached health care providers for treatment of their symptoms and in the case of women many were tested because their husbands were tested positive. Some women were detected to be positive either during their antenatal check-ups (ANC), or because they were suffering from symptoms. So in a majority cases the health care provider was the person diagnosing and disclosing their HIV status.

As can be seen in the Graph 1, in case of men, the report was usually disclosed only to him (more than 50% of cases). There were incidents where the status was first disclosed to someone else from the natal



Graph 1: First disclosure
(Men n = 48 and Women n = 28 – we could not get the disclosure related data for two men and one women in the first interview and they did not come for the second interview.)

family or to his wife. (The details of process and content of disclosure by health care providers (HCP) are given in the chapter on stigma under the section on stigma and discrimination in health facilities).

The situation was exactly opposite in case of women. In a very few cases the report was disclosed only to her (4 cases of total 28). In several cases the report was not disclosed to her at all. Normally, the report was disclosed to her husband or someone else from her natal family and she came to know about it later. It is important to note the gender difference in this pattern particularly to understand the further dissemination of information about the HIV status of that individual.

1.2 Further Diffusion of Information

Before we look in to the data related to the patterns of disclosure, let us look at the gender differences in the timing and extent of disclosure of an individual's HIV status to significant others. There were striking gender difference observed in terms of when the status was disclosed and to how many people it was disclosed. For men, most of the disclosure occurred within one or two months after diagnosis, after which there were very few disclosures. Much of disclosure process was in his control. As we saw in graph 1, the man himself was the first person to whom the status was disclosed in 26 cases. On the other hand, for women in our sample the disclosure process was often out of her control. There were only 4 cases where she was the first person to learn about her HIV status. Inferentially,

only in these cases was there a possibility to effectively 'control' the further disclosure of her HIV status to others. In 24 of 28 cases her husband and others came to know about her HIV status before she did, or at the same moment that she did.

There were some important consequences of this imbalance in learning the initial information about HIV status:

- 1 There was seldom any issue about the women "disclosing" to her spouse, whereas among the men, disclosure to a wife was a major issue and that disclosure was often delayed for a considerable time.
- 2 Conversely, given that the husband was usually quick to know his wife's HIV status, it follows that in the cases of women, the husband played a major role in disclosing her status to others, particularly to her in-laws.
- 3 Inferentially, the HIV status of women was disclosed to more persons as compared to men

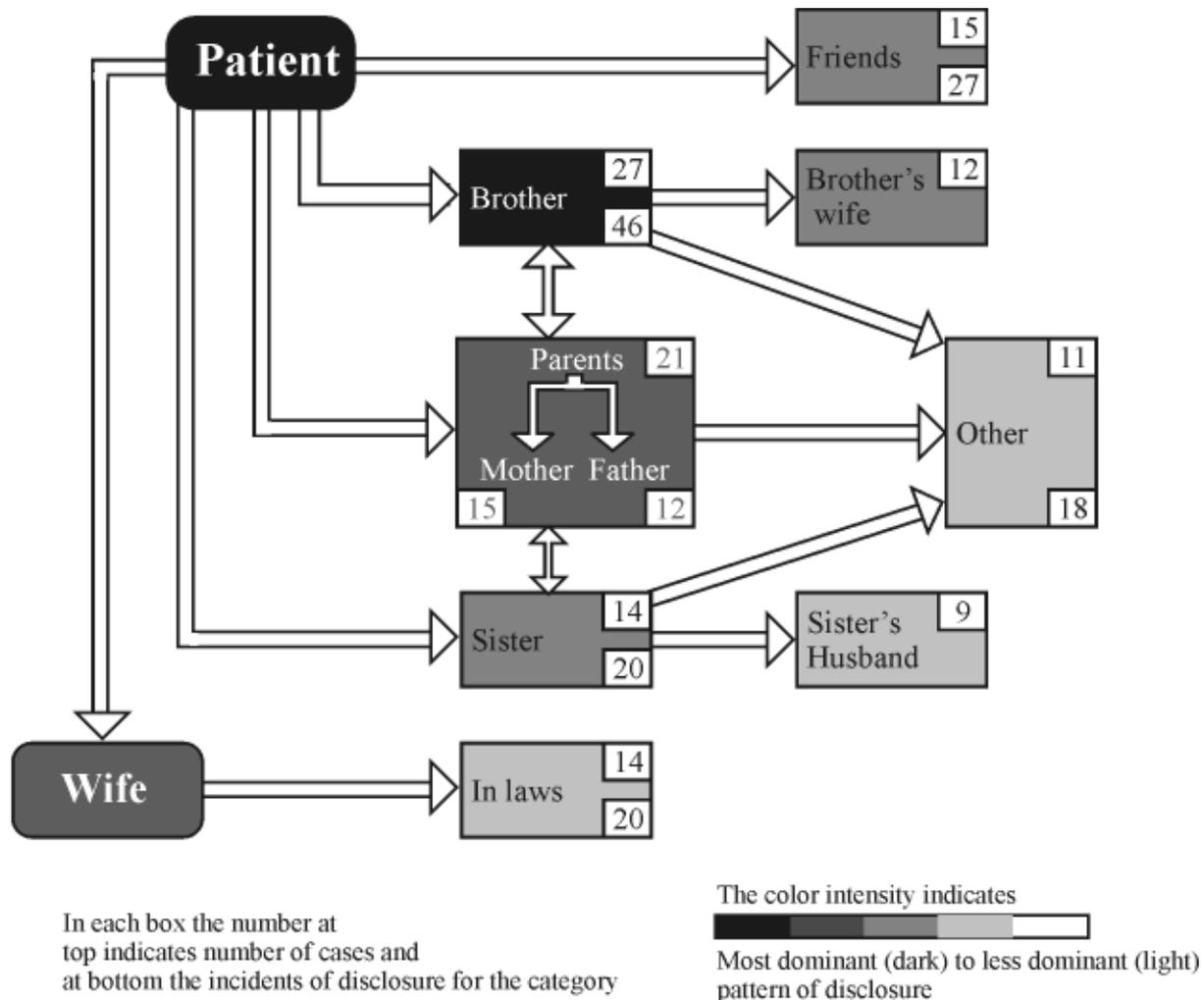
This gender imbalance in the disclosure of the HIV status of a person was important for influencing the further diffusion of information of his/her HIV status to others.

1.2a Patterns of disclosure in cases of HIV positive men

We had the disclosure related data from 48 men. Six of these 48 did not disclose their HIV status to anyone except their wives. These men belonged to medium to high socio-economic strata and were staying in nuclear families. Five of them were taking antiretroviral treatment and one was asymptomatic. All of them reached this clinic within one to two months after the diagnosis and were interviewed within six months after they came to the clinic.

In case of men, disclosure was mainly made by themselves and members of their natal family. Since most men were first to know about their own status, they had choice and control over their disclosure. However, there were a few cases where the family members further disseminated the information about the HIV status without the patient's knowledge and wish.

The Diagram 1 explains the pattern of disclosure of the HIV status of men in their social network. This diagram is a representation of the dominant pattern in the process of disclosure and does not consider the minor variations in individual cases.



Graph 2: Pattern of disclosure in cases of HIV positive men

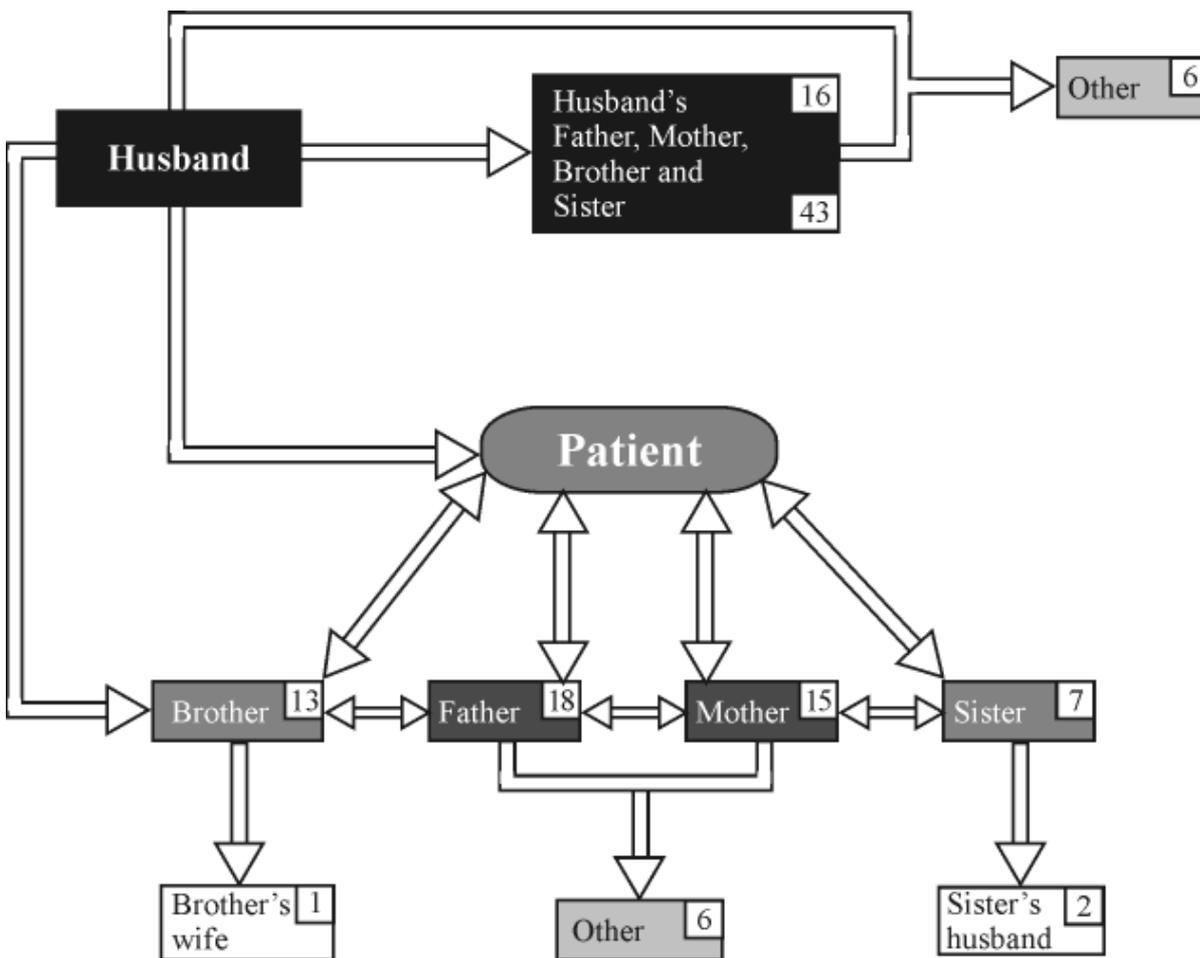
(Please note: The numbers given at the top of each box represent the number of cases in which the status was known to that person and the number at the bottom represent the number of individuals in that category.)

We have put brother as a separate category because many disclosed their status first to their brothers. The most common reason for this was the feeling that being of the same generation a brother would 'understand' and provide the patient with appropriate support and guidance. After this the information about his status was largely contained within the family. It was also seen that the brother, accordingly disseminated the information to his wife (patient's sister in-law in 12 cases) probably with the specific information of not disclosing the status any further. It seems that the women obeyed this instruction as there were hardly any disclosures made by them.

In the case of men, their wives played very little role in diffusing the information about their status. In a few cases, the wife had disclosed her husband's status to her parents. The information about a male patient's

HIV status was restricted to a very few people amongst his in-laws. By and large, in this sample, disclosure, in cases of men, was very controlled and limited to their close relatives. Many felt that one can disclose about "such things" (having HIV) only to family members. There were cases where there was no disclosure even to parents. The reasons given were not related to fear of stigmatisation but were due to concern about parent's age and health. Some felt that since their parents did not know much about HIV, they would not be able to understand it, but would only get scared.

In Diagram 2 we can see that some patients also disclosed their status to someone outside the close family- mainly to friends (in 15 cases). Having a strong relationship before the diagnosis of HIV was an important factor in disclosing the status to friends. It was also observed that in such cases, the friend was either a doctor or health care provider or someone able to help provide information related to the treatment of HIV infection. If the status was disclosed to friends, patients were quite confident that there would not be any discrimination from them.



In each box the number at top indicates number of cases and at bottom the incidents of disclosure for the category

The color intensity indicates Most dominant (dark) to less dominant (light) pattern of disclosure

Graph 3: Pattern of disclosure in cases of HIV positive women

There were 11 cases where the HIV status was disclosed to 'others'. The category of others included the extended family members such as uncles and aunts and such people as neighbours.

1.2b Patterns of disclosure in cases of HIV positive women

The pattern of disclosure in cases of HIV positive women was quite different from that of men. In the case of a woman, her husband and her natal family played a major role in disclosing her status. Graph 3 represents the pattern of disclosure in HIV positive women.

After a woman's diagnosis her husband disclosed her status to her in-laws (his parents). In the cases of 16 of the 28 women, her HIV status was disclosed to her in-laws. Of these 11 women were living in joint families. For women the disclosure was seldom restricted only to the in-laws but was extended to other relatives such as sisters-in-law and their husbands etc. Ultimately the total number of disclosures to in-laws were significantly higher for women as compared to men (43 disclosures for women and 14 disclosures for men) In the cases of women who got support from their husbands and in-laws, the disclosure to their natal family was comparatively less. Often the husband insisted on this secrecy and most women agreed to it for the sake of avoiding strain in the marital relationship.

In four cases, the husband and the in-laws disclosed the status to other people in their social network. In such cases, according to the patient, the motive behind such disclosure was to stigmatise and defame her.

As shown in the Graph, the natal family also disclosed a woman's status to many others, mainly her distant relatives. The reason for such disclosures was to seek some support in the form of information regarding treatment or to seek financial help.

"Since I was ill my sister thought that I should consult a doctor. There was a doctor who stays next to our house. He is my brother's friend. So my sister called that doctor to our house and told him everything (about my HIV). Then he referred us to this clinic" (32 F Widow)

It was observed that women were not involved in the process of disclosure either by their husbands or their natal family. So they had no choice or control over disclosure of their status. Many women came to know after a long time that their status was disclosed to someone else.

Reasons for disclosure

- Seeking support –emotional or financial
- Seeking guidance regarding treatment of the disease
- Help in future
 - For medical help in case of sickness
 - For taking care of their children in the event of death

"I had to tell my family. What if something happens to me? It is better if they know about it as they will be in a position to help me" (M 35 married)

1.3 Disclosure to Spouse

Disclosure of HIV status to the spouse was observed to be a major issue in the life of an HIV positive person. On one hand there was concern and anxiety about transmission of the infection. On the other hand telling about their HIV status to a spouse invariably raised questions about when and from whom the patient had acquired the infection. Since there were different factors influencing disclosure to the spouse for men and for women, we will look at the processes, content and patterns of disclosure to wife and to husband separately.

1.3a Disclosure to wife

How was the status disclosed to her?

Telling a wife about his HIV status was a harrowing process for the male patient. It was not just the disclosure of HIV status but also the disclosure of his 'immoral and unacceptable behaviour'. Before disclosing the status, there was fear and anxiety about her reactions.

"I still have not got the nerve to tell my wife. I fear telling her. I am certainly going to tell her sometime. I know, I have to... I mean I must tell her. Not just that, I have to get her test done after 2-3 months." (M 32 married)

Even in those few cases when the route of transmission was apparently not sexual, there was an anxiety in disclosing the status. Apart from the fear of her reaction, there was embarrassment about the disclosure.

Before disclosing the status to a wife there seemed to be a lot of thought about her probable reactions, planning when and how to talk and how to tackle the consequence. One man from our study did not disclose his status to his wife for 5 years. Finally he decided to tell her when he could not escape the insistence of the health care provider. In this case his wife was detected HIV positive during her pregnancy and the doctor gave the report to him. He was really

concerned about her health, and was monitoring her CD4/CD8 all through these five years and did not tell her while she was still asymptomatic.

"I am going to tell her (as if rehearsing the conversation) In the sixth month of the year 1997, I got to know your report. But the reason I didn't tell you was that I had the strength to walk with you through this. I had money for the treatment and medicines. Till now for the last five years I have seen to it that you get care even if you didn't know about it. And there is no reason to get scared. Within five years there will be some cure for this. And suppose it doesn't come out then we have the strength to continue taking medicines for 50 years." After telling her this, I plan to get her here (the clinic) for five minutes. After getting her here I will take the prescription... in the beginning she will be emotionally disturbed. I will spend a month or so with her just relaxing at some outstation. This will ease out all the tension. That is all that I have thought." (36 M married)

As we mentioned earlier, men reported a tremendous fear of some adverse reaction from their wives. Almost all felt better after disclosure.

"I have spent so many bad days before coming here (to this clinic). I used to just sit, all by myself. I had not told even my wife about it. Then the doctor suggested that I should frankly talk to my wife about it. When I finally told my wife, I didn't feel that I had committed a big crime or anything. She didn't react in an hysterical manner. On the contrary she discussed the matter with me with so much poise. I felt so good." (M 38 married, businessman)

What was being disclosed to her?

The issue of how the patient contracted the infection was one of the important factors associated with the disclosure to a spouse. In some cases, the patient confessed to his wife about his sexual relations with some other person as the probable mode of acquiring HIV. As expected, there seemed to be stress in the relationship after that. In many cases a husband did not tell how he acquired the infection. Either there was absolutely no communication on this topic because wives did not ask specifically about it or there was some story concocted to hide the man's sexual relations responsible for acquiring the infection. Husbands put the blame on other modes of acquiring the infection such as infected needles.

As told by one respondent who was planning to disclose his status to his wife –

*I – Are you scared that she might ask you how you got it?
R – No, I am not scared of that. I have cut a few articles from yesterday's newspaper. I will tell her to read the newspaper (which reported a case of a person who got the infection through needles). I want to make my life happy and prosperous, so I will have to do some manoeuvring. I will have to tell her that this disease can be acquired through*

infected needles and I acquired it through them." (36 M Married)

Other thing observed in the content of disclosure especially in the patients who disclosed their status after talking with the counsellor at the clinic was portrayal of the positive aspects of the disease. Many emphasized the availability of antiretroviral medicines and their role in improving health status. They also emphasized that it is useless to think about "how this happened and when this happened, now we must think about what to do next."

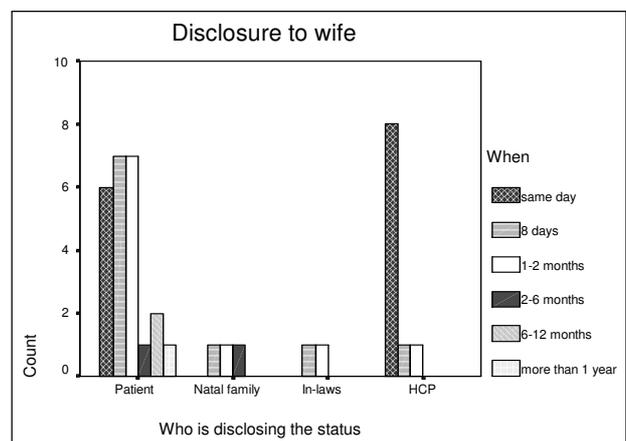
Who disclosed the status and when?

Graph 5 shown below is the cross-tabulation of data of persons who disclosed his status to wife with the apparent time taken to disclose the status after diagnosis. As can be seen in the graph, patient and health care providers played a major role in the disclosure. In the situation where both of them were tested together, or the husband was symptomatic and was hospitalised, health care providers were mainly responsible for disclosing the husband's status to the wife.

In all the cases where patient disclosed his status to his wife, there was unwillingness on his part to talk to her about it. The time taken for disclosing status varied in different cases. Most disclosures occurred within 1-2 months. Cases where the status was not disclosed for more than a year were relatively fewer. The main reason for disclosing the status to a wife was when the doctor and the counsellor expressed the need to get her tested for HIV.

The support from the physician and the counsellor played a very important role in encouraging men to disclose their status to their wives. This was quite evident from this narrative.

"I have told her now. But till the time doctor told me, I couldn't gather courage; I couldn't make up my mind. I didn't know much about the disease. I didn't know where



Graph 4: Disclosure to wife

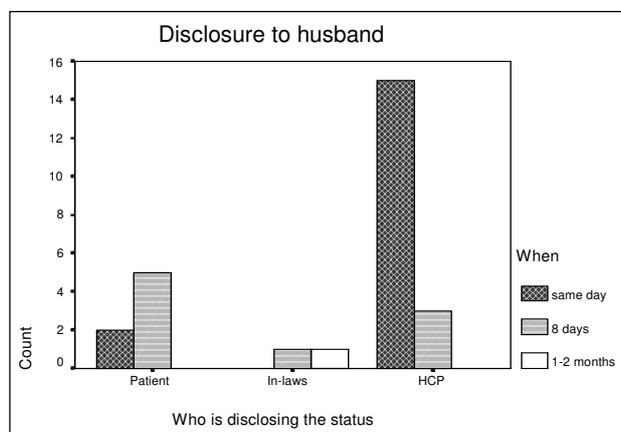
this disease would take me. My entire family would collapse because of this (after knowing about my status). When I went home from here (clinic) I told her about my status. I also told her that the doctor has assured that if I take medicines I will be all right.” (34 M married)

The important factors in encouraging these disclosures were the non-judgmental approach of the counsellor, provision of the right knowledge about the disease and the availability of antiretroviral treatment. This removed of the fear of death, giving these men the hope of improvement in health.

1.4b Disclosure to husband

In the case of a women, it is important to divide the cases according to whether she was tested positive before her husband or after he was diagnosed. It was observed that when she was tested because her husband was tested positive, he came to know about the report on the same day of the test either from the lab or from the health care provider. When women were detected positive during their antenatal checkups, then the status was disclosed within 8 days.

There was only one case where a woman had not disclosed her status to her husband because she was scared that after learning about her status he would throw her out of the house.



Graph 5: Disclosure to husband

In cases where she was diagnosed first, usually her husband accompanied her to the test, and her status was disclosed to both of them at the same time. In some cases, when she went to live with her natal family during her pregnancy and then got diagnosed, the disclosure of her status to the husband put her at a disadvantage. In a few cases, there was a considerable resistance from the husband for getting himself tested. Wives were blamed by their husbands for being the route of transmission and were generally not given any kind of support.

“Then after the report came positive, doctor asked to get my husband here. My husband did hesitate to get the test done. Means... We went to my husband’s place (after knowing my report) and told him “you are also asked to do the test.” He first said, “Why is my test required? What for? I don’t have money, you give me the money, and then I will see what to do!” I was after him continuously for 2-3 days. Then somehow he got his test done.” (W30 married)

To summarize, data related to disclosure showed that it was a multifaceted and multidimensional process. Patients found disclosing their status to another person was a difficult decision and the disclosure process was extremely anxiety provoking even when a positive outcome was expected. Disclosure was largely restricted to family members, mainly from the natal family, and the presence of an emotional bond and feelings of trust and confidence in the relationships were important factors influencing the disclosing of the HIV positive status to another person. Non-disclosure of status was predominantly seen at the workplace, and with people such as friends and neighbours.

The gender differences in the patterns, process and control over disclosure were quite striking. Women generally had less choice and control over disclosure of their status. The consequences of disclosure of a patient’s status were diverse. It helped them to cope with the stress and guilt of having the infection and facilitated the process of seeking support. On the other hand, there were experiences of stigmatisation and discrimination because of the disclosure. In these situations, there was a fear of subsequent disclosures, which generated tremendous anxiety and stress.

*Some say
Side effects
Are the scariest
My sadness is that stigma
That keeps you a stranger.*

– Anonymous

2 Stigma

The process of data collection and its analysis revealed certain important aspects of stigma, especially when we looked at this issue from the perspective of people living with HIV/AIDS. Another person's knowledge about a patient's HIV status was an important determinant in understanding the interactions of HIV positive people with them. Based on this fact, stigma could be seen to be in two categories.

1. **Fear of stigma** – the fear of how people would react if they came to know about the patient's HIV status.
2. **Enacted stigma** – the experiences of stigmatisation and discrimination from those who knew about the HIV status.

2.1 FEAR OF STIGMA

While narrating their fears, the common feeling shared by most of the respondents was that 'other people should not come to know about this' (i.e. "my HIV status"). These 'other' people could be their family members, relatives, friends, health care providers, co-workers or members of any other group. In this particular study the fear of stigmatisation and discrimination from family members, especially the natal family was not evident because in most cases the status was disclosed to the natal family. So the fear of stigmatisation was largely restricted to other distant relatives, friends, co-workers and so on.

The major fears expressed by PLWHA were

1) *Being the subject of Gossip* – From quite a few interviews this fear about breach of confidentiality and certain possibility of gossip was evident. Most of them felt this threat was from the distant relatives and friends.

"Such things (information about one's HIV status) spread very rapidly in society (Ashya gostincha propaganda hoto na)" (M 40 married)

One respondent also said that even if he discloses his status to his friends then they will not treat him differently but the news will spread from them to their wives and from there to everyone so it is better not to disclose it to anyone.

2) *Losing respect (ijjat) and esteem (maan)* – Both men and women mentioned about fear of losing respect in the community if others came to know about their status.

"If people come to know then they will say, "He has AIDS". When one person comes to know it doesn't take time for the news to spread. If this happens, one's image in society gets tarnished (samajat image kharab honar). So it is important not to disclose it to anybody." (M 42 married)

Some men also expressed their fear that even their family members would suffer from social disapproval. Potential stigmatisation of family members generated fears about the projected problems associated with children's schooling or arranging marriages for anyone in the family.

For women, this devaluation had a different meaning. For married women living with their husbands, devaluation was mainly in terms of being a wife of an HIV positive person. There was obvious concern about people labelling them as being of 'bad character' but this was more evident in women who were separated and widowed.

3) *Rejection* – Fear of rejection from family members, spouse, friends and in the workplace was expressed by many respondents. Six men in this sample did not disclose their HIV status to any other person mainly from the fear of stigmatisation. They believed that the behaviour of others might change if they disclose their HIV status. Fear of rejection from spouse and from in-laws was felt more by women while rejection by friends was the major concern for men. Many men expressed fear of rejection in the workplace. They were almost certain that they would be thrown out of their jobs if the employers knew about their status.

4) *Isolation* – Another major fear was that of isolation. Most respondents believed that society ostracizes (walit taktat, vegala thewataat- outcast them, isolate them) a person with HIV/AIDS. Many of them feared that if people came to know about their HIV status then they would avoid them, would not visit their house and would keep them away.

"If some one comes to know about this then he won't talk to me. I feel that I might be treated as an outcast. Nobody will come to my house". (M 25 unmarried)

Most men feared that their friends would isolate them and distance themselves.

Why do people keep a distance from HIV positive individual?

When we asked this question most of the respondents said that because there were a lot of misconceptions about the disease in the community, people avoid talking to or being with HIV positive people. Some of them also mentioned that people have this fear that if they are seen with HIV positive people, then other people will have doubts about their character.

“People are not so much aware as yet. They have a fear that they will also get it because of these people and if somebody stays with a person with this disease then people say even he seems to be involved (in some ‘immoral’ activities such as visiting sex workers). So, in order to maintain his social status, he tries to avoid being with HIV positive people.” (M 36 Married)

Note – further details of the respondents are not provided to protect their identity.

PLWHA who had actually experienced stigmatisation either from relatives or from health care providers expressed an increased fear of further stigmatisation. In cases where the status was haphazardly disclosed to many people, there was tremendous anxiety about further disclosure and consequent stigmatisation. In such cases they were quite convinced that people would not accept them.

“I feel that all these people are behaving nicely with me right now because they don’t know. But what if they come to know everything? Then they won’t come to my house. They will also cast aspersions on my character (charitrya). If someone knowledgeable and great (mothyani) like the doctor considered me worthless (Tuchchha) then are other people going to accept me?” (F 25 separated)

Thus the fear of potential stigmatisation was a major stress for all PLWHA and had affected their lives in many ways.

2.2 ENACTED STIGMA

The other aspect of stigma is stigmatisation and discrimination from people who knew about a person’s HIV positive status. Since we are looking at stigma from the perspective of PLWHA, we have considered those acts, which were perceived as stigmatising, irrespective of the intentions of the person who acted in any particular manner. The experiences of the PLWHA of stigmatisation can be analysed in the following groups.

- Natal family
- In-laws
- Other relatives and neighbours
- Co-workers and friends
- Spouse

Natal family

In this particular sample there were not many incidents of overt acts of discrimination from the natal family. Forty-four of 50 men and 23 of 29 women had disclosed their status to at least one member from their natal family. Only 6 men and none of the women reported discriminatory behaviours from the natal family. This finding supports our observation that generally the natal family supports HIV positive persons very well.

Some men mentioned that the initial reaction was anger from the family members because of the ‘immorality’ of their behaviours, which resulted in acquiring this infection. There was the feeling among family members that *this person had got the disease because of his own (bad) deeds so he should face the consequences*. This was communicated mainly non-verbally through various behaviour and gestures.

“I am the main person in the house, so in the past, whenever anything had to be done, my brothers would ask me (take my opinion). But now they decide it among themselves and do it. The conversation between us has reduced. I have lost all the respect. It is like being devalued (Awamulyana zalaya).” (M 35 married)

However after the initial reaction of anger and blame comes acceptance and support from the natal family. Only in the cases (3 cases in men) where there was already a disturbed relationship before the diagnosis of HIV, non-acceptance of the patient’s behaviour and holding him responsible for his disease persisted.

Discrimination from the natal family was apparently due to lack of knowledge about the disease and fear of contracting it through casual contacts.

“Recently I had gone to my brother’s place but I have always noticed that every time they serve me on the same plate. I never said anything about it to him. One of my other brothers never drinks tea from the same cup I use.” (M 54 divorced)

In these cases the family members had asked the person to take certain precautions like keeping their shaving kit or towel separate. Such experiences happened more often when the person had some obviously visible signs of the disease such as skin rash, diarrhoea or cough.

Respondents who lived in a joint family with children reported stigmatising behaviours from the family

members out of fear of transmitting the infection to the children. It seemed that people were less concerned about adults but were extremely worried about children acquiring the infection through casual contact. Stigmatisation was felt when children were asked to or were deliberately kept away from HIV positive persons.

"I play with the children. My family members don't show they have any objection to that but recently I have started feeling their discomfort." (M 35 married)

None of the women reported stigmatisation from their natal family. In the case of some women who were separated from the husband, family members had some concerns because of the financial burden of treatment but overall women received complete support from their natal family. In one case only, the patient's brother's wife left him when the respondent went to stay with her natal family. However her brother and mother continued to support her.

To summarize, the natal family is generally supportive; however there are experiences of discrimination caused mainly by the family's fear of acquiring the disease by casual contact.

In-laws

The stigmatising behaviours from the in-laws in case of men were quite different from that of women. As we mentioned in the chapter on disclosure only 10 men out of 50 disclosed their status to their in-laws and generally disclosure was restricted to the senior generation (their parents in-law). Very few men reported stigmatisation from in-laws. In the interviews with couples it was seen that there was anger and blame for spoiling a daughter's life. Generally it was expressed to their daughters but not to her husband, the patient. Nonverbally this anger was expressed in very subtle way.

"My in-laws know about my status but they don't say anything to me. But you can sense their anger (naraji lakshat yete)... means there is a difference between their earlier and present behaviour... Their visits have also decreased. (M 32 married)

Reactions from in-laws were more severe and overtly expressed towards women. In this sample the HIV status of 16 women out of 29 was known to their in-law family members. The following table is a summary of type of family where the women were living and disclosure to in-laws.

Type of family	Disclosure to in-laws
Women living in joint family = 16	13
Women living in nuclear family = 13	3

Of the 16 women who disclosed their status to in-laws 6 reported experiences of stigmatising behaviours from them.

When the women had some physical and visible signs of the disease, the reactions of the in-laws were more severe and harsh. This could result even in separation from the family.

"I had developed a rash on my skin so my in-laws asked my mother to take me back because they were embarrassed when people asked them what had happened to me. Now their son himself was so obviously ill. People must also be asking them about him but they would vent their emotions only on me."

A sick woman was seen as a burden to the family especially when she was symptomatic and needed treatment. Apparently the reactions were even more severe after the death of the husband. They were blamed for giving the infection to the husband, held responsible for his death and made to realize indirectly that they were a burden.

"My in-laws don't tell me to keep my things separately but they suggest these things indirectly. Like they have kept their cups and glasses separate. Ironically enough they don't mind me cooking, I mean why would they when they are getting someone to work free of cost. When my husband was alive, or even 5-6 months after his death, they always behaved nicely, I did not experience such things. But in the last 3-4 months they have been taunting me. Maybe they feel, "let this trouble not be there in our house" (nakoch hi byaad gharat). They must be feeling that I am a burden on them. I am not even dependent on them financially, but still... maybe they think that they might have to look after me later in my illness. Sometimes they even taunt me by saying that my husband got the infection from me (kunachi bimari kunala lagali)" (F 40 widow)

In one case her in-laws extended their blame even to her natal family

"Nothing seemed to cure my husband's illness. My father used to come to see my husband, used to suggest again and again that they should get his blood test done. But those people (in-laws) started doubting my father's intention. They told my husband that my father had done some black magic and caused this disease to him." (F 35 married)

Though the lives of both men and women with HIV infection become vulnerable to physical, emotional and social discrimination, there are striking gender differences in the context of their experiences. The existing gender discrimination in the social system, low social status, absence of power in family relationships, emotional and financial dependency contribute to a large extent towards a more adverse impact of HIV infection on women.

Other relatives/neighbours

In those few cases where the disclosure was uncontrolled and many people came to know about the status, the patients had some stigmatising experiences from other relatives and neighbours. Saying things that hurt, making the person ashamed, and insulting him were some of the ways in which these people behaved with PLWHA.

"One person asked me in front of the other people, 'Are the medicines working?' He indirectly started the topic of HIV in front of everybody." (M 56 divorced)

"People do change their behaviour. You come to know from the way they treat you, from their gestures, from their facial expressions...these things give you a clue and that's the reason I avoid socializing". (M 32 married)

Other people's stigmatising behaviour due to the perception that 'people with HIV die soon' seemed to come more from the distant relatives, neighbours and other people in the community rather than from the immediate family members or close friends.

"There are 2 or 3 places where I contribute to a 'chit fund'. For the past 10 years we have been doing it. Those people came to know from my friend about my HIV status. So in two days they came home and asked me for the money. They thought that this fellow wouldn't live for long, so they will lose all their money. At that time I didn't have money so, just in 2 hours I had to collect the money and give it to them. This has never happened before. I felt very bad." (35 M Married)*

(* chit-fund – this is a common practice among rural as well as urban people. A group is formed and the amount to be contributed by every member is decided based on their paying capacities. Every member contributes this amount generally every month. One member (randomly selected by a draw) of the group gets all the money collected for that month. This continues till everybody receives his share. The advantage of this system is that one gets lump sum amount to spend without paying any interest on it.)

For these PLWHA to perceive any act as stigmatising it was necessary for them to believe that the other person knew about their status. This was more important than whether the person really knew about it or not. Uncontrolled disclosure to many people had led them to perceive most acts as discriminatory. There was always a feeling that the person might have come to know about the status. Under such circumstances even a general enquiry about a person's health or certain acts were perceived as stigmatising.

"Just 2 months back I had gone for a housewarming party at my friend's place. Chairs and tables were arranged for people to have food. The moment I sat on one of the empty chairs in the middle, people sitting next to me got up and left. They must have come to know from somebody about

my disease. They left their plates untouched and got up. Then I also could not eat anything. I felt very bad. I felt even death was preferable to such a life." (M 35 married)

Friends and co-workers

In the present study, stigmatisation and discrimination from friends and co-workers/employers did not emerge as a major theme. The main reason was non-disclosure of HIV status especially at the workplace. In 15 cases men had disclosed their status to friends. The patients made most of these disclosures. When there was disclosure to friends, it was to those with whom they shared a close relationship and they got support. Only 3 men reported some experiences of discrimination from friends.

Following is a quote by a 36 years old businessman who disclosed his status to one of his friends. It suggests that the discrimination was mainly out of fear of acquiring the infection.

"For first few days he did behave in a peculiar manner with me. Before this whenever we smoked together we used to share a cigarette. But then he told me to smoke separate cigarette. He said that our friendship is good and that he intended that it should remain like that. He asked me to take all precaution from my side and he promised me that in return of that he would never tell anyone about it. I still go to his place. And I take precautions from my side, for example if I go to his place I won't drink water. Before this, they used to call me even to lunch or dinner. Today also I go (for lunch or dinner) but I go if it's absolutely unavoidable. These measures ensure that they are also safe and I am also safe. Even now we two (I and my friend) go to a restaurant for dinner but we both make sure that our glasses don't get interchanged. He keeps his to his side and I keep mine to my side."

In one case when a health care provider disclosed the status to friends, there were experiences of stigmatisation in the form of avoiding talking to the person, not visiting his house etc.

As we mentioned earlier, women did not disclose their status to friends so there were no experience of stigmatisation and discrimination.

Many respondents expressed a heightened fear of social isolation; devaluation and stigmatisation from co-workers and loss of job if they were to reveal their HIV status at the workplace. Some of them were more worried about losing respect and self-esteem at workplace than about losing their job.

In this sample there was one case of a man who was tested before taking up a job and was tested HIV positive. He was denied that job on the grounds that they do not employ HIV positive people.

It is important to note here that the very fact of non-disclosure at the workplace suggests the expected negative outcome after disclosure for many PLWHA. Therefore the workplace was in no way perceived as a support system by most PLWHA.

Spouse

It was a difficult task to explore stigmatisation in the marital relationship for several reasons. During the process of interviewing, we observed that respondents were not very willing to talk about their relationship with their spouse. They generally gave monosyllabic answers, denied any strain in their relations or made generalized statements such as 'in a disease like HIV it is very important to have support from your wife'.

Based on the available data we have tried to look at the issue under two headings.

- Stigma from husband
- Stigma from wife.

Stigma from the husband

By and large husbands had been supportive and caring. This might not have been entirely out of love but mainly out of feeling of guilt (the details of support from husband are given in the chapter on support systems). Yet there were examples of stigmatisation from the husband. Six women reported their experiences of stigmatisation from their husbands. This stigmatisation was mainly seen in the form of

- Blaming her for the disease
- Haphazard disclosure about her status to many people
- Defaming her
- Abusing her verbally and physically
- Harassing her for money
- Deserting her

"When we went to S hospital, the first thing he did was, he told the doctor in front of everybody there, that because of me he got infected. (Started crying)" (F 30 Separated)

The blame was expressed more when a wife's condition was detected prior to her husband's, when the non-sexual mode was not explicit and when she was symptomatic. In some cases husbands also blamed a wife's natal family and abused them.

Stigma from the wife

When we asked the question about their relationship with their wife almost everybody maintained that it was the same as it was before diagnosis of HIV. All of them said that the wife accepted the infection and was

very understanding. All men, irrespective of the HIV status of their wives reported this. Therefore, there were no reported incidents of stigmatisation from a wife. However, from the interviews with couples, our impression is that it was not so easy for women to accept their husband's infection. The anger and blame did get expressed but in a very subtle way. Women who were living with their husbands did not talk about this blame, as did the separated women or widows. The issues associated with testing their children or illness episode made the blame towards husband more explicit. The stigma from a wife was also reflected in the form of increased quarrels between husband and wife cantering around the issue of how the husband acquired the infection.

"Quite often I get angry on him while speaking. I tell him 'because of you I lost everything. He listens to it. I ask him from whom he got the disease and all. He keeps mum on that.'" (F 28 married)

It was also reflected in their sexual desires and behaviours. Women reported diminished interest in sex because of betrayal from their husbands

"I have lost all interest in life. I don't want that person, or those things (related to sex). I feel disgusted with sex. My life was so beautiful before, but because of this (sex) my life became so vile and bad, that I don't want anything of that sort." (F 30 married)

Understanding stigma in marital relationships is extremely difficult. Most often respondents are not comfortable talking about these issues. The expression of stigma in such a relationship seems to remain very subtle and intricately linked with the complexities of the whole relationship.

2.3 STIGMA AND DISCRIMINATION AT HEALTH FACILITIES

"The doctor told me that I had the horrifying disease (Mahabhayanak bimari). He told me that I would have to bear so many things now (bohoh sahena padega). He also said that I would have to prepare my self to listen to peoples' taunts (because you got the disease by your own mistake). He told me all these things in details. He was behaving with me in such a way as if I was guilty of some big crime." (35 M Married)

"It was my first experience... there was an assistant doctor in that hospital. She came to collect the blood. I will never ever forget in my entire life the way she looked at me... just one look..." (39 M married)

PLWHA had various stigmatising experiences in their interaction with health care providers (HCPs). These experiences happened when the HIV positive report was disclosed and when they were admitted to the hospitals for their illness.

Often HCPs just told the patient that there was something wrong with his/her blood and they needed to see another doctor.

An analysis of the content of disclosure of their status suggested that HCPs emphasized certain things while disclosing the report

1. 'You have a serious/ dreadful (Bhayanak) disease'
2. 'This report is your death sentence'
3. 'There are no medicines for this disease'
4. 'You are responsible for your infection'
5. 'There is no use of taking any treatment'
6. 'We don't treat such patients'
7. 'Anyway you don't have much life to live so you can start drinking alcohol and enjoy your life'

In a few cases improper and unethical disclosure from health care providers was also evident. The primary "dictum" about disclosure of a person's HIV positive status is that only the patient should be told of his or her condition and complete confidentiality about the patient's status should be maintained, except where the information is essential to protect the health of others. However, violation of these ethical standards and breach of rules of confidentiality are routinely observed in hospital and medical facilities in India.

As mentioned earlier in the chapter on disclosure (graph 1), in many cases the patient was not the first person told of his or her HIV status. This ethical violation and breach of confidentiality occurred much more frequently in the case of women, for whom it was often their spouse, or natal family who were told directly about the HIV infection. In addition health care providers in some cases divulged a person's HIV status to others without the patient's consent.

"When I was admitted in J hospital, one of my relatives was also admitted there. He knew Dr. X who was treating me. Dr. X told my relative about my HIV status and afterwards the news spread to all my relatives" (M 56 divorced)

When their family doctors diagnosed HIV there was much fear that other people would come to know about their status from the doctor. This certainly had an impact on their further treatment seeking because many avoided going to that doctor.

Experiences in the hospital

Patients who were symptomatic had experiences of hospitalisation for their illness. Some patients were rejected care in the hospital outright and some were referred to other health care facilities. There was one case of a pregnant woman who went to the hospital when she was about to deliver a baby. Because there was no time to do her HIV testing the doctor concerned conducted her delivery and later

discovered that she was HIV positive. The doctor was very angry when she learnt it. The doctor said that if she knew about the patient's HIV status before her delivery she would never have risked her life by treating her.

Government hospitals and some private hospitals did provide care to PLWHA but at these hospitals too PLWHA had experiences of stigmatisation and discrimination. Various hospital policies and the behaviour of doctors as well as the nursing staff were certainly discriminatory.

"In G hospital doctors don't allow any patient to come close to the table. They ask you from a distance about your problem. We have to tell them from distance. They observe your condition from a distance. They don't examine you. They don't even touch you. They see your reports, and give you medicines and call you back after 8 days, there's a separate ward for HIV positive patients." (M 33 Married)

The following were some of the experiences in the health care system.

- Putting labels such as 'HIV positive' or 'Bio-hazard' on the top of the file
- Keeping HIV positive patient in a separate ward
- Avoiding touching or giving injections
- Using gloves while measuring blood pressure, temperature etc.
- Warning other people to use gloves if dealing with the patient
- Gossiping about the patient
- Making faces, showing lack of interest in treating them
- Neglect (in the form of not attending them promptly)
- Asking the patients or relatives to change the soiled linen, or clean the soiled surfaces
- Destroying or burning things that were used by such patients
- Charging higher fees than to other patients

"I was in the male general ward. There the nurses used to avoid giving me injections. I used to realize that from their behaviour. They used to whisper among themselves, and tell others (other nurses) to wear gloves etc. There are 2-3 nurses who used to gossip continuously, make faces, didn't come to check me, used to neglect me." (M 34 Married)

The health care system, hospitals, clinics and health care providers are of central importance for PLWHA, who have to interact with them for the treatment of their symptoms. A majority of PLWHA interviewed first confronted their HIV status in the health care system. They talked about their first experience of stigmatisation and discrimination by health care providers (HCPs) at the point of their diagnosis (advising an HIV test and disclosing the report). Often patients (usually women patients) were not aware that

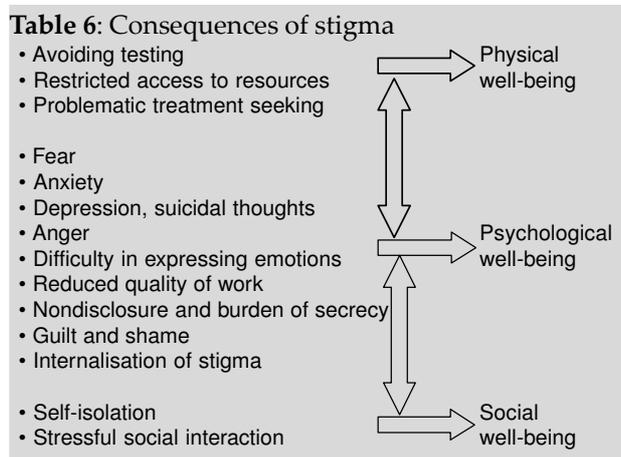
the doctor was testing them for HIV. Even when the patient was told about the test, it was generally only a mention that the test was needed. Almost always it was without any kind of pretest counseling.

PLWHA perceived the 'different-ness' with which health care providers looked at them while advising the test or while disclosing the positive report. The meaning of this "different look" for most PLWHA was 'you seem to be a good person then how can you have done such a thing?'

It seemed that the fear of contracting the disease is not the only reason for health care providers to discriminate against PLWHA. Their own value framework, notions about moral and immoral sexual behaviour also affect their attitudes towards PLWHA. Their judgmental attitude seems to be reflected in how they advise the test and whom they suspect of having HIV infection. There were incidents where HIV test was not advised in spite of patient having symptoms strongly associated with HIV disease.

"I had T.B. four years back. I took the treatment and recovered from it. Then a year after that I developed herpes zoster (Nagin). Because it was so severe, I consulted Dr. X. He is M.B.B.S. M.D. you know. But he did not advise me to do my HIV test. He must have wondered as to how I would get this disease" (M 21 Unmarried)

2.4 CONSEQUENCES OF FEAR AND/OR EXPERIENCES OF STIGMA



The consequences of the fear and/or experiences of stigmatisation are diverse and affect physical, psychological and social dimensions of health. It limits access to various support systems and resources such as asking reimbursement for medical bills or visiting a health care provider for treatment of minor illnesses. Some patients avoid visiting doctors, avoid testing and delay treatment seeking as long as possible, harming their health in the process. Some also try seeking treatment from charlatans in the hope of dealing with the situation before others know about it.

PLWHA reported various negative emotional reactions as an outcome of stigmatisation and discrimination. Fear, anxiety, anger, suicidal thoughts, guilt and shame were mentioned quite frequently by them in their narratives. Their fear of transmitting the infection by casual contact was difficult to remove because they had experienced that even health care providers avoided touching them. Anger was the emotion mainly expressed towards health care providers. One of the patients mentioned about his rage against the doctor who disclosed his status to his family members and his 90 year old grandmother.

"I missed the opportunity of warning Dr. X about it. I am still scared that he (Dr. X) would disclose it to my other relatives. I plan to warn him sometime in the future about not doing it. I am going to tell him that otherwise I might end up committing some criminal act." (M 40 married)

Their anger and frustration towards charlatans who had exploited them by promising a complete cure was also quite evident. Sometimes this rage was also expressed towards the government and policy makers for not doing anything against the existence of these unqualified doctors. Following is the quote of a man who has taken treatment from Mr. xxx, a charlatan who claims he can cure HIV infection. This patient used to travel a distance of around 1000 kms to take the medicines and used to spent around 8000 rupees a month on the treatment.

"Because of xxx (person who claims to have a complete cure for AIDS) so many people have lost their lives. Because of him the disease is spreading rapidly. After taking his medicines he tells everybody that you are negative. Then it is natural for a person to forget about it (HIV). And that is the reason for spreading the infection. Sometimes I feel like taking the gun and shooting this person" (M 37 widower)

To some extent the shame and stigma was internalised by a few PLWHA. There was a tendency among them towards self-blame. They felt guilty and inferior and tolerated judgmental attitudes of other people.

"I 'slipped' once, it was my fault, so there is no point in blaming other people. Even if people scorn at me, they are right. I have to pay for my mistake. If some one doesn't talk to me properly or ridicules me, I don't blame him, I don't even get angry. Its natural, what they are doing... so I have decided one thing... that I won't mix socially." (M 52 divorced)

2.5 WHAT DO OTHER PEOPLE THINK ABOUT HIV POSITIVE PEOPLE? PLWHA PERSPECTIVE

During the interviews the HIV positive persons frequently referred to their impressions of "what people in general think of PLWHA." While talking about their impressions they referred to items in the

newspapers, direct observations of how other PLWHA were treated in the community and also the casual conversations among their relatives and friends. In many cases they could directly observe and hear the negative attitudes of their friends, co-workers and others towards PLWHA.

In the perceptions of PLWHA, we saw two major dimensions of the stereotype of HIV positive individuals. One was attributed to sexual morality and the other was related to (mis) concepts about the disease. PLWHA believed that people thought that if a person had HIV he must have had sexual contacts with sex workers (SW). By sex worker they meant women from any designated red light area, which was thought to be a 'dirty place'. They also believed that such a person was considered as thoroughly irresponsible, the some one who did not understand his duties and had various bad habits such as drinking alcohol and smoking.

"People say 'what a useless person he is (kay phaltu manus ahe). He goes out (frequents sex workers) means he perhaps has other bad habits'." (M 37 married)

Some respondents mentioned that people thought that even the family members of HIV positive person were opinionated (as bad and irresponsible); this extended the devaluation to the family.

"When people come to know that some one is HIV positive they say that he is not from a good family, even his ancestors were like him (bad) (te bap jadyanpasun asech aahet)" (M 42 married)

The other important attribute perceived in an HIV positive person was high mortality; a feeling that such a person was going to die very soon. The signs and symptoms, such as suffering from repeated illnesses, losing weight, having long lasting coughs, looking weak and emaciated were believed as 'community markers' for HIV. Some respondents mentioned that people knew only about how the disease was transmitted – that is. through the sexual mode. They were not aware about how the disease was not transmitted. Thus people thought that they would acquire the infection even by casual contact.

"People feel 'If I sit with him then I will get it, so I will not be with him. I will not use his clothes, drink tea with him, eat with him or even go along with him'." (M 32 married)

Perceptions about AIDS

- AIDS as a scary disease – *Mahabhayanak*
- AIDS as a dirty disease – *Ghanerada* – affecting dirty people who have sex at dirty places
- AIDS as a punishment – *Shiksha* – for their bad deed (*pap*)
- AIDS as a curse – *Shrapa*

Words/phrases for having sex with sex worker

- | | |
|---------------------------------|---|
| • <i>Shen khane</i> | Eating cow dung (shit) |
| • <i>Nalayakpana</i> | Irresponsible behavior |
| • <i>Chuk</i> | M i s t a k e / w r o n g behavior |
| • <i>Baheer jane</i> | Go 'outside' (have sexual relations outside marriage) |
| • <i>Waiit kam</i> | Bad task |
| • <i>Phaltu kam</i> | Worthless task |
| • <i>Anaitik sambandha</i> | Immoral relations |
-

PLWHA had input from various sources to construct their views about what other people thought of an HIV positive person. They built these notions as a member of society and also as the member of the stigmatised group. From the data collected by us we could identify some of these sources.

1) Messages about HIV in the media – many respondents mentioned that the most common impression they got from various awareness campaigns was that AIDS was acquired through having sex with sex workers and there are no medicines for this disease.

Often these messages were fear-based and took a moralistic stand by designating such sexual behaviours as immoral (*anaitik*). This was responsible for people linking the disease to having sex with sex-worker rather than linking it to unsafe sex. This definitely had implications to their perceptions of being at risk.

Stereotyping and risk perception

In this study 17 of 50 men had acquired the disease from sexual contact with a woman who was not a so-called 'commercial sex worker'. After their diagnosis most of them were surprised at how they got the disease. Though they had unprotected high-risk sexual contacts they had never perceived themselves at risk of acquiring the disease.

"I had a bit of fun but I never went to any dirty places so I don't understand how I got this disease. So to be sure I did the test 3-4 times." (M 37 married)

Another way the media (mainly news papers) generated fear among people was by reporting the incidents of stigmatisation in the community.

“Recently there was a piece of news that one person was detected HIV positive and society isolated him (walit takala) ... There was also a piece of news that one doctor denied treatment to HIV positive person. These kind of news items increase the stigma.” (M 34 married)

Though it was the role of the media to provide factual and unbiased information to society, the information provided could have unfortunate consequences. Reporting such incidents led individuals to believe that there was no support system in the society for infected people.

2) Communication with friends and other relatives – What do people say about AIDS?

In this study not many had disclosed their status to their friends so their HIV status was not something to consider during their conversation with them. Some of the respondent mentioned that their friends did talk of HIV sometimes. Generally these talks were in the form of gossip about a person who they knew or believed to be HIV positive.

“Sometimes in our circle of friends these young boys bring up this topic (of HIV). They say it’s caused due to CSWs, this is a deadly disease and there is no cure... all such things are discussed (M 34 married)”

What these friends said among themselves about the disease seemed to generate strong fear about the possibility of rejection and negative judgment by society. Generally any incident of death or severe sickness of a person because of HIV generated this kind of talk among them. As compared to men, not many women reported that they engaged in HIV related talk before they were diagnosed to be positive.

3) Experiences of how PLWHA were treated in the community

Many respondents reported that they had not much experience of stigmatising behaviours from their family members and others but at the same time they mentioned that there were other people with HIV in the community who did not get support from their family. Though the feeling that they were getting support from their family had helped them, at the same time the experiences of how other positive people were treated had generated a fear of being stigmatised if their status became public knowledge. These experiences added to their own stress because they consolidated already prevalent notions.

A 35 year-old postgraduate working in a private company told us about how people in his office behaved and thought about two of his co-workers who were HIV positive. He had not disclosed his status at the office.

“I see these things happening in my office... I mean in my office people don’t know about my status but there are two people who are HIV positive. They have taken financial help from the company for their treatment and thus everybody came to know about their status. Even the doctors write ‘HIV positive’ on the discharge card they give you from the hospital. People in my office say bad things about them... They gossip... they stay away from them. People think that one who has this disease must have visited a CSW (Baher jaun ala asel)... They think that now this person is finished (ha sampala atta). His words have no value once people know that he has HIV. It is very disturbing... that’s why I don’t tell about my status to anyone.”

At this stage he was struggling hard to cope with his financial needs and the major burden was buying antiretroviral treatment. He could get the money he was spending on the treatment reimbursed from his company but he said that he was not going to disclose his status at any cost.

A 46-year old man, working as a technical assistant in a school told a story about how his friends who had AIDS were treated in the village.

“Many years ago, they used to keep the leprosy-affected people outside the village. I saw 2-3 patients in my village who had AIDS were treated in the same way. They passed away eventually. Just because they were neglected (by the family and community) they met such a fate. If they were given proper treatment and had been cared for like my family is caring for me then they wouldn’t have met this fate. This is an example from my village. I have seen it with my own eyes. One of them was my friend. He committed suicide. He felt very bad because of the harassment from his family members and the villagers so he spilt petrol and burned himself. If the family outcasts you, then the news (about status) leaks out. As a result the society outcasts you. One person (HIV positive) in my village had a cloth store, but no one bought anything from his shop. People used to say, “don’t buy clothes from him, he has AIDS.” This has to have an impact on your mind.”

In a majority of the cases where they reported their experiences of how HIV positive people were treated in the community, they always talked about incidents of severe illness or death. This could largely be because most of the individuals got diagnosed after they became symptomatic. This could also be because of the symptoms, prolonged ill health or death made it difficult to conceal the status of an individual.

“When such (HIV infected) person dies, people behave badly (Hidis – fidis kartat) when such person dies, people say,

“come on, don’t wash him, no need of wood, put him in electric cremator”. I have seen as well as heard these things happening outside (in the community).” (M 32 married)

Witnessing such incidents in the community generated strong fear that people with this disease die soon and other people would not accept such a person even after their death.

So based on the data the PLWHA’s perceptions of the image of HIV positive person in the community could be represented in the form of the following graphic.

To summarize, stigma is a complex phenomenon deeply intertwined with social values. The expression of stigma takes different forms at different levels. In the context of a close relationship such as natal family or in marital relationship the expressions often remain subtle. Whereas in the health care context they are often blatant. Such experiences often result into an exaggerated fear of stigmatization from the society In general. However such experiences are not always necessary to produce adverse impact on the lives of PLWHA, even the fear of potential stigmatization has many consequences affecting their physical, psychological and social well being. The fear of stigma generates not only from previous experiences but also from their beliefs about what other people think of the HIV positive person. They build these notions as a member of the society and also as the member of the stigmatized group.

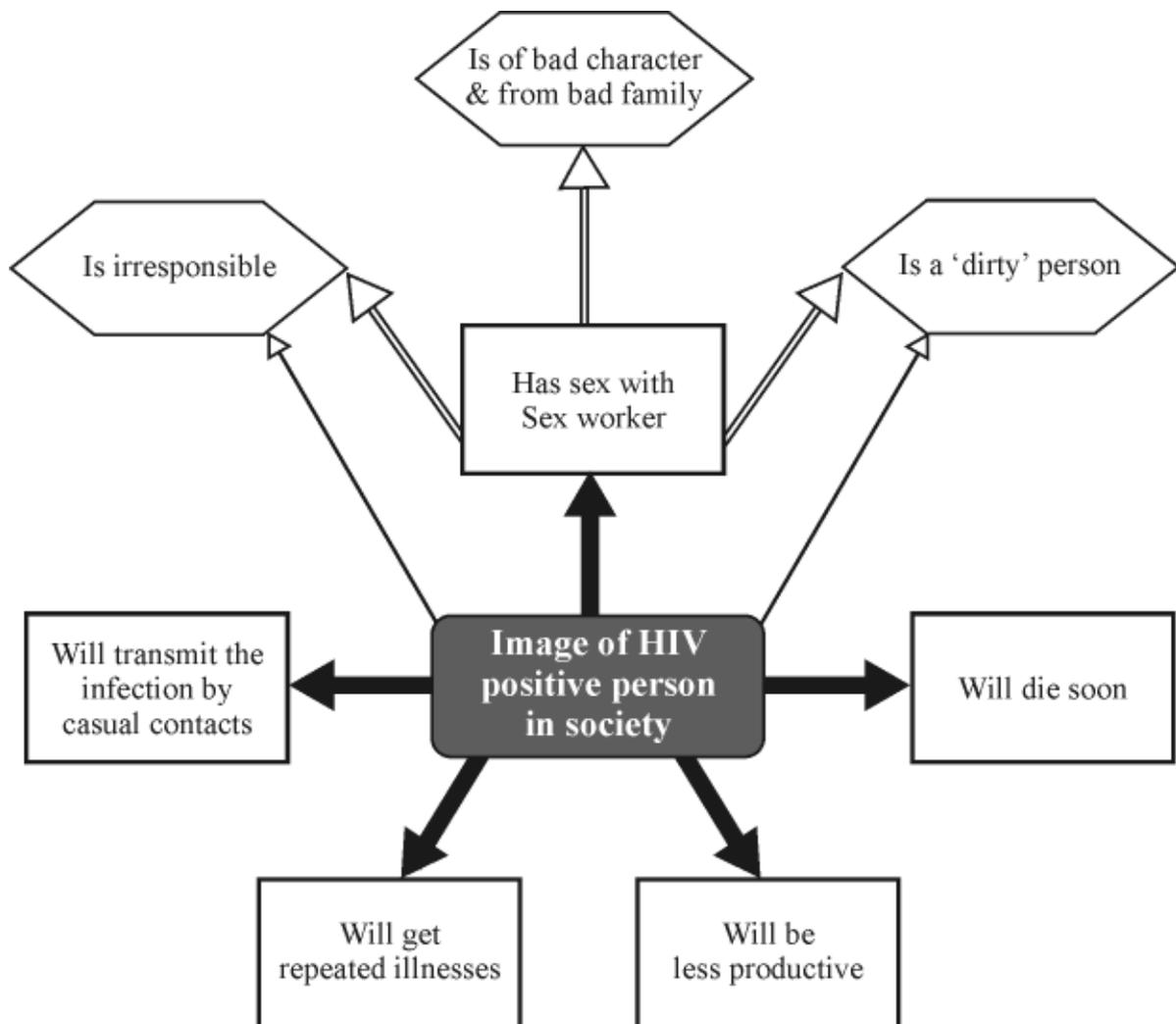


Fig. 3: Stereotype image of HIV positive person in the society: PLWHA perspective

We can help....

*To save yourself
From our brand of
Sickness, Syringes, Shots, and Stigma.*

But we are helpless...

*To protect you
From life's
Surprises, Sadness, Sorrow, and Struggle.*

So you see,

*Perhaps we are not
So different from one another
As you would like to believe*

Anonymous

3 Coping

The stress from HIV starts right from the point when the patient is advised to get the test done. There is anxiety and fear of the test results turning out to be positive for HIV. Confirmation about one's HIV infection brings numerous stressors. After diagnosis almost everybody expressed the feeling of restlessness and despair. 'Why me?' was the question, which produced tremendous stress for all PLWHA irrespective of the mode of acquiring the infection. Those who were infected through high-risk sexual behaviour felt this stress because they knew that not everybody who engages in such behaviour gets the disease. The same was true for those who acquired the infection through other modes such as blood transfusion. Along with this stress, there were several fears expressed by PLWHA after diagnosis. The dominant fears were

- Fear of stigma
- Fear of partner and children having the infection
- Fear of death
- Fear of facing spouse and relatives after disclosing the HIV status.

These fears were perceived as a major threat to which PLWHA reacted in many different ways. Some absconded from home for few days, others started drinking alcohol and completely isolated themselves from the outer world. Some denied that they had the infection at all and got themselves tested for HIV several times in different laboratories with the hope that the test result might turn out negative. These were the acute reactions to the stress and did not contribute to their coping with the disease. After some time (the duration was different for every individual depending on his/her personal and social resources) they voluntarily and consciously took efforts to alter the situation or to adapt to it. These efforts were their strategies to cope with different stressors.

In this chapter, we explain the different coping strategies adopted by PLWHA while coping with different stressors. We are conceptualising peoples coping strategies into two broad categories: "disengagement strategies" and "engagement strategies". As the label implies, "disengagement" generally refers to ways in which individuals try to avoid facing up to their personal crisis through denial, avoidance, and chasing after "magical solutions". In many cases these actions of "disengagement" were the first reactions of the patients, at the time when they faced maximum fear, realization of stigmatisation, as well as actual health problems. For most of the individuals in our sample "engagement

strategies" developed somewhat later, with the help of familial support, counseling and increased level of information. However, it is important to note that the stress responses are dynamic, multifaceted and interdependent. Positive or negative feedback from one response may alter the next response and a person may use multiple coping strategies simultaneously to cope with a stressful situation.

The following are some of the strategies adopted by PLWHA while coping with anticipated or actual stress.

3.1 DISENGAGEMENT COPING STRATEGIES

The diagnosis of HIV brought the stress of being perceived as 'different' and 'immoral'. There was a fear that others would come to know about their status and consequently the community would see them as worthless. There was tremendous fear of death. The reactions to cope with such stressors came in the form of denial and/or blaming someone else, seeking magical cures, avoiding people, and 'hiding'.

1) Denial and other Defensive Reactions

A) 'It is not my mistake' – putting the responsibility on another

Some men and women adopted this coping strategy where they blamed either the other person or the situation for their disease. Many men blamed their friends or parents. The disturbed relationship with parents was the reason given for their high-risk sexual behaviour.

"Eighty percent of people get HIV because they don't get good treatment from their parents. Because of such hurtful treatment from parents they take on drinking and go outside (visit sex workers)" (M 37 married)

Some also said that it was because of peer pressure they drank alcohol and under its influence they had sexual relations with sex worker.

Some women said that they would not suffer much from this disease, as they had not committed any 'mistake'. They got the disease because of their husband's mistake.

"I am sure god is watching all these things from up there. I have not done any wrong deed. I have been loyal to my husband, and why should my sons and I get punished for

that? Some day god will have pity on us. Some day there will be a medicine, which will completely cure this disease.” (F 26 married)

Most of the women could realistically put the blame on someone else, as they acquired the infection from their husbands. However, most women in the study especially those living with their husbands did not openly talk about the blame in the interviews. Widows and women who separated from their husbands did explicitly blame their husbands for their suffering. This could have its basis in the pattern of existing gender relations in Indian culture, where women generally do not openly criticize their husbands. This needs to be explored further and validated.

B) ‘I am not that kind of a person’ – separating themselves from the stereotyped image

The other form of coping strategy seen was patients separating themselves from the stereotyped category of HIV positive people.

“You know, sir (his expressions were as if he was feeling guilty)...s even my public image is not like a drunkard. This is only a mistake. I am not of that character. I am from a Maratha (warrior cast) family. It’s a good family. This is only a mistake. I had relations only for a time (temporary because of my work)(Kama nimitta)” (M 37 married)

The mode of acquiring the infection was a major factor in whether people adopted this coping strategy. Those who acquired the disease through sexual relations with women other than sex workers or those who got it through a non-sexual route used this as a coping strategy. Those who adopted this coping strategy repeatedly talked about the stress of having the disease without committing any ‘mistake’.

“Sometimes I get traumatized by the thought that I have never committed a mistake but still this has happened to me.” (M 37 married)

C) ‘I did what others do’- integrating themselves with the majority

Some people maintained that they got the disease because they did (engage in high risk sexual behaviour) what every body does. This was in a way an attempt to cope with people’s perception that HIV positive people are different. Thus in order to do so they justified their behaviours by saying that everybody does this and they had not done anything different.

“You tell me who is so clean (sajuk)? There is only one among hundred who has not done anything wrong. It’s my experience in the society that only 1% or maximum 5% people are there who don’t try out sex when they are young.. Some people go out (SW) or some people go somewhere else. I tell you that it’s same with me. So I don’t

feel anything about it. I mean the person may be an educated one or uneducated one...anyone.... this urge is natural. It has not stopped and will not stop.” (M 34 married)

2) Avoidance

It was seen in the form of avoiding -

- Meeting friends, relatives
- Communication on the topics related to HIV- It seemed that after the status was disclosed, communication with spouse or other family members was mainly restricted regarding the illness and treatment. Many deliberately avoided communication on the topic of HIV. Women said that they did not ask their husbands about how and when they got the disease to avoid straining the relationship.
- Reading books or watching programs related to HIV on TV in front of others.
- Visiting the family physician or any other doctor who is aware about the patient’s status.

3) Hiding

This was to avoid being identified as HIV positive. Patients hid the documents related to their HIV disease such as laboratory reports, hospital discharge cards, prescriptions from the doctor, and medicines. They especially concealed personal identification factors such as their name address, and occupation. The positive aspect of avoidance and hiding was that it minimized their stress at being identified as HIV positive. On the other hand the stigma and these coping strategies restricted the access of PLWHA to many resources.

4) Seeking “magical cures”

In this sample there were 5 PLWHA who ‘tried’ medicines that they believed would cure the HIV infection. Most patients mentioned that after their diagnosis they were in constant search for medicines that could cure this disease. They came to know about such “magical cures” mainly through newspaper advertisements which claim complete cure for the disease.

Following is the quote of one of the respondent who took treatment from a charlatan who claimed to give a complete cure. The patient took the treatment for six months but his health deteriorated and the laboratory report showed HIV infection even after six months of treatment. After that he was referred to this clinic.

“I was just on the look out for medicines for this disease. I used to go through the newspaper daily. That’s when I came

across the advertisement by a person from X place (who claimed to cure this disease). So I went there. All my tests were done and then I took the treatment for six months." (M 28 married)

Apart from the media, there were incidents where the respondent got the information about alternative treatment from their relatives, friends and even health care providers.

"Once I had asked my family physician, I didn't tell him that I have this disease... he told me about that medicine from Cochon. He said that you have to take that medicine for 1 to 2 yrs but it cures AIDS." (M 34 married)

Incurability, stigma and seeking treatment from unqualified doctors

Perceived seriousness of the disease, lack of knowledge about availability of ART and the stigma attached to this disease compelled many PLWHA to seek such treatment, which was supposed to cure their disease completely. Many respondents had travelled long distances and spent much money to take such treatment.

'Whether a practical technique or a fraud is involved, the quest (often a secret) that results provides a special indication of extremes to which the stigmatized is willing to go, and hence the painfulness of the situation that leads them to these extremes'.

(Goffman, 1968)

5) Wishful thinking

This was another coping strategy used by some respondents by which they believed that things would be all right in the near future. Their wish was mainly in the form of hope for complete future cure.

"They are showing on TV that research is going on in this field (medicines for HIV) sometime in the near future there might be a good medicine for this disease and I am sure that after taking that medicine I will be all right (cured) so I have settled down in the past 6-7 years." (M 40 married)

3.2 ENGAGEMENT COPING STRATEGIES

For most of the respondents more productive and apparently positive strategies – the engagement strategies - developed rather later. The care provided at the clinic by the counsellor and the physician played a major role in developing these strategies. Following are the engagement coping strategies adopted by PLWHA.

1) Seeking information and treatment

As we had already seen, most men in this study were diagnosed because of their illness. So the immediate concern was to seek information about the treatment available for the disease. At the time of diagnosis, all of them believed that there were no medicines for this disease, but they were able to find this clinic and get treatment because they actively sought information either from health care providers or from other sources.

"I was falling ill frequently so my sister, who is a nurse, thought that I should consult a doctor. There is Dr. K who stays next to our house. He is my brother's friend. So my sister called him at our place and told him everything (about my HIV status). He (Dr. K) referred us to this clinic." (F 32 widow)

For most of the respondents the major source for information was health care providers. There is one case of a businessman who immediately after his diagnosis disclosed his status to his 3 friends, all of them were doctors and he inquired about the treatment options for this disease. One of them suggested he visit this clinic. There is only one case of an educated woman who mentioned accessing the Internet to seek information about the disease.

Though health care providers were the important source of information for many PLWHA, it was observed that many of the HCPs could not provide correct information and referred the patients to charlatans.

The stigma attached to this disease was a major factor affecting the way they sought information and treatment. Out of fear of being identified they had to seek the information and treatment secretly or anonymously.

2) Selective disclosure and communication

In the earlier section we pointed out that PLWHA protected themselves from the feared stigmatisation and discrimination by keeping their HIV status a secret from most of their wider circle of relatives, friends, and people in the workplace. On the other hand, most individuals realized that they could only get social support if they disclosed their HIV status to those persons from whom they hoped for psychological and financial help.

Sharing the information about their HIV status with someone had helped relieve their burden. Being able to talk to that person whenever they felt the need was very comforting.

"After my husband's death my mother stayed with me for a month. My in-laws did not want me to tell my mother

about it (HIV). But I could not hold myself back. I told her everything. After I told her I felt that as if some burden was lifted from my chest" (F 38 widow)

The counsellor was a person who provided most of them the space for sharing their feelings and emotions.

"After coming here, Madam (counsellor) gave us a lot of emotional support. My innermost thoughts, my personal problem...I could discuss it only with madam. She really helped us a lot." (F 28 married)

3) Modified the way of looking at the problem- Cognitive restructuring

As mentioned earlier, diagnosis of HIV was a shocking incident in the lives of PLWHA. There was the constant stress of having a serious disease. Comparing this disease with any other chronic disease such as diabetes minimized the seriousness of the illness for them. For most of the individuals in our sample, the re-definition of HIV as something they could cope with happened only after some time, specifically after they had received counseling and began to receive effective treatment (including antiretroviral treatment)

"This disease is just like diabetes. One has to take medicines regularly and that's it." (M 40 married)

Many believed that there was no need to be scared of this disease. They could lead normal life if they took the medicines regularly. It is important to mention here that all respondents were tremendously scared of the disease when they reached the clinic. Only after talking to the counsellor and taking ART they could change their way of looking at the disease. This alteration in their attitude also helped them in coping with the fear of death.

"One who is born is bound to die one someday. People die of accidents or any other things." (M 34 married)

Case History

A 40 year-old man, a graduate and working in a company as a sales officer, is married with two daughters and lives in a joint family with his brother. He was having constant fever and weakness for which he consulted a doctor and took the treatment but it did not work. Then he was tested for HIV and was detected positive. After that he was referred to this clinic. He had to travelled a distance of more than 400 kms to reach the clinic.

Following quote explains his reactions when he came to know about his HIV status.

"When I came to know about my report I was shocked...I thought that everything is finished now...my aim..ambitions...there is nothing for me to live...at that time I thought lets not trouble anybody from my family...it is better to commit suicide (Aapan aapala swaah- aatmahattya karawi)"

After that he disclosed his status to his wife and to brother and his wife. They give him courage and brought him to the clinic. At the clinic he met the physician and the counsellor. After the first session of counseling his fear of death lessened as he came to know about antiretroviral treatment. A few counseling sessions were required to remove his fear that he could transmit the infection to others by casual contacts. He was symptomatic when he reached the clinic, and was put on ART.

Before he was interviewed for the study he had undergone six counseling session at one month intervals and there was improvement in his health condition.

"People are convinced that there is no treatment for AIDS. It is written everywhere (on the hoardings) that there is no treatment. Those people should be told that AIDS is like diabetes. There are medicines for treating this disease. Then there will not be much fear of it. I am taking the medicines now and I know that one day there will be cure for this disease. Earlier (in the past) we did not have medicines for malaria, TB and people used to die of these diseases but now we have treatment for them. Similarly one day we will have a cure for HIV."

4) Adopting activities for maintaining good health

After the initial shock of being diagnosed as HIV positive, PLWHA engaged themselves in activities to keep their health in good condition.

Following were some of the activities and behavioural patterns adopted by PLWHA to maintain their health.

- **Drinking boiled water-** most of the respondents mentioned that they always drink boiled water and carry a water bottle with them whenever out of the home. Even during the interview when we asked some of the respondents if they wanted water, they refused to have it saying that they drink only boiled water.

I - Want some water?

R - No... I don't drink water outside. I always drink boiled water. (M 35 married)

- **Having meals regularly preferably at home and eating nutritious food.**

"I have given up all addictions. I just have my regular meals; have milk and almonds in the mornings. I try to maintain my health." (M 30 married)

I - Do you do any thing to maintain your health?

R - Exercise... I consume one liter of milk daily and six bananas. I regularly do all these things...I started doing it after diagnosis. In this disease it's not that the patient would feel better only with the medicines. Even if you are taking medicines and if your weight reduces even by one kilo then you just lose hope every time you look at yourself. Then you can't prepare yourself mentally. After all we want to increase immunity. And exercise and proper diet is necessary for that. Medicines alone cannot help you. If you want to be alive, if you want to struggle, then all these things need to be done. (M 28 married, graduate)

- **Avoiding strenuous work**
- **Doing physical exercise**
- **Avoiding alcohol**

I - Do you take alcohol?

R - Earlier. I used to take it but since I have understood about the disease I have stopped. I take medicines and alcohol might affect it (reduce the efficacy of the medicines) so I have stopped.

- **Quitting unhealthy habits like smoking, tobacco chewing, etc.**

Providing counseling support and helping patients develop a positive attitude towards the disease was important in encouraging them towards activities to maintain their health.

5) Change in sexual behaviour

Condom use

In this particular sample 19 of 50 men and 22 of 29 women were concordant and 17 men and 5 women were discordant. Very few were completely abstaining from sex with the spouse. Majority of the couples, both concordant and discordant, were sexually active though most of them mentioned that the frequency of sexual acts had diminished after knowing about the disease.

Most of them were using condom. Only in two concordant cases husband reported inconsistency in using condoms. In one case he was a chronic alcoholic.

"R: At that time, doctor had told that if we wanted to have contact, then we should use condom.

I: Have you had contacts in past 4-5 years?

R: Yes.

I: Do you use condom?

R: No. I did not use it.

I: Is there any reason for not using it?

R: I did not remember to use it." (M 34 businessman)

His wife also said that when he was drunk he would force her for sexual relations and then there was no question of using condom at such time

"If I say no to it then he fights with me next day by bringing up some other issue. When he is drunk, there is no question of condoms at such times. He is not in his mind. All these are so difficult questions for me." (W 29 HW)

In the other case he mentioned that since both of them were HIV positive there was no need to use condom.

"Some times we do and some times we don't.

I: Why?

R: I don't feel the need to use condom. Now both of us are positive so what difference it is going to make. And she has undergone a family planning operation so there is no need to use condom." (M 40 Business man)

For those who used condom as a safe practice; most of them had no problem in either getting the condoms or using them or even disposing them off after the act. Only one respondent mentioned that he did not get complete satisfaction by using a condom.

In the discordant couples using condom, they were not worried about transmitting the infection to the spouse. They were quite confident about the condom use.

Abstinence

Concordant couples

In this particular sample 19 of 50 men and 22 of 29 women were concordant.

Very few were completely abstaining from sex with the spouse. Those who abstained gave the following reasons for abstinence:

- a) Diminished interest in sex for of various reasons
- b) Physical illness of the spouse
- c) To maintain good health

In some cases abstinence was seen as a coping strategy to maintain good health.

I: Did you have sexual relationships with your wife after you came to know about the disease?

R: Not at all. Doctor has told me that both of us are HIV positive so we can have sexual relations. We should just use condom. But my CD4 count is too low... so to avoid cross infection we didn't have the sexual relations at all. After my CD4 count becomes normal I will take the suggestion and then we will see. (M 34 Service)

Sometimes times, the decision was also based on myths and misconceptions in the minds of the men. Most of these were about virility and concepts of strength associated with semen. One would not bother about it when 'healthy' but when feeling sick the men wanted to preserve whatever strength they had, even by conserving their 'semen'.

"I had read somewhere that if you avoid physical relation it helps your health. I am trying this for the past 6 months and it's working.

I: Is it helping you?

R: Yes. When I used to have sex I used to get some troubles, but now for the past 6 months I have no such problems.

I: What problems did you use to get?

R: Whenever I used to have sex I used to get tired, used to feel lazy. I couldn't concentrate on anything." (M 34 teacher)

One man abstained from sex simply to follow the restrictions imposed by health care provider.

"For a year, I was told not to keep any contact when I was taking Ayurvedic medicine. He had told me to observe celibacy (Bramhachary) for 1 year.

I: Did you get upset (tras) because of abstinence?

R: In such situation, I decided for once, I wouldn't do, means I wouldn't. I have to have my will power strong." (M 40 Businessman)

There were six cases where wife was not tested for HIV and 3 of these cases were abstaining from sex. The major concern was the fear of transmitting the infection to the wife. They were not confident about the safety provide by condom.

"I find it risky. I feel that I have disease but no other person should get it from me. If we know about it, we should take care."

There was only one case where a woman had not disclosed her status to her husband and he was not tested. In this case also she was able to abstain from sex though it was very difficult for her. She has managed to just tell that she has 'some' illness.

Discordant couples

Out of 17 men only 4 abstained from sex, the prime concern being the fear of transmitting the infection to their spouse.

"I have stopped all those things. Next month it will be a year since I came to know about my status. I have stopped sex completely. I feel like doing it but then the thought that my wife is negative dawns upon me, I don't find it right to cause it to her. So I control this urge of mine." (M 28 farmer)

Apart from the fear of transmitting the infection to wife there was also concern that if she got the infection then it would not be possible to afford the anti-retroviral treatment for both of them

"If we had sex then she might contract it. Right now we are able to afford the treatment of a single person but if tomorrow she also gets positive, then we don't have so much property that we can afford her treatment also." (M 30 Service)

We did not raise the hypothetical issue, what if they had enough resources?

Out of 5 discordant women two reported to be abstaining.

Two women were detected during ANC and we could not asked about their sexual relationships. In both cases the sex was anyway stopped because of the pregnancy, the immediate concern was the fate of the child and the issue of concern about sex in the future remained too distant.

6) Planning for future of family members

Fear of death and concern about the future of family members who were dependent on them produced a lot of stress among PLWHA. This stress was most evident when they talked about the future of their children. Making financial arrangements for their children such as investing money in fixed deposit schemes and taking out insurance policies helped them cope with the stress of worrying what would happen to their children after their death. It also gave them the feeling of fulfilling their duty towards their family members.

However, in this sample many respondents could not make any kind of financial arrangement for their children because of limited resources. A major part of their earnings was spent on their treatment (ART). In these cases the stress of not being able to 'do anything' for their children, remained.

7) Emotional regulation

Not allowing oneself to get troubled by the situation was another coping strategy. After their diagnosis these patients decided not to get angry about any thing and to remain calm.

“There is no point in getting troubled (tras karun ghenyat). But I am concentrating on how to come out of it. I avoid anger and keep myself calm and quiet. (M 32 married)

“I have controlled myself a lot. I never express anger. Initially I used to have many fights but as soon as I came to know about this, I become cool and calm.” (M 27 unmarried)

Many also said that they controlled their emotions by engaging themselves in activities such as meditation, spiritual practices, reading or keeping themselves occupied in some work

“If I get any free time, the thoughts start in my mind. I keep myself occupied in something or the other so as to avoid thinking of it.” (F 26 married)

Some respondents said that comparing their situation with other people who were in worse situations helped them to cope with the burden of having the disease.

“When I am distressed I look at the people from lower strata of society. We are in a much better position than them. There are people who love us, who come running to help us.” (F 38 separated)

When the stress became unbearable and beyond control, expressing the emotion by crying seemed to be a relieving experience.

“Sometimes I feel like going to the terrace and cry my heart out and let me tell you, I have done that a number of times.” (M 37 married)

Role of Anti retroviral treatment (ART) in coping

In this study most of the respondents i.e. 44 men and 13 women were on ART. These medicines were being given to them because they were symptomatic. Improvement in health status because of ART was obvious to the patient. There was a reduction in symptoms, weight gain, improved appetite, sense of well being and improvement in the immunological parameters as seen in the lab reports. Experiencing improvement in the health status from a point where they were quite sure that they would not survive for long was the important factor in boosting their confidence. It was also seen that this improvement encouraged patients to adopt various activities to

maintain good health and to quit alcohol and smoking. It has also discouraged them from seeking treatment from quacks doctors. Improvement in their health condition enabled many to work more efficiently and meet the financial demands of their family. Reduction in the physical signs of the disease reduced their fear of people learning about their HIV status and fear of discrimination. Thus ART had helped not only in improving their health condition but also helped in reducing their fear of death and has helped in coping with fear of stigmatization.

Though ART played a major role in coping, it also produced certain stressors among PLWHA. The major concern was the large amount of money needed for medicines. Financial problems were the major reason for inadequate adherence to ART. Stigma further complicated the issue by restricting their access to the available resources and support systems.

To summarize, PLWHA have to cope with the different stressors produced by the biological, psychological and social effects of HIV infection. The perception of intensity of these stressors depends on the availability of personal and social resources. However stigma is an important factor, which affects their coping by increasing the stressors as well as reducing the availability of support. It is also an independent stressor with which they have to cope.

The various coping strategies adopted by PLWHA can be grouped into the categories of engagement and disengagement: coping strategies based on their efforts to engage with the stress or divert their attention away from it.

Table 7: Coping strategies

Engagement coping strategies	Disengagement coping strategies
<ul style="list-style-type: none"> • Treatment seeking • Adopting activities to maintain health • Change in sexual behaviour • Planning for the future • Cognitive restructuring • Selective communication • Emotional regulation 	<ul style="list-style-type: none"> • Denial/Defending oneself • Avoidance • Hiding • Seeking magical cures • Wishful thinking

It is important to note here that all the respondents were seeking counseling support at the clinic. The support from the counsellor and the physician was important for them to accept the situation and adopt certain coping strategies. Though most of the respondents had a certain level of acceptance of the

disease and the situation, there were obvious gender differences in the facts that they had to accept. For most men it was the acceptance of their responsibility in acquiring the infection and transmitting it to a spouse. Whereas for most women it was the acceptance of a husband's unfaithfulness. It seemed that accepting the situation was more stressful when the infection was believed to be caused by the 'mistake' of some other person or situation. These patients also seemed to adopt more disengagement coping strategies such as wishful thinking or

avoidance. In cases where there was complete acceptance of the situation, engagement coping strategies such as information seeking, efforts to maintain health and a positive attitude towards the disease were dominantly observed. Previous research on coping suggests that the adaptability of disengagement coping strategies is generally not good. However, further examination is needed to understand these coping strategies in order to help PLWHA to cope with HIV infection.

*Wipe the tears of
One of us
And you would have touched
The tears of thousands*

Anonymous

4 Support Systems

Support provided by different people play an important role in the severely stressed life of a HIV positive person, influencing his/her coping with the disease. Though we named this chapter 'Support Systems', which we intended to explore when we conceptualised the study, the chapter explains the different sources of social support PLWHA in this sample received. It is debatable if we should label them as 'systems' as they are fragmented, often unconnected sources of support.

We shall see these sources of support for HIV positive persons under two broad categories

- 1) Relational source of support – Family members and other relatives
- 2) Professional source of support – Medical care and counseling
- 3) Other sources of support – Institutional, legal etc

4.1 RELATIONAL SOURCE OF SUPPORT

People who were related through either blood or through social ties- were a major source of support for many people living with HIV/AIDS. Natal family, in-laws, other relatives, and friends were the sources for this support.

The diagram below shows different people from their social network perceived as supportive by HIV

positive men and women. Analysis of qualitative data was the main source for deducing the information related to the perceived importance of relations as a source of support. We analysed the reactions of different people in the social network after the HIV status was disclosed to them and the emotional and tangible support provided by them. Since we looked at the data from a PLWHA perspective we gave more importance to their perceptions in analysing our data. We also used the disclosure data for plotting the importance of these categories. This was particularly helpful in the case of male patients as most of the disclosure was under their control. In women the disclosure data was less significantly helpful as the disclosure was 'uncontrolled' in most cases and she hardly had choice of the person to whom the status was disclosed.

In Figure 4 the person represented in the close circle was perceived as more supportive than the person shown in the distant circle. The categories of the relations mentioned in one circle were more or less perceived as equally important sources of support. The gender differences were quite evident in the support network of men and women.

Support from spouse is discussed separately because of its complexities as well as its importance in coping.

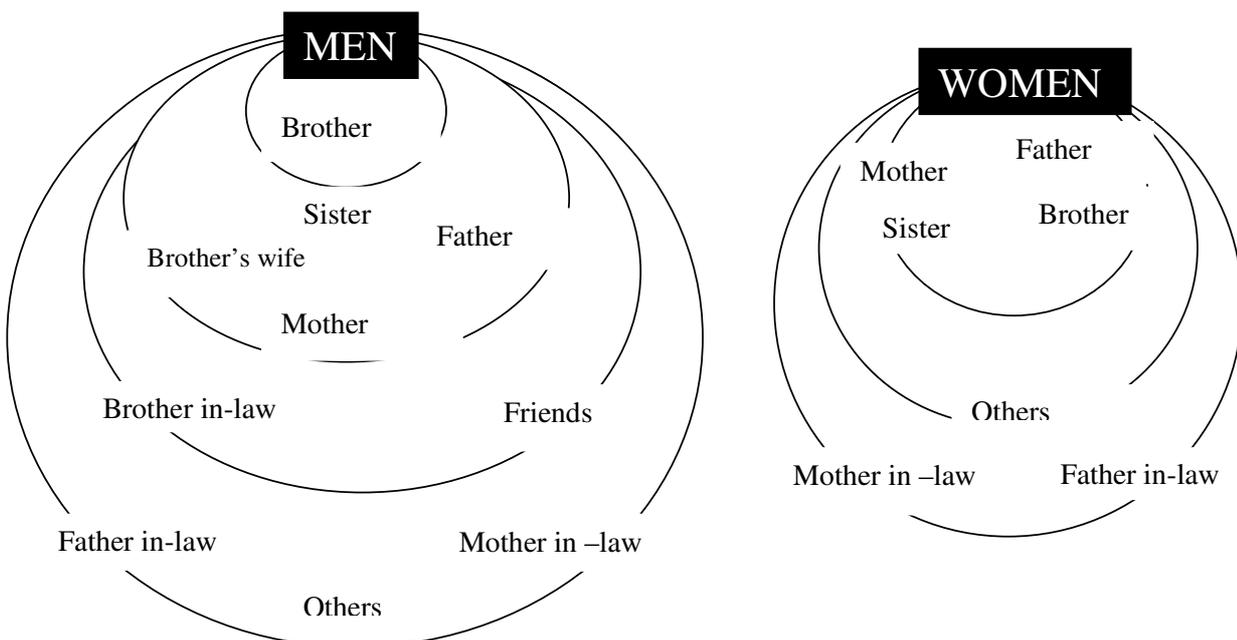


Fig. 4: Network of support: The gender differences

As can be seen in both the diagrams, the natal family was playing a major role in providing support for PLWHA. Men perceived their brothers as most supportive whereas for women, their parent's support was the most important. In the above diagram, in the case of women, we have shown some gap between natal family and in-laws. This was to indicate that very few women got support from both natal family and in-laws at the same time.

When we looked at different people who provided support, it appeared that the density of the support network (number of people actually providing emotional and/or tangible support) was more for men than for women. For men, generally, people from their natal family and in-laws, when they knew their health status, were supportive. For women it was seen that when they were getting support from their in-laws and husband, they did not disclose their status to their natal family. In such cases seeking support from their natal family was restricted. For women who were separated from their husbands and for widows, their natal family were the only support. In such situation, many people, sometimes distant relatives, knew a woman's status but only her natal family provided emotional and tangible support. So, at any given point, there were fewer people providing support to a woman as compared to a man. Thus, by and large, the density of the support network was less for women. This had an impact on their coping with the disease. Women who did not disclose their status to their natal family were getting support from their husband and in-laws, but they did express their desire to share their feelings and stress with someone from their natal family. So emotional expression as a coping strategy was limited in such cases.

Another category missing in the support network of women was friends. In some cases male patients had friends who provided much emotional and other support whereas none of the women perceived their friends as actual or potential sources of support.

4.1a Nature of support from the relational network

A) Support in seeking treatment – after disclosing the status to family members, these relatives were actively involved in seeking information regarding the treatment of this disease.

“One of my brothers works in a sugar factory at xxx. In xxx there is a madam (social worker), he talked to her. He also took me to xxx to meet her. She said that I should consult Dr. X for treatment. So she gave me the address (of this clinic). Then immediately the same night I caught the bus and next day with my brother I came here to see Dr X.” (M 40 married)

B) Financial support – many respondents who were taking ART had to take financial support from their

family at least for some period. Brother and father mainly provided this financial support.

“Without my brother's support I wouldn't have lived this long. To get this much money, is very difficult for one person” (M 35 Married)

After starting ART their health improved and they could go back to their work and start earning. This was a major encouragement for them as it reduced the burden of being dependent on their family members. Separated women and widows who were staying with their natal family were completely dependent on them for their treatment and for their living expenses. Though they were getting support from their family, for them the stress of being a burden on their natal family was difficult to bear. Additionally, they also had to cope with the stigma of living with their natal family after marriage. (Should we explain this for foreign readers?)

C) Emotional support – Different relations provided emotional support whenever required. Men mostly got this support from their brothers, sisters, friends and in a few cases from their brother's wife (*Vahini*). Most men mentioned that they could not share their feelings with their fathers. Women got emotional support from their mothers, fathers, and siblings and in a very few cases from their mothers in-law. It seemed that men generally avoided seeking emotional support from their family mainly because of their guilt at acquiring the infection. The commonest feeling shared by most of them was *'how can I talk about it when it was my mistake'* (*Apalich chuk asatana apan kase kaya bolnar*).

Negative orientation towards relational support

A few men in this study mentioned that no one from their family is supportive. They themselves were their own supports. Though they were getting financial support from their natal family, they did not perceive it as supportive. In all these cases they did not have good relations with their family members before their diagnosis. Coping with stress was difficult in such a situation because there was a constant feeling of loneliness.

4.1b Support from spouse

A) Support from wife – Acquiring the HIV infection produced tremendous guilt in men. Therefore disclosing the status to a wife was a major concern. Accepting the infection and providing support was important to overcome this guilt.

“The most important thing is that your partner should understand. My wife empathized with me. I got good

support from her. Otherwise it would have been difficult if she had nagged continuously about how I contracted it (HIV). But she didn't do that. She was understanding." (28 M Married)

Accepting the disease and not asking questions about how a husband acquired the disease was perceived as most supportive. Other supportive behaviours were in the form of taking more care, providing emotional support, avoiding discussion on topics which would generate stress, etc. Most men said that since the diagnosis of HIV, they have a more loving relationship with their spouse.

During the interview, all men said that their wives understood them and provided support. They also maintained that there is not much of a strain in their relationship after the diagnosis of HIV. However, from the interviews with couples and from the counsellor's notes, it seemed that there was under-reporting of strain in their relationship with their wives. The expression of guilt, blame, and anger largely remained subtle. Though in this study we could not explore these aspects in detail, we can definitely say that suppression of these emotions must be affecting their coping in many ways. Sometimes they did not report the strain in their relationship with their spouse even during counseling sessions. This posed a hindrance in providing counseling support to them.

B) Support from husband – We could see a spectrum in the reactions of husbands after diagnosis of their HIV status. On one hand they blamed their wives and stigmatised them. On the other hand they provided them with care and support. In this sample of 29 women, 19 were living with their husbands. The important factors influencing supportive behaviours towards their wives were:

- The nature of the relationship before diagnosis of HIV- when they had already a disturbed relation before diagnosis of HIV, husband was generally not supportive.
- When a wife had acquired the infection through an explicitly non-sexual mode such as blood transfusion, occupational exposure or from her first husband.
- When he accepted that he was responsible for transmitting the infection to his wife- the support was out of guilt

Of these 19 women living with their husbands, one did not disclose her status to her husband, 10 women explicitly mentioned that their husbands were a major source of support for them. Five did say that their husbands were supportive but did not openly talk about it. From the way they spoke (or avoided speaking) it appeared that the husbands were probably not very supportive, whereas 3 women said definitely that they did not have any support from their husbands.

Many women said that their husbands became caring and understanding after the diagnosis of their HIV status. They felt better because the husband was paying them attention. The analysis of data from the interviews with couples (both husband and wife) suggests that the supportive behaviours from husbands may not be completely out of love but may be because of the guilt of transmitting the infection to their spouse. Since many male patients avoided talking about their relationship with their spouse, this interpretation is largely based on the interviewers observations during the process of interviews. However there were quotations in a few cases, which supports this observation. Following is a quote of a 32 years old man. His wife was tested positive for HIV during her routine antenatal check-up. In her interview she mentioned that she is getting support from him whereas he mentioned the guilt of transmitting the infection to her.

I - What did you feel when you saw the report?

R - It was my fault only... because of me she had to bear lot of pain... trouble of visiting the hospital... she couldn't sleep at night.

The guilt was also seen among women who were infected first either from their first husband or through blood transfusion or occupational exposure. In such cases acceptance by their husbands was of utmost importance for them. The fact that their husbands did not blame them for having the disease and cared for them helped them greatly in coping with the situation.

"When I came to know my report I thought, whether he (my husband) would take me close... but he didn't give me any trouble. Didn't even say any harsh words. He didn't tell anybody about my status. He gave me a lot of support (Sath) (Khup sambhalun ghetale) (23 F married)

There was only one case when a woman got the infection through her sexual relationship with a friend before marriage and was getting complete support from her husband. His support was of utmost importance to her.

4.2 PROFESSIONAL SOURCE OF SUPPORT – Medical care and counseling

The source of professional support for PLWHA are people and/or organizations with special skills to provide guidance regarding medical care and counseling.. In this study, PLWHA mainly sought professional support from health care providers (HCP) from the private sector. As mentioned earlier in connection with 'stigma in health care facilities' most of the persons in our sample had had negative experiences of stigmatisation and discrimination, unethical breaches of confidentiality and other problems with health care providers. Very few

respondents mentioned getting good support and guidance from the doctor who diagnosed their status. The major pattern of referring the patient to this clinic was without prior counseling. Sometimes the patients were referred without informing them about their HIV status. (The details of their experiences of stigmatisation from HCPs are given in the chapter on 'Stigma'). The few cases where the doctor was non-judgmental, did not behave differently to them and maintained confidentiality about their status were perceived as most supportive. The other support drawn from these doctors was in the form of giving advice regarding the treatment for this disease. Following is a quote of a 43-year-old man.

I - Who referred you to this clinic?

R - Our family doctor (FP). He is a BHMS doctor. He asked me go to this clinic.

I - How did you family doctor come to know about your HIV status?

R - My wife was feeling very weak after she had undergone an abortion (medical termination of pregnancy), and for that she had to take saline infusion twice or thrice. So while giving the medical history (about her illness) I told my family doctor about our HIV status. He told me that her illness was probably because of HIV. So he suggested that I better take her to this clinic.

I - Do you visit your family doctor even now.

R - Yes.

I - Do you find any change in his behaviour after you disclosed your status to him?

R - No... in fact he helps me... he always tries to get me the medicines for less price (M 45 Married)

Thus support from health care providers before reaching this clinic has usually influenced their treatment seeking behaviour.

The structural difference in the care and support provided at this clinic as compared to other private health care facilities is the provision of counseling services to PLWHA and their family members. As mentioned earlier, all the respondents were making use of the counseling services at this clinic. The role of support from the counsellor in their coping with the disease was clearly seen in their narratives.

"I had lots of problems before I came here (to this clinic). Madam (counsellor) gave me a lot of emotional support. I could discuss all my problems and share everything with her. She does such nice counseling... she really teaches one how to live." (F 28 married)

It was also observed that as well as emotional support, providing knowledge about the disease and about the availability of anti-retroviral medicines, which could improve their health, was important for giving the patients the courage to think about the disease in a more positive way.

"Initially I was very scared about transmitting the infection to my son. I did not allow him to come close to me. But after I talked to madam my fear reduced. Now there is nothing like that... I take my son close and play with him" (M 30 married)

"When I came to know about my status I felt like committing suicide... but after I came here, the doctor gave me a lot of support (adhar). He told me that though there were no medicines, which can cure this disease, there were some medicines, which can control the disease... I thought, anyway I was going to die so I had decided that I would end my life. (p)... and because of it (ART) I feel that I got a new life." (M 35 married)

Counseling the family members was also an important aspect of formal support. It helped family members to accept the person and did away with their fear of contracting the infection through causal contacts. Acceptance from the family and non-discriminatory behaviour from them was a major support for PLWHA.

"My family members don't have any fear or anything. Madam had explained to them everything (about the disease) so they don't feel anything like that (they are not afraid of contracting the infection)" (M 42 married)

Many people completely rely on this clinic for their treatment. They are unwilling to see any other doctor even for a minor illness. This is mainly because of their actual experiences and/or potential fear of stigmatisation from other health care providers.

I - Have you ever taken treatment from any other doctor?

R - No. I have never taken any treatment from any other doctor. If we (he and his wife) have any problem (any symptoms) then we consult the doctor at this clinic. One night I had pain in my stomach so I phoned the doctor at 1-30 at night to ask him the medicine. (M 26 married symptomatic and taking ART)

The following is the table of perceived support from the physician and the counsellor and its role in influencing different coping strategies.

Table 8: Role of professional support in coping

Supportive behaviours	Coping process
<ul style="list-style-type: none"> • Non-judgmental and sympathetic attitude • Providing knowledge about the disease • Educating family members • Help in disclosing the HIV status • Providing space to express feelings and emotions • Explaining the positive side of the situation 	<ul style="list-style-type: none"> • Accepting the disease • Positive attitude/adopting activities to maintain health • Change in the way of looking at the disease • Alleviated fear of transmitting the disease to other • Alleviated fear of death • Able to express their emotions • Able to regulate their emotions

It is quite clear that professional support has a wide-ranging impact on the coping process of PLWHA. Proper support from the physician and the counsellor not only helps them to cope with the disease but also helps them to accept being HIV positive without great emotional stress..

4.3 OTHER SOURCES OF SUPPORT

There could be sources of financial and other support from some institutions, in their workplace, insurance companies or the legal system. However, because of fear of stigmatisation, the people in our sample have

not sought help from such sources. Especially any help or support from facilities in the workplaces was avoided for the fear that it would lead to disclosure and loss of their employment. Following is a quote from a person who works in a pharmaceutical company (one of the manufacturers of antiretroviral drugs). He could get the reimbursement for the money he is spending on his treatment, but he has not disclosed his status at his workplace

I - What would happen if you disclose you HIV status in your company?

R - (Immediately said) if its known in the company, then I'll lose my job.

I- But legally, they cannot do it, isn't it ?

R - No, they cannot, but they can show... some thing like – medically unfit etc... there is no guarantee in a private. company. Nowadays the rules for workers are such that worker is late by 5 min, then they can suspend him.

To summarize, the support PLWHA got from the counsellor and the physician and from their relational network was the important factor enabling their coping with the disease. The natal family was a major source of support for both men and women. However, there were gender differences in the density of their support network. By and large, stigma affected their access to formal support systems and thus posed difficulties in their coping with the disease.

Conclusions

The study was conducted in a specialized population of PLWHA attending a private clinic where care and support was available to them. Although not the best-known or best-financed programme for PLWHA, it provides care of a high quality with special attention to humane and through counselling and medical treatment.)

The sample size of 79 cases is also small.

The particular nature of our sample was evident in the fact that the majority of individuals were able to afford the cost of ART, although for many people it would be a severe financial strain. Thus, very few of our sample were representative of the many poor people living with HIV/AIDS in India.

The conclusions of the study should be seen in the light of these limitations.

The study documented the different forms, levels and context of stigmatisation from the perspectives of PLWHA. The insider's perspective explains the way PLWHA construct their social world as members of a stigmatised group. They are not just the passive recipients of stigmatisation and discrimination but rather actively attempt to find a comfortable space for themselves by utilizing available resources. However, stigma tremendously affects their efforts to cope with the disease and this remains a harsh reality. The study clearly showed the wide-ranging impact of stigma on the life of HIV positive individuals, producing various stressors and affecting their mobilization of support networks. The findings highlighted their complexities and interdependence on one other.

For PLWHA stigma operates in two major forms

1. Fear of stigma
2. Enacted stigma

Fear of stigmatisation from the society and from those who are not yet aware of their status is a major stress for them. The dominant fears expressed are those of rejection by family and friends, losing respect and esteem in society, being ostracized and becoming a subject of gossip. There is an additional fear of stigmatisation because of separation and widowhood in the case women.

It seemed that these fears came mainly from the patients' perceptions of the image of an HIV positive person in the community. Two major dimensions are seen in their perceptions. They are related to the

- Societal norms about moral and immoral sexual behaviour
- Misconceptions about the disease.

PLWHA believe that people consider an HIV positive person as irresponsible, dirty, of a bad character and someone who has sexual relations with sex workers. They also believe that an HIV positive person is thought to be less productive, gets repeated illness and dies soon because there is no treatment for this disease. Their perceptions are not baseless. They received such moralistic and fear based messages from the media and through interactions with their friend and relatives. They also see and hear how society condemns and ostracizes other PLWHA. Sometimes experiencing stigma from the family or from health care providers heightens their fear about potential stigmatisation from the whole society.

There are very few experiences of blatant and overt acts of stigmatisation from their immediate family and other relatives. In most situations, the expressions are subtle. However some women do experience overt and extreme stigmatisation and discrimination from in-laws and their husbands in the form of blame, rejection, acts of defaming and verbal and physical abuse. Men generally are reluctant to report stigmatising behaviours from their wives.

The health care system is another context for stigmatisation and discrimination, which have devastating impact on the lives of PLWHA. HIV positive people's testimonies about their experiences of stigmatisation in the health care system suggest the insensitive and biased approach of some HCPs towards them. They experience stigma in certain hospital policies and from doctors and paramedical staff. The nature and extent of stigmatisation in health care organizations ranges from overt acts of discrimination such as denial of services, breach of confidentiality, verbal abuse and subtle acts such as neglecting their needs and gossiping about them or giving a 'different look'.

Inadequate knowledge of the disease and unscientific fear of contracting the infection are not the only reasons for discriminating against PLWHA. HCPs value framework and their notions about moral and immoral behaviours are also responsible of considering PLWHA as 'worthless' and 'guilty'.

Stigmatisation in the workplace did not emerge as a major theme in this study. The explanation lies in the fact that most PLWHA maintained secrecy about their

HIV status at their workplace. It is least likely that PLWHA will share the information about their status at workplace because of fear of stigmatisation. Even if they are not thrown out of their jobs, the discomfort because of devaluation and discrimination is a major threat.

Such experiences and/or fears of stigmatisation affect PLWHA's physical, psychological and social dimensions of health. They avoid seeking help and treatment for as long as possible, harming their health in the process. Various negative emotional reactions such as fear, anxiety, anger, despair, suicidal thoughts, guilt and shame were expressed by many PLWHA as an outcome of stigmatisation. At times these feelings were internalised leading to low self-esteem, guilt and a feeling of inferiority.

It is quite clearly seen from the data that

- Stigma is a complex phenomenon, which is deeply intertwined in social values.
- The expression of stigma is based in the existing gender and social inequalities as well as power relationships.
- Stigma also alters the (place in?) the power structure of PLWHA to some extent
- Actual experiences of overt acts of discriminations are not necessary for stigma to have adverse effect on PLWHA. Even the fear of stigmatisation can have a devastating impact on them.
- All PLWHA are adversely affected by stigma irrespective of the mode of acquiring the infection
- Fear-based and moralistic messages from the media and biased and discriminatory behaviours from health care providers perpetuate stigma in the community to a great extent.

Because of the stigma, the process of mobilization of support becomes difficult. The dominant theme while understanding the interrelations of stigma and support was 'disclosure' of one's HIV status. PLWHA's knowledge about who knows their status, how the information spreads, and what was being disclosed were crucial issues.

The in-depth exploration of the data related to disclosure showed that:

- Disclosure is a multifaceted and multidimensional process.
- The process of disclosure starts from the point of knowing the lab report. In most cases, the HCPs disclosed their report. Disclosing the report in an obviously stigmatising manner produces tremendous stress.
- Disclosing one's status to a person is a difficult choice and the process is extremely anxiety provoking even when a positive outcome is expected.

- Presence of strong emotional bonds and feelings of trust and confidence in the relationship and the feeling that the person would understand and accept the patient's behaviour are important factors influencing their choice of disclosing the status.
- There are differences in the reasons for disclosing their status to other relatives and to the spouse
 - Disclosure to other relatives is almost always for seeking emotional or tangible support
 - Disclosure to spouse is mainly for getting her tested for HIV.
- There is tremendous fear and anxiety at disclosing the status to a spouse. This fear has been seen more in men mainly because of the mode of acquiring the infection. Disclosure of HIV status also means disclosure of 'immoral' behaviour. Men often engage in planning and preparing themselves for disclosing their status to their wives. When? How? and What? to disclose to their wives are the difficult questions for them.
- PLWHA often require help and support when disclosing their status to a spouse. Support from the counsellor is important in encouraging them to disclose their status to their spouse
- The gender differences in the patterns, processes and control over disclosure are quite striking. For men disclosure was limited to their close relatives and they had control over their disclosure. For women
 - Husband and natal family played a major role in disclosing their status
 - They generally have less choice and control over the disclosure of their status.
 - Often, disclosure of a woman's status to her natal family is related to some specific events which demand support from them
 - More people come to know about her status especially when she is staying with her natal family either because of separation from husband or widowhood
- The consequences of disclosure of HIV status were seen to be diverse. In one way, it helped patients to cope with the stress and guilt of having the infection and facilitated the process of seeking support. On the other hand, there were experiences of stigmatisation and discrimination because of disclosing their status. In such situations there was fear of consequent disclosure to others, which generated tremendous anxiety and stress.

PLWHA have to cope with the stress of being diagnosed with a serious and incurable disease, which is regarded as shameful by society. The data showed that

- Coping is a complex process
- The mode of acquiring the infection does affect the process of coping. Coping is difficult where the infection is perceived to be caused by the 'mistake' of another person or by some other means (should we add? Rather than as the result of the patient's own actions).
- There are gender differences in the coping process because of the differences in mode of infection and availability of resources
- Availability of support and resources affects the process of coping
- Multiple coping strategies are adopted for coping with different stressors
- Stigma affects the coping strategies not only by affecting the process of mobilization of support but it is a stress in itself with which PLWHA have to cope
- Knowledge about availability of ART and improvement in health because of ART is not only helpful for coping with the disease but it also helps PLWHA in coping with stigma.

Support from various people in the social network is important to cope with the adverse situation. For PLWHA there are two major support systems

- Professional/ formal support system
- Relational/ informal support system

The professional source of support

- Though the respondents coming to this clinic were receiving care and support, their access to other formal support systems, such as health care systems, workplace or the legal system were largely restricted because of stigma.
- A non-judgmental attitude towards them, provision of correct information about the disease, educating and counseling their family members, providing them space for expressing their emotions and inculcating

them with a positive attitude were perceived as supportive behaviours from the physician and the counsellor.

- Professional support is important for encouraging PLWHA to disclose their status especially to their spouse.
- Professional support is not only required to cope with the disease but it is also important in coping with the emotional stress.
- Professional support to the family members through counseling increases the acceptance of PLWHA in the family by reducing the fear of acquiring the infection by casual contact.
- Because stigma is quite prevalent in the health care system, the importance of getting good care and support(? from one professional source) increases greatly.

Relational source of support

- Most PLWHA get support from their natal family.
- There are gender differences in the composition and density of the support network. The density of the support network (number of people actually providing emotional and/or tangible support) is greater for men as compared to women.
- The important supportive behaviours from the informal support network were seen to be providing help in seeking treatment, providing financial help and emotional support.
- For women, unlike men the informal network is not a major source of emotional support.

To conclude, stigma related to HIV/AIDS is pervasive, affecting the process of seeking support and coping with the disease. Many of these findings are the general observations made during the provision of care to PLWHA. But this study substantiated these observations from the perspective of PLWHA and brought out new dimensions, which can be worked on further to improve the quality of care and support services to PLWHA.

Recommendations

The study suggests following broad recommendations with the view to improve the quality of care for PLWHA and to reduce the impact of stigma on them.

A) To Improve Quality of Care to PLWHA

This study identifies three critical components

1) Health Care Sector and Health Care Providers

The doctor-patient relationship should be that of a professional and client but it is generally seen as the relationship of a caregiver and care-receiver. This points out the dynamics of the power relations in the relationship. The study showed how this imbalance affects the behaviour of health care providers. Therefore there is an urgent need to increase recognition of this power structure among health care providers. Though some of these components are addressed in the present curricula of medical training, we recommend that the training of these aspects (doctor-patient relationship, counseling, patient's right to health) should be more vigorously addressed.

Training of health care providers should be taken as a priority as the stigmatising experiences with them have a devastating impact on the lives of PLWHA.

The programs for training of HCPs should consider the following essential points

- o Training doctors as well as paramedical staff
- o Improving their knowledge base of HIV and universal precautions
- o Changing their attitude to the disease and to PLWHA
- o Increasing awareness of stigma in the health care system and its consequences for PLWHA in particular and on the epidemic in general.
- o Increasing awareness about pretest counseling, informed consent and the issues related to confidentiality. There is also need to make HCPs realize the ethical and legal aspects of disclosing HIV status of a person to other people as well as the adverse impact of haphazard disclosure on PLWHA

2) Counseling Care for PLWHA

The findings from this research suggest that counseling is one of the most important factors helping PLWHA to cope with the disease. A skilled, well-trained counsellor should be available in health care institutions providing services to PLWHA. The counsellor should do the following:

- o Help PLWHA to identify their support network by explaining the positive and negative aspects of disclosure to a particular person
- o Help in the process of disclosure
- o Influence the process of coping by encouraging them to adopt more of engagement coping strategies
- o Counsel family members and those who are providing care to PLWHA to remove their fear, to educate them about the emotional needs of PLWHA and to make them aware about the subtle forms of stigma and its consequences for PLWHA

3) People Living with HIV/AIDS (PLWHA)

- Educate PLWHA on their rights and build their skills for collective action to fight against the stigma

B) To Help PLWHA in Coping with the Disease

- 1) Making ART available and accessible
- 2) Taking action against quack doctors
- 3) Providing health insurance coverage to PLWHA
- 4) Increasing interaction between professional and relational support systems

C) To Reduce Impact of Stigma on PLWHA

There is a need to change the image of the HIV disease and people who have this disease. Vigorous efforts should be made to make the community aware of:

- o The ground realities of people's sexual behaviours and sexual networking to de-link HIV with commercial sex and to address the issue of 'Us and Them'
- o The modes of transmission of HIV and, more importantly, the modes through which HIV cannot be transmitted
- o With the availability of newer and better drug molecules for treatment of HIV, it is not a killer disease anymore. Vigorous efforts should be made to percolate this message in the community as mere knowledge of availability of treatment helped PLWHA to cope with the disease.

The media are an important source for creating images and influencing people's attitudes and behaviour. Media can play a very important role in changing the current 'scary' image of HIV in the community. However it is unfortunate that the messages from media largely have a negative impact on PLWHA. They increase stigma, discourage people from volunteering for testing and seeking information and delay treatment. This undermines the primary media role of empowering society to deal with the epidemic. Therefore a more sensitive and sensible response from media is urgently required.

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Annexure 1

Consent Form

My name is Dr. _____

I work for an organization called Prayas. Prayas is a non-government organization working in the fields of health, energy, learning and parenthood. Prayas health group works on various issues related to HIV/AIDS and is currently conducting a research project related to it.

For a person infected with HIV, along with physical disease HIV/AIDS brings forth many psychological, familial and social problems. Many have to face stigma and discrimination not only from the society but also from the family members. How do they cope with it? From where do they get support? Whether all these things have an impact on their health? We will be studying these factors in this research project.

We feel that the findings will help in taking a positive step while providing care for people living with HIV/AIDS.

We will be taking 3 consecutive interviews over the period of 3 to 6 months; each session may last for around 45 minutes.

We will be asking you some information about yourself during the session. It will include some personal questions, your reactions after the diagnosis of HIV, your experiences, and your coping with the situation, also about the perceived changes in yourself and others around you.

I would request you to be comfortable while talking to me. If you feel awkward while answering any question or you don't want to answer certain questions or you want to stop the interview, please do not hesitate to communicate so. You have full right to stop the interview at any point

We will not provide you reimbursement in the form of cash or kind for participating in the study.

With your permission we will like to record the interview and take notes while talking. These records or the notes will be used only for the purpose of the study. We assure you that your identity will not get disclosed at any point. The same remains true if there is reference of some other persons or institutions during the interview. The taped cassettes and the notes will be kept in a locker and only myself and my colleagues in this project will have access to this information.

If you have any queries about the study, you are welcome to ask them. We would respond to all your queries. For further clarification you can contact Dr Vinay Kulkarni; project director at 5441230 or the following address; Amrita Clinic, Athawale Corner, Deccan Gymkhana, Pune 411004.

Prayas will not be responsible for any untoward occurrences not related to the study. We do not have any provision for compensation for such an event.

Please sign below if you agree to participate in the study.

Sign

Name of the participant

Sign

Name of the interviewer

● PRAYAS

Initiatives in Health, Energy,
Learning and Parenthood.



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संशोधन प्रकल्पाबद्दलचे स्पष्टीकरण

माझं नाव : डॉ.

आम्ही प्रयास या संस्थेसाठी काम करत आहोत. प्रयास ही संस्था आरोग्य, शिक्षण आणि ऊर्जा बचतीच्या संदर्भात काम करते. प्रयास आरोग्य गटातर्फे आता आम्ही एच्.आय.व्ही./एड्स ह्या आजारासंदर्भातील एका शोध प्रकल्पावर काम करत आहोत.

एच्.आय.व्ही./एड्स हा आजार शारीरिक व्याधींबरोबर अनेक वैयक्तिक, कौटुंबिक व सामाजिक प्रश्न निर्माण करतो. या प्रश्नांबरोबरच अनेक जणांना दूषण, कौटुंबिक व सामाजिक बहिष्कारालाही तोंड द्यावे लागते. या परिस्थितीशी जुळवून घेताना आपण काय करतो? कुटुंबाचा व समाजाचा त्यात कितपत सहभाग मिळतो? या सर्व गोष्टींचा एच्.आय.व्ही./एड्स बाधित व्यक्तीच्या आरोग्यावर कसा व काय परिणाम होतो ह्याचा अभ्यास आम्ही या प्रकल्पात करणार आहोत.

एच्.आय.व्ही./एड्स बाधित लोकांना मिळणाऱ्या सेवेत योग्य ते बदल किंवा सुधारणा घडवून आणण्याच्या दृष्टीने या माहितीची मदत होईल असा आमचा विश्वास आहे.

ह्या अभ्यासासाठी आम्ही ३ ते ६ महिन्यांच्या कालावधीत तुमच्या ३ मुलाखती घेऊ एक मुलाखत साधारण ४५ मिनिटे चालेल.

या मुलाखतीमध्ये आम्ही तुम्हाला तुमच्या विषयी माहिती विचारणार आहोत. ह्या आजाराची लागण झालेली कळल्यावर तुमची व इतरांची झालेली प्रतिक्रिया, तुम्हाला आलेले अनुभव, परिस्थितीशी जुळवून घेताना तुम्ही काय काय केले, तुमच्या व इतरांच्या वागण्यात तुम्हाला आढळून आलेले बदल, जवळच्या व दूरच्या नात्यांमध्ये पडलेला फरक तसेच तुमच्या आयुष्यात घडलेले अनेक छोटे-मोठे बदल याविषयी व इतर काही वैयक्तिक स्वरूपाचे प्रश्न आम्ही तुम्हाला विचारू.

या मुलाखती दरम्यान आपण मनमोकळेपणाने बोलावे अशी आमची इच्छा आहे. जर ही मुलाखत सुरु असताना तुम्हाला एखाद्या प्रश्नाचे उत्तर द्यायचं नसेल किंवा उत्तर देणे अवघड वाटत असेल तसेच मुलाखत थांबवायची इच्छा असेल तर न कचरता तसे आम्हाला जरूर सांगा. या प्रकल्पात भाग घेण्याबद्दल तुम्हाला रोख मोबदला मिळणार नाही.

आपली परवानगी असेल तर आम्ही टेपरेकॉर्डवर आपली मुलाखत ध्वनिफीत वापरून ध्वनीमुद्रित करणार आहोत आणि मुलाखत सुरु असताना काही नोंदीही करणार आहोत. ध्वनिफीत व नोंदी केवळ संशोधनासाठीच आहेत आणि त्याचा वापर करताना आम्ही तुमचं नाव आणि तुमच्याबद्दल कुठलीही माहिती कुठेही बाहेर येणार नाही याची खात्री देतो. बोलण्याच्या ओघात आपल्याकडून जर इतर काही व्यक्तींबद्दलची माहिती दिली गेली तरी त्यांची देखील नाव व माहिती कुठेही बाहेर येणार नाही. केवळ मी आणि माझे सहकारी यांनाच ही माहिती मिळू शकेल आणि त्याची वैयक्तिकता जपण्याचा कायद्याच्या चौकटीत शक्य तेवढा आटोकाट प्रयत्न केला जाईल. ही सर्व माहिती कुलूपबंद कपाटात राहिल आणि केवळ मी व माझे सहकारीच ती माहिती पाहू शकतील.

ही मुलाखत कधीही थांबवण्याचा तुम्हाला अधिकार आहे. या प्रकल्पाबद्दल जर तुमच्या मनात काही प्रश्न असेल तर अवश्य विचारा. या संदर्भात कोणतीही समस्या आली तर प्रकल्प प्रमुख डॉ. विनय कुलकर्णी यांच्याशी वैयक्तिक रित्या अमृता क्लिनिक, आठवले कॉन्ड, डेक्कन जिमखाना, पुणे ४११ ००४ या पत्त्यावर अथवा २५४४९२३० या दूरध्वनी क्रमांकावर संपर्क साधावा.

या प्रकल्पाशिवायच्या कोणत्याही कारणामुळे झालेल्या त्रासाची जबाबदारी प्रयास घेऊ शकणार नाही व त्याबद्दल नुकसान भरपाई देण्याची कोणतीही योजना प्रयासकडे नाही.

जर या प्रकल्पात भाग घेवून मुलाखत देण्याची तुमची तयारी असेल तर खाली सही करा.

सही -

सही -

मुलाखत देणाऱ्याचे नाव-.....

मुलाखत घेणाऱ्याचे नाव-.....

Annexure 2

Interview Guidelines

Date:

Demographic Data sheet ID No. _____

1. Age
2. Sex
3. Marital status
4. No. Marriages
5. Number of children
6. Live dead (If so, probable cause of death with history)
7. Spouse HIV status
8. Place of residence
9. Education
10. Occupation
11. Type of family
12. Number of people in household
13. Socio-economic status-overall impression: 1. Very poor 2. Poor 3. Middle class 4. Rich 5. Very Rich
14. Reason for HIV testing
15. Knows about his/her HIV status since
16. Coming to this clinic since
17. Probable mode of acquiring the infection
18. Clinical stage of HIV disease
19. Is currently taking ART
20. Specific comments of counselor

Guideline for in-depth interview

HIV History: Testing and diagnosis

- What did you know of HIV/AIDS prior to diagnosis?
- What was the source of this knowledge? Friends, TV, radio newspaper, school, knew an HIV positive person,
- What was your attitude and perception about the disease and PLWHAs at that time?
- How you came to know your status. The process of diagnosis
- Reasons for HIV test:
 - o ANC, surgery, premarital testing, other
 - o Did you suspect infection-if so why?
 - o Suggested by other-doctor, relative, friend. Why did they suggest?
- Where did you go for testing? Who was with you? Narrate experience at the time of testing?
- Why did you go to that particular place for testing?
 - o Anonymity, close to home, doctor's recommendation, other reasons?
- Who disclosed your status to you and how?

- How did they treat you?
- Pre test counseling? If yes, by whom and what was said?
- Post test counseling? If yes, by whom and what was said?
- Probable route of transmission?
 - o Explore the issue - Other people have similar situations/behaviors, but did not get the disease. Why do you did?
- What was the immediate impact on you and your immediate reaction upon diagnosis?
 - o Anger, fear, denial, depression, suicidal ideation, guilt, perceived oneself as contaminated dirty, infected.
- What did you do afterwards?
 - o Talked with doctor, spouse/family-natal and in-law/friend, kept silent.
 - o Actions taken? Suicide attempts, prayer, try not to think about it, cried, other.
- Did your reaction changed over time?
 - o What sort of change?

Information about their disclosure and support network

Before the diagnosis –

- Who do you interact with on a regular basis?
- What do you do when you have a problem or are feeling badly?
 - o Talk with counselor, friends, doctor, neighbors, co-workers, other or keep silent.
 - o Talk with family –spouse, natal family, in-laws

After diagnosis –

- Who of these, or anyone else, did you tell of your status?
- How long after diagnosis did you wait to tell them and why did you wait?
- How did you tell them?
- What difficulties did you have in telling them?
- What did you do to overcome these difficulties?
- Why did you tell that person/those people?
- What was EACH of their responses?
- Why do you think they had that response?
- How has your relationship to that person changed as a result?
- How does EACH treat you now? How has this affected you?
- What have you done to cope with that?
- Any changes in behavior, or in the kinds/nature of interactions with them.
- In your social circle, whom did you NOT tell? Why not?
- Who knows of your status of those NOT told by you?
- How did they come to know?
- What was EACH of their responses?
- How does EACH treat you now?
- How has your relationship to that person changed as a result?
- How has this affected you?
- Who do you suspect knows?
- What makes you suspect?
- How do you think they came to know?
- What has changed in their treatment of you since they found out?
- How has this affected you?
- How has your relationship to that person changed as a result?
- Who else in the family was tested?

- When? Why?
- What was the result of the test?
- What was its impact on you?
- What was the impact on the family-natal and in-law?
- Was there an HIV related death in the family? What was the impact on you and the family?

Progression of health status –

- Did the progression in symptoms bring any change in interactions with people within family-natal and in-law, and out side the family.
 - From whom? What is the change? For what reason?
- What were the changes in you because of the progression of the disease?
- Did the progression cause emotional, psychological worries or new concerns?
- Occupational change -i.e. relationship with co-workers, ability to work, earning capacity promotions, requiring loans because of not working or burden of medical care, needed less demanding job or new job?

If a symptomatic

- Do you go for regular doctor visits?
- Are there any difficulties in making these visits?
 - Secrecy, making explanations to others for your travel/absence
- Are you taking medicines? Do others know?

Information Seeking Behaviour

- Did/do you want to learn more about HIV/AIDS?
- What information are you interested in? Transmission, disease course, treatment/cure, etc.
- Why did you want to know more about the disease?
- Whom/where did you seek out for further information? Medical professional, lay person, books, pamphlets, internet etc
- What information did you receive?
- How did the new information affect you?
- Who helped you gather information? How did they help?
- How has having HIV changed your attitude towards the disease and PLWHAs?
- Did others around you want to know more? Who? Why? And what information?

Treatment seeking behaviour

- Whom did you go to for your medical care for HIV?
- When did you first seek medical care for HIV? Why?
- Why did you choose that caregiver?
- Who came with you at that time? Did they know of your status? Did they see the Dr. with you?
- Was there any time lapse between the diagnosis and treatment seeking?
- Was there any pressure or obstacle about going to the doctor? From whom, what?
- What did you do in response to this obstacle?
- How far is the hospital/clinic/doctor you visit? How difficult is it to reach there?
- What did they do for you?
- What did they tell/counsel you?
- What was their attitude toward you?
- Did you follow their advice/instruction?
- For what problems did you go to doctor?
- Did you speak with your doctor about issues other than symptoms? If so, what else?

Relationship with the caregiver

- Rapport, privacy, confidentiality, comfort level, trust?
- Gender of the caregiver and how comfortable are you about it?
- For medical problems unrelated to HIV/AIDS, have you avoided medical care or medical procedures out of fear of your status being known?
- If so, what did you do instead? Quack doctors, Ayurved doctor, home remedy, nothing, other.

Hospital Stay

- Have you visited a hospital for any treatment? What was your experience?
- Please tell us of any incidents that were negative with respect to your treatment in the hospital?
 - Care in the ward, confidentiality of status, etc.
- What was your experience with the medical staff who knew about your status?
- Do you feel you were given the same quality of care as given to other (HIV uninfected) patients at the hospital?
- With what level of staff did you experience discrimination? Which staff level was the most discriminating against you?
- How has this affected your medical care?
 - Willingness to visit doctors, seek care, take treatment, etc
- What were your expectations from the medical staff?
- Have you ever visited a government hospital? What were your experiences there?

Behavioural adjustments

- How have your interactions with, family members -natal and in-law, friends, co-workers and others changed?
- In there any change in your socializing? why?
- Which of these changes did you decide to make? Which 'just happened'?
- Was there any change in your use of alcohol, cigarettes, other drugs? Why?
- Did you take any help in doing so?

Relationship with spouse and sexual behaviour

- How was your relationship with your spouse before and after diagnosis?
 - In terms of trust, satisfaction, love communication, affection, responsibilities, disagreements.
- How has this change affected you?
- Are you worried about transmitting the infection to your partner?
- Please tell us about your present sexual practices in terms of frequency, satisfaction, methods of contraception etc.
- Are you presently practicing safe sex?
- Any problems with availability of condoms?
- Do you have communication with your partner about sexual matters? Are you comfortable with this level of communication?
- How are you dealing with your sexual feelings and desires?

Issues related to pregnancy and childbearing

- What do you know about pregnancy and HIV?
- Do you want your own child?
 - If so, do you have any questions, fear, worries, etc about pregnancy and parenting?
 - If not, are you worried about being/becoming pregnant?

If pregnant

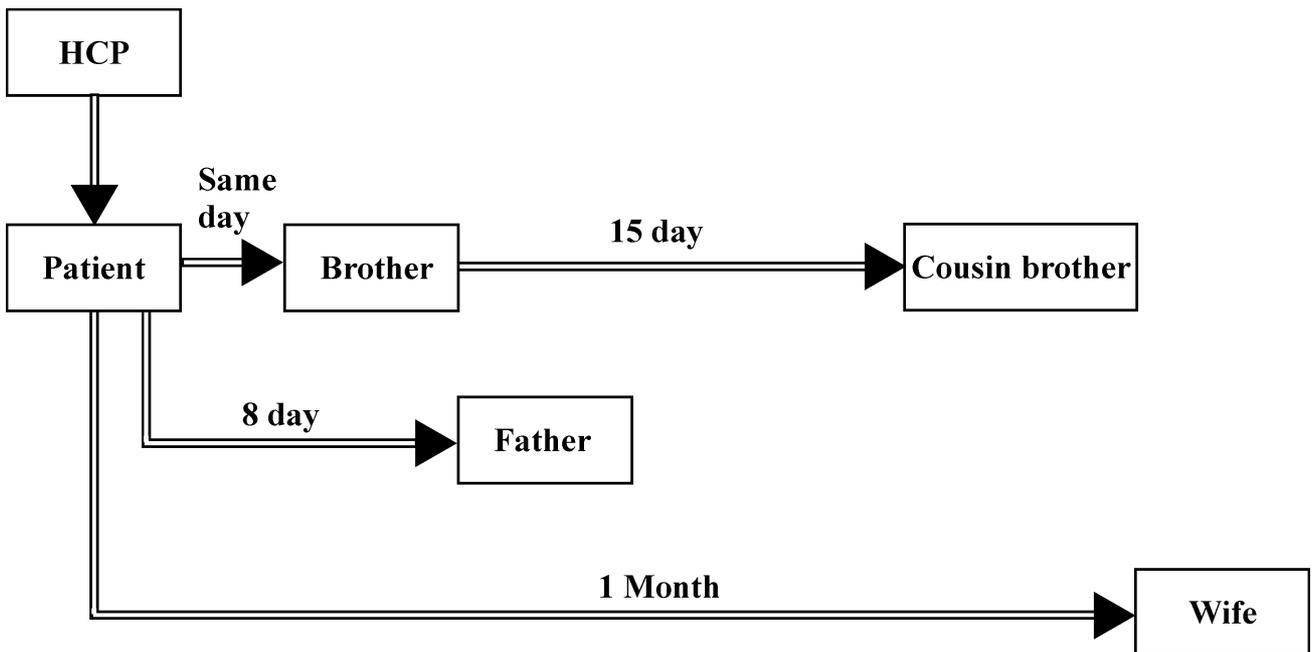
- What was your wish for continuation of the pregnancy? Why?
- What was the wish of spouse and family members-natal and in-law?
- Who else was involved in the decision? Natal family?

- What was the wish of your doctor?
- What was your doctor's advice? Terminate, counselled on all options, not helpful
- Did you have to face any kind of problem because of your decision?
- How do/did you cope with the decision?
- Are you comfortable with your decision?

Annexure 3

Disclosure graphs

From our previous experience at the clinic and also from our conceptual exercises while considering this study of stigma and support, we felt that disclosure of a person's HIV status is one of the most important components influencing stigma and support. It is probably the central theme or the key to understanding the various factors and their interplay. We felt the need to collect the disclosure related data plotted temporally, as it happened in the person's life. We collected this data in the form of a graph.



We collected such graphs from our respondents. While plotting this graph we also collected qualitative data regarding the reasons for disclosure and the reactions of other people after they came to know about his/her status. The data collected in graphical format were grouped into relevant categories and analyzed with the help of SPSS. We cross-tabulated the information with other socio-demographic variables to see if there existed any specific patterns. Plotting the information in a graphical form was easier than using a structured interviews schedule. We could also collect qualitative data along with it, which provided context to our data.

Annexure 4

Prayas HIV stigma scale: Exploring the development of a stigma scale

As an adjunct to the mainly qualitative study, we attempted to ‘measure’ stigma. After reviewing literature on HIV/AIDS stigma, we found that the items in the stigma scale developed by Berger (1996, 2001), from a convenience sample of 318 adult PLWHA in the US. These items were reviewed and adapted to the Indian scenario as evidenced in the qualitative study. The modified instrument was administered to 45 participants (27 men and 18 women). The questions were thematically grouped into five subscales.

This stigma scale has five subscales in it

1. Personalized stigma subscale
2. Disclosure subscale
3. Self-stigma subscale
4. Public attitude subscale
5. Health care provider stigma subscale

The designation of the subscale to which the question belongs is put on the left side of the question.

Each response is coded as

- Strongly disagree (SD) – 1
- Disagree (D) – 2
- Can’t say (CS) – 0
- Agree (A) – 3
- Strongly agree (SA) – 4

There are three questions, which have reverse coding. (Q. 8, 29 and 32)

After reversing the scores for these questions, adding up all the values will give the total stigma score.

There are 40 items so total stigma score will range from 40 to 160

- For personalized stigma subscale the range will be 10 to 40
- For disclosure subscale it will be 11 to 44
- For self-stigma subscale it will be 6 to 24
- For public attitude subscale it will be 14 to 56
- For health care provider stigma subscale it will be 9 to 36

In addition to the 4 point Likert scale (strongly disagree, disagree, agree and strongly agree), a ‘can’t say’ option was added as the sample consisted of PLHWA who had not disclosed their status or only disclosed to a few as seen in the table below.

Extent of Disclosure

Statement	Can’t say	%	Disagree	%	Agree	%
1 Very few people related to me know that I have HIV	0	0.0	4	8.9	41	91.1
3 I am very careful who I tell that I have HIV	0	0.0	3	6.7	42	93.3
5 I try my best to keep my HIV a secret	0	0.0	2	4.4	43	95.6

Perhaps because of this lack of disclosure a large proportion of 45 participants respond 'can't say' questions regarding loss of job if status is revealed to employer (16), avoidance of home visits (12) ostracisation of positive people (9) and avoiding physical contact (9).

Concerns about disclosure

Statement	Can't say	%	Disagree	%	Agree	%
12 I worry that people who know that I have HIV will tell others	1	2.2	17	37.8	27	60.0
39 I have told to people close to me to keep the fact secret that I have HIV	2	4.4	7	15.6	36	80.0
21 I worry that others might come to know about my status from my family physician	2	4.4	33	73.3	10	22.2

The findings from the analysis of the responses for various items in the scale corroborated our findings from the qualitative data. The fear of stigmatization, loss of image in public, stigmatization from health care providers etc. emerged as dominant patterns.

Further modification and statistical analysis is required to validate the scale.

Prayas HIV Stigma Scale

ID No.

Date

Interviewer: _____

This questionnaire tries to understand your views about some of the psychosocial aspect of having HIV. There are some items, which assume that you have told other people about your HIV. This may not be true for you. If the item refers to something that has not actually happened to you then please imagine yourself in that situation and then answer the question.

			Strongly disagree	Disagree	can't say	Agree	Strongly agree
<input type="checkbox"/>	2	1. Very few people related to me know that I have HIV	SD	D	CS	A	SA
<input type="checkbox"/>	3	2. I feel guilty because I have this disease	SD	D	CS	A	SA
<input type="checkbox"/>	2	3. I am very careful who I tell that I have HIV	SD	D	CS	A	SA
<input type="checkbox"/>	4	4. Most people believe that person with HIV dies soon	SD	D	CS	A	SA
<input type="checkbox"/>	2	5. I try my best to keep my HIV a secret	SD	D	CS	A	SA
<input type="checkbox"/>	2,4	6. I worry that people may judge me when they learn I have HIV	SD	D	CS	A	SA
<input type="checkbox"/>	4	7. People with HIV lose their jobs when their employers find out	SD	D	CS	A	SA
<input type="checkbox"/>	3	8. I never feel ashamed of having HIV	SD	D	CS	A	SA
<input type="checkbox"/>	4	9. People with HIV are treated like outcast	SD	D	CS	A	SA
<input type="checkbox"/>	2	10. It is better to avoid close relations with any person because they might come to know about my status	SD	D	CS	A	SA
<input type="checkbox"/>	1,4	11. If people come to know about my HIV status they will also think less of other family members	SD	D	CS	A	SA
<input type="checkbox"/>	2	12. I worry that people who know that I have HIV will tell others	SD	D	CS	A	SA
<input type="checkbox"/>	3	13. I think less of myself because I have this disease	SD	D	CS	A	SA
<input type="checkbox"/>	3	14. I don't hold children close to me though no one asks me not to do so	SD	D	CS	A	SA
<input type="checkbox"/>	1,4	15. People see an HIV positive person as a person with a bad character	SD	D	CS	A	SA
<input type="checkbox"/>	1	16. I have stopped socializing with some people because of their reaction to my having HIV	SD	D	CS	A	SA
<input type="checkbox"/>	5	17. A doctor denied me treatment after knowing my status	SD	D	CS	A	SA
<input type="checkbox"/>	4	18. Some people will avoid touching me after knowing my status	SD	D	CS	A	SA
<input type="checkbox"/>	5	19. Nurses/ward boys in the hospital gossiped about me when they realized I have HIV	SD	D	CS	A	SA

Reverse coding

<input type="checkbox"/>	1,4	20. If people come to know about my status, it might be difficult for someone in my family to get married	SD	D	CS	A	SA
<input type="checkbox"/>	5,2	21. I worry that others might come to know about my status from my family physician	SD	D	CS	A	SA
<input type="checkbox"/>	5	22. In hospitals, writing "HIV positive" on my file/case paper is distressing	SD	D	CS	A	SA
<input type="checkbox"/>	4	23. Most people think that getting HIV is what I deserve for the way I lived my life.	SD	D	CS	A	SA
<input type="checkbox"/>	1	24. Some people close to me are afraid others will reject them if it becomes known that I have HIV	SD	D	CS	A	SA
<input type="checkbox"/>	5	25. I could make out from the doctor's expression that s/he has lost respect for me after knowing about my status.	SD	D	CS	A	SA
<input type="checkbox"/>	5	26. After knowing my status doctor avoided touching/ examining me	SD	D	CS	A	SA
<input type="checkbox"/>	1	27. My words will have less value once people will know about my status	SD	D	CS	A	SA
<input type="checkbox"/>	1,4	28. Most people will avoid visiting my home once they know my status	SD	D	CS	A	SA
Reverse coding							
<input type="checkbox"/>	2	29. I never feel the need to hide the fact that I have HIV	SD	D	CS	A	SA
<input type="checkbox"/>	1,4	30. People won't like me around their children once they know that I have HIV	SD	D	CS	A	SA
<input type="checkbox"/>	5	31. I never feel the need to tell any health care provider about my HIV status	SD	D	CS	A	SA
Reverse coding							
<input type="checkbox"/>	3,4	32. I think people's discriminatory behaviours towards HIV positive individuals are justified to some extent	SD	D	CS	A	SA
<input type="checkbox"/>	5	33. I have been hurt by how the health care provider reacted after knowing my HIV status	SD	D	CS	A	SA
<input type="checkbox"/>	3	34. I keep my vessels separate though no one asks me to do so	SD	D	CS	A	SA
<input type="checkbox"/>	2	35. If HIV was not a sexually transmitted disease, then I would have not bothered about people knowing my status	SD	D	CS	A	SA
<input type="checkbox"/>	1,4	36. After knowing about my status people will tend to ignore my good points	SD	D	CS	A	SA
<input type="checkbox"/>	5	37. Most doctors avoid treating HIV positive people	SD	D	CS	A	SA
<input type="checkbox"/>	2,4	38. Since learning I have HIV, I worry about people discriminating against me	SD	D	CS	A	SA
<input type="checkbox"/>	2	39. I have told to people close to me to keep the fact secret that I have HIV	SD	D	CS	A	SA
<input type="checkbox"/>	1	40. Some people who know I have HIV have grown more distant	SD	D	CS	A	SA

About Prayas Health Group

Prayas, an NGO established in 1994 works in the area of health, energy, learning, parenthood and resources and livelihood.

The health group of Prayas works on various medical and social aspects on HIV/AIDS. The group is active in community education, training of health care providers, provision of medical and counseling care to people living with HIV/AIDS, socio-behavioral research and prevention of mother-to-child transmission of HIV etc.

Publications

- *"HIV/AIDS Vishayee He Mala Mahit Have!"* (Marathi) (I must know this about HIV/AIDS) (First edition 1995, second edition 1999, third edition 2002)
- *'Madhamanshi Maitree'* (Marathi) (Friendship with media) - Handbook for working with the media: (1998)
- *'HIV/AIDS Mhanaje Ahe Tari Kay?'* (Marathi) (What is HIV/AIDS?) - Awareness booklet for media personnel: (1998)
- *'Pudhe Kay?'* (Marathi) (What Next?) -A booklet for HIV infected individuals and their family members:(1999)
- *HIV/AIDS Diagnosis and Management: A Physician's Handbook* (1999)
- *'Prashna Aapala Uttar Aaplech'* (Marathi) (Our problem, our solution) - A booklet for HIV infected individuals: (2002)
- HIV disease in pregnant women and neonates - A manual for PMTCT programs: (2002)
- *'Aai Hotana'* (Becoming a mother) (Marathi) - A booklet for pregnant women about care during pregnancy: (2003) - This booklet is translated in Hindi (Maa Bananese Pahile) and English (Becoming A Mother)
- *'Tari Suddha Aai Hotana'* (Marathi) ('And Yet' ...Becoming a mother) - A booklet for HIV positive pregnant women: (2004)

Training material and resources

1. Slide set for conducting HIV awareness programs in the community (Marathi, Hindi, English)
2. Training material for counselors (ANC and PMTCT counseling)
3. Module for training health care providers (about HIV)
4. PMTCT training module for Health care providers
5. "Am I at risk?" a film on universal precautions (Marathi and English)
6. Poster about universal precautions
7. Data management software for PMTCT programs

The Prayas study is a significant addition to understanding the complex public reactions and institutional responses to the increasing presence of HIV/AIDS victims in Indian society. The study documents the continuing ill-informed stigmatizing of people living with HIV/AIDS (PLWHAs), within families, communities, and in institutional settings. Most distressing in their data is the evidence of persistent, often gross, discriminatory practices and violations of human rights in health care settings.

The brighter, hopeful side of their study is the evidence that humane, sensitive, well-informed counseling can have very positive effects on the emotional well-being and coping strengths of PLWHAs. The study also shows that persons who are able to afford to pay for antiretroviral medications can, indeed, carry on full functioning in their workplaces and families. Those findings underscore the urgency of vastly increased funding for programs to provide the needed ARV treatment to the large numbers of persons who cannot afford those medications.

The majority of PLWHAs in their sample kept their HIV status hidden from the wider community, and especially from people in their workplaces. On the other hand, some individuals (especially women) did not have full control over the disclosure of HIV status. In a number of cases the “breach of secrecy” was caused by thoughtless disclosures by doctors and others in health facilities. The study suggests that such breaches of confidentiality are more likely to be experienced by female patients, probably reflecting long-standing “traditional” patterns of dealing with patients and their families in health care settings.

The Prayas researchers explored innovative methods of documenting and analyzing the pathways through which information about individuals’ HIV status was disseminated. Their data suggest important further research that is needed for understanding both the patterning of stigma/discrimination and the ways in which PLWHAs disclose or conceal their status in relation to their strategies of coping with this personal crisis.

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PRAYAS
Initiatives in Health, Energy,
Learning and Parenthood