



# HIV/AIDS in India: stigmatization as a process of communication and social relationship

## SIDA/VIH en India: La estigmatización como un proceso de comunicación y relación social

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**Resumen**— Pese a que el estigma del Sida ha sido un problema mayor en el mundo entero, y en la India en particular, no existe una comprensión cabal sobre el proceso detrás de este fenómeno. El presente estudio examina la percepción de la gente ante distintos niveles de exposición al Sida y al VIH, a través de ocho focus groups y 24 entrevistas en profundidad, realizados en la India durante 2008 y 2009. Los hallazgos revelan las dinámicas (niveles) del estigma en tres períodos de tiempo (antes, durante y después de la detección del VIH en la sangre) y en tres dimensiones, la psicológica, social y económica. El aspecto psicológico del estigma emerge más a menudo en términos de contagio y rechazo del cuerpo; en lo social y económico, está asociado principalmente al aislamiento y la pérdida del trabajo o los negocios. El conocimiento del ciclo de infección del VIH, la actitud hacia la vida y la resiliencia o adaptabilidad emergen como los principales factores detrás del estigma.

**Palabras claves:** estigma circunstancial, India, curva del estigma, dimensiones del SIDA, dinámicas.

**Abstract**— While HIV related stigma has been a major problem world-wide and India in particular, a clear understanding about the process behind such phenomenon is non-existent. The current study examines perception of people at different levels of exposure to HIV and AIDS by employing eight Focus Group Discussions and gathering 24 Narratives, in western India during 2008-2009. Findings reveal the dynamics (level) of stigma in 3 broad time phases such as before, immediately during and sometimes after finding HIV in blood (presented in a 2-dimensional graph), and 3 broad dimensions such as physiological, social and economic contexts. Physiological stigma emerged more often in terms of contagiousness and abomination of the body, whereas social distance and the loss of job or business are the major social and economic stigmas attached to HIV. Knowledge on HIV infection cycle, attitude towards life and resilience or adaptability emerged as the important factors behind stigma.

**Keywords:** Circumstantial stigma, India, Stigma curve, AIDS dimensions, Dynamics

## 1. BACKGROUND

Checking the proliferation of HIV (Human Immuno-deficiency Virus) across the world is hindered by people who face enormous barriers in practicing preventive behaviors (AED, 2008). Fear of discrimination by the society aggravates HIV related stigma many times over. While AIDS (Acquired Immuno Deficiency Syndrome) is considered to be the modern pandemic of the world, with more than 5 million people estimated to be living with HIV/AIDS, India's prevalence is second only to South Africa. More than 20 years after the first AIDS case was diagnosed in the southern city of Chennai, India is still juggling different public health priorities, while maintaining and increasing its spending on HIV/AIDS programs. India's citizens may share a single time zone, but they live in regions vastly separated by immense distances and customs. They speak 22 officially recognized languages in addition to English and Hindi, practice different religions, have customs, and face diverse HIV/AIDS crises. The epidemic also follows different trends in different places. Even in a country with the professional talent that India has, lack of capacity—medical, managerial, and infrastructure often puts a barrier in the way of an effective response to the AIDS pandemic. Stigma toward HIV and AIDS is quite strong in India. It is grounded in different socio-economic categories within the Indian population and is responsible for manifold problems in prevention, care, and treatment (Singhal and Rogers, 2003).

Varied circumstances may be responsible for differential in the characteristics and magnitude of stigma. Although different organizations take actions to address stigma in combating the proliferation of HIV and improving the standard of living for Persons Living with HIV (PLH), these actions are not supported by a bio-social understanding of stigma and AIDS-related discrimination (Piot 2003). And while the Joint United Nations Program on HIV/AIDS (UNAIDS, 2004) expressly refers to the need to fight stigma as part of combating HIV/AIDS, it does not present a clear definition of stigma.

The aim of this study is therefore to understand the stigmatization process with the view of communication and social processes, particularly in India. This process can reduce the misconceptions of HIV and AIDS that contribute to the stigmatization process among people in general as well as infected persons.

### 1.1 Theoretical Understanding

Stigma has been visualized and defined from various theoretical points of view. In the early 1960s, Goffman defined stigma as an 'identification' that a social group creates of a person (or group of people) based on a certain physical, beha-

vioral, or social trait perceived to be abnormal and different from current norms. This socially constructed standing presents groundwork for further disqualification of membership from a group in which the person was originally included in. Importantly, Goffman emphasized that stigma does not rest in individual traits or attributes but in social interactions and relationships. Goffman (1963) notes that stigma is not merely an attribute, but represent a language of relationships. Drawing from Goffman (1963), Alonzo and Reynolds (1995) argue that the stigmatized are a pejorative category of people who are devalued, shunned, or otherwise lessened in their life chances and in access to the humanizing benefit of free and unfettered social intercourse. Gerhard Falk (2001) a sociologist, describes stigma as of two categories, "existential stigma" and "achieved stigma." Existential stigma is described as stigma deriving from a condition which the target of the stigma either did not cause or over which he has little control. The achieved stigma is the one that is earned because of conduct and/or because they contributed heavily to attaining the stigma in question.

Brown, Macintyre & Trujillo, (2003) describe stigma in two forms: perceived or enacted. The perceived (or felt) stigma occurs when there is a real or imagined fear of societal attitudes regarding a particular condition and a concern that this could result in acts of discrimination directed to individuals with that condition. Enacted (or actual) stigma, in turn, refers to experiences of discrimination directed to individuals because of specific attributes or conditions that characterize them. Herek and Capitano (1998) and Herek (1986, 2002) add the concept of "instrumental stigma" to explain intended discrimination based on an inflated fear of contracting HIV, as well as intended discrimination based on resource concerns due to judgments about the likely social contribution of a person living with HIV/AIDS. This includes not being willing to shake hands with such a person or refusing to care for or financially support a family member with HIV/AIDS. Herek and Capitano (1998) use the term "symbolic stigma" to describe the kinds of moral judgments that may cause a third type of discrimination, such as refusing to provide the same treatment for intravenous drug users and "innocent victims" of HIV/AIDS because the former are judged to be more blameworthy for contracting the disease, or not allowing PLHA to serve on a school board because they are judged as immoral.

Numerous theoretical works have explained stigma as occurring psychologically and limiting its negative effects

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to self-process within individuals (Lawrence and Arthur, 2008). The majority of the psychological research focuses on individualistic perceptions and attitudes rather than on the broader social context in which such perceptions are grounded. Again, the studies often discuss the implications of these beliefs in terms of misunderstandings, misinformation, and negative attitudes as far as efforts to change the perceptions of the stigmatizer are concerned. Such approaches seek to improve HIV/AIDS related education, enhance sensitivity and provide empathy training or tolerance through personal contact with people living with HIV.

However laudable such efforts have been, they have placed little emphasis on the larger economic and political processes in which stigma is grounded (Castro and Farmer, 2003). More recently, some anthropologists (Parker & Aggleton, 2003; Farmer, 2002) have challenged approaches that emphasize cognitivist explanations of stigma rather than the structural violence that generates the social inequalities in which stigma is invariably rooted. In a conceptualization by Link and Phelan (2001), stigma exists when a set of interrelated individual-social components converge. In the first component, people distinguish and label human differences and then the dominant cultural beliefs link the labeled persons to undesirable characteristics to negative stereotypes. Finally, the labeled persons are placed in discrete categories to accomplish some degree of separation of “us” from “them” followed by labeled persons experiencing the loss of status and discrimination that lead to unequal outcomes. Finally, stigmatization is entirely contingent upon access to social, economic, and political power that allows the identification of different-ness, the construction of stereotypes, the separation of labeled persons into distinct categories, and the full execution of disapproval, rejection, exclusion, and discrimination.

There are some theories that describe the processes in-

involved in self-stigmatization. Self-stigmatization happens when people internalize stigmatizing views of themselves. People may blame and discredit themselves for having HIV, which can result in depression, withdrawal, and loss of self-esteem (Santana & Dancy 2000). Chapman (1998) and other memory work projects (Morgan 2004) have looked at the way that the internalization of HIV/AIDS stigma and the experience of the illness changes the perception of the body over the course of an illness. Kübler-Ross's (1969) Grief Cycle model describes five discrete phases—denial, anger, bargaining, depression, and acceptance—by which people deal with grief and tragedy, especially when diagnosed with a terminal illness. Kübler-Ross originally applied these phases to any form of catastrophic personal loss (job, income, freedom), including the death of a loved one, divorce, drug addiction, or infertility. She claims these steps do not necessarily come in the order noted above, nor are all steps experienced by all patients, however, a person will always experience at least two of them. Stigma can also be internalized, leading to self-doubt, lower self-esteem, depression, immuno-suppression and even premature death (Berger, Ferrans & Lashley, 2001); Fife & Wright, 2000; Frable, Wortman, & Joseph, 1997; Santana & Dancy, 2000). The nature and depth of perceived stigma, as well as the views of external agencies (such as media) that affect the perceptions of PLH (People living with HIV), is thus an essential aspect of research. How stigmatization affects PLH depends on their own perceptions of stigma, the stage of the disease, the resources available to them, and the social context in which a stigmatizing interaction occurs.

At the individual level of stigmatization, Alonzo and Reynolds (1995) observe that stigmatizing illnesses often initially pass through the process being considered sinful, then willfully deviant, followed by illness, and finally if lobbying

efforts are successful, a normal, accepted variation. Stigmatizing illness, however, does not achieve acceptance at the individual level; at best it only achieves tolerance. Freidson (1970), on the other hand, maintains that certain diseases are inherently seen as illegitimate and stigmatizing. From a social constructionist perspective, if one can socially and politically lobby for or against an illness in terms of whether it is sinful, deviant or an illness, than the degree of extrinsic meaning attached to it must have little intrinsic value, aside from the disease interfering with the value of life (Alonzo and Reynolds, 1995, p. 9).

The biology of a disease is an important factor that influences the depth and nature of the stigma, but the interpretation of the phenomena is often culturally mediated. Hence change in knowledge about biological processes is of great interest. Crandall & Glor. (1997) suggest that knowledge about the severity, contagiousness, and tractability of a disease are significant determinants of instrumental stigma; knowledge about a disease does not necessarily filter directly from medical experts to the lay public, especially if there is a cultural mismatch or a low-trust relationship. Alonzo and Reynolds (1995) suggest that PLHA in different phases of HIV/AIDS experience stigma differently. They describe the changing experience of stigmatization in different phases of HIV/AIDS as a "stigma trajectory." The HIV/AIDS stigma trajectory is described by four phases: (1) at risk: pre-stigma and the worried well; (2) diagnosis: confronting an altered identity; (3) latent: living between illness and health; and (4) manifest: passage to social and physical death.

The same disease can be stigmatized differently in varying times and spaces (places and communities). Works by Goffman (1963), Katz (1979) and Alonzo and Reynolds (1995:305) draw upon a number of factors that affect the intensity and nature of disease stigmatization. The nature of specific cultural associations of the disease with particular marginalized groups (gay men, for example) or with behaviors already labeled as deviant can lead to stigmatization, because they transgress moral codes (e.g. female promiscuity, unfaithfulness in marriage). The social acceptability of expressing stigmatizing beliefs toward a specific group can be determined by cultural or community norms as well as mass media, politicians and other social leaders. Sometimes there are cultural associations linked with other historically stigmatized diseases (Wailoo, 2001; Brandt, 1985). At the individual level, culturally mediated assessments of the role and responsibility of the individual in contracting the disease may be the root cause of self-stigmatization. Sometimes controllability, responsibility and blame may have different psychological constructs that form an attributional hierarchy in which blame is the final step (Mantler et al., 2003).

However, in the situational context, stigmatization (both actual and perceived) varies according to the social context of and the power differentials in an interaction (Malcolm et al., 1998; Worthington & Myers, 2003) that can include the number and status of stigmatized people present. In certain socio-economic contexts such as resource-poor situations where there is little state support, some beliefs about PLHA will have greater impact (e.g. that they will be draining on resources) and create more of a focus for stigmatizing ideology (Patient & Orr, 2003).

In the Indian context, social components such as families and communities generally provide a supportive environment for illness management and treatment and thereby influence the associated stigma (Bharat, 1996). This phenomenon may vary by different circumstances (different categories of people). An Indian study found that out of people who had shared their HIV status with their families received care and support, it was largely men than women who qualified for such care (Bharat, 1996). Forms of discrimination against women with HIV included refusing them shelter, denying them a share of household property, denying them access to treatment and care, and blaming them for their husbands' HIV diagnosis, especially when the diagnosis was made soon after marriage.

In the Indian situation, family responses to infected relatives are heavily influenced by community perceptions of the disease. Families that include an individual with HIV may fear isolation and ostracism within the community (Warwick et al, 1998; Bharat & Aggleton, 1999). Consequently, they may try to conceal an HIV diagnosis, which in turn may cause considerable stress and depression within the family (Bharat & Aggleton, 1999).

### **1.2 Contextualization of the Study**

A critical analysis of studies by Goffman (1963), Katz (1979) and Alonzo and Reynolds (1995), reveals the effects, manifestations or types of stigma. But the process or mechanism behind the development of the stigmatization in specific situations and different populations remains unclear. Most studies visualize the concept of stigma as a single, composite product and explicitly discuss other possible facets of the same without explaining how the concept may change under varying circumstances. Parker and Aggleton (2003) observe that "...though stigma were a static attitude rather than a constantly changing (and often resisted) social process has seriously limited the ways in which stigmatization and discrimination have been approached in relation to HIV

and AIDS.” For example, the factor of “time lapse” could have both a reducing and an amplifying effect on the intensity of stigma. If a person (PLH) gains proper knowledge about the epidemiology and contagiousness of HIV and AIDS or is exposed to subsequent rehabilitation programs, the magnitude of the stigma can be reduced. Alternatively, the progress toward advanced phases of AIDS-related illness leading to death can heighten the stigma.

A number of researchers (Alonzo and Reynolds, 1995; Freidson, 1970) agree that the stigma attached to HIV/AIDS occurs either at the individual or social level, which may or may not be in relation to society at large. Some have mixed the individual level stigma with non-individual levels such as societal or family level stigma. As a result, this does not provide a clear picture, because stigma related to the self (individual) may have reasons and processes that differ from those related to the family or society (social process). Even though sociologist Gerhard Falk (2001) recognized the role of the stigmatizer to be important in understanding stigma, little emphasis appears in other studies. Hence the role of stigmatized person itself, that is the individual / internal role vis-à-vis role of external or social factors in influence the stigma needs to be explored. Bond et al. and Lie & Biswalo (in Visser et al. 2007) observe that people are sometimes more fearful of the social consequences of AIDS than of the disease itself. However, not many studies have made a disaggregated analysis to explain such a phenomenon in terms of the nature and intensity of stigma in different contexts. Stigma adds negativity to the existing value of life, the intensity of which varies from person to person with changing aspects of life.

Dwelling on all these various viewpoints, this study operationalizes the concept of ‘stigma’ as the combination of both perceived and enacted stigma since a thin line between the two is tricky when persons stigmatizing about one or more actual acts of discrimination might have occurred to them or any similar other person. Further we also take into consideration the self stigma perceived at individual level which is not actually a direct contribution of any outsider. Similarly, this paper does not make any attempt to bring about distinctions between expression of stigma regarding HIV infection and individuals at risk of such infection. The objective the study is to understand the process in exploring causes (underlying factors) and possible variations in the nature and intensity of stigma at varying time and contexts. .

## 2. HYPOTHESES

Based on literature reviews and theoretical understanding, the following hypotheses are proposed.

H1: At the individual level, the higher the level of knowledge about epidemiology of HIV and AIDS, interaction with infected persons, and adaptability, the lower the stigma

H2: The higher the level of social (familial) support and resilience, the lower the degree of stigma

H3: The level of stigmatization depends on whether the context is physiological, economic, social, or a combination of any such contexts.

## 3. MATERIALS AND METHODS

This study employs qualitative tools such as 8 Focus Group Discussions (FGD) and 24 Narratives to elicit information from HIV-positive persons. To understand the stigma perceptions before, during, and after being HIV positive, the study collected information from three categories of persons such as:

A. Not-yet-identified HIV positive: This category covers

- i. people not yet interacted with any HIV positive person
- ii. people interacted with any HIV positive person or AIDS patient
- iii. trained HIV and AIDS counselors

B. Just-identified as HIV positive: People who recently received pathological test report that confirms HIV in blood

C. Already-living-with HIV: Persons and few HIV counselors living with HIV in their blood for last one year up to 10 years.

The information were mainly gathered from AIDS service organizations, Associations of HIV positive people, government hospital, Integrated Counseling and Testing Center (ICTC), few villages in Ahmedabad and Mehsana districts of Gujarat, which are a sort of high prevalence districts of India (NACO, 2007). The information were collected from major socio-economic categories such as age group, sex, education status, standard of living, religion and epidemiological categories such as period of diagnosis, ART (Anti-Retroviral Therapy) status etc. Data collection was conducted through different phases of face-to-face discussions during August 2008–January 2009. The data collection process followed the ethical principles while contacting HIV positive persons and conducting Focus Group Discussions. While the respondents were not mandated to sign a consent form, they were clearly explained that the information they provide will not be divulged to anyone, and it will be used for research purpose only and that they were free not to respond to all or

any of the questions put to them. Their decision would be respected and it will in no way harm them or held against them at any point.

Following are some of the limitations of the study:

- Geographical location as this study looks for one Indian province
- Limited case studies as the study solely depends on focus group discussions
- Limited data analysis, as this study is a qualitative one

#### 4. FINDINGS.

##### 4.1. Circumstantial Dimensions (Nature) of Stigma surrounding HIV and AIDS

By now it is well established that HIV related stigma is neither a single composite product, nor static by nature (Parker and Aggleton, 2003; Alonzo and Reynolds, 1995), and can be influenced by the stigmatizer (Gerhard Falk, 2001). Same is the case that stigma could well vary by nature and magnitude, in different aspects of life (circumstances). The circumstances in its broad nature could be:

1. Physiological Dimensions: perceived or enacted stigma related to the body
2. Social Dimensions: In terms of social aspects of life, the stigma develops through interaction with society in terms of

the person's cultural, religious or political life.

3. Economic Dimensions: relates to perceived problems in income generation process of the stigmatized person.

By aspects of life, it is tricky process to identify thin lines between the stigma in terms of physiological, social and economic dimensions, not only as the circumstances are inclusive in nature, but also because the stigma could be the outcome of additive or interactive effects of all the three contexts. The information of the current study are tested by three such dimensions. It also included the stigma perceived about self (HIV positive person) as well as its family/ society. For the sake of reference convenience, the responses are categorized and presented by three broad time phases of HIV diagnosis. The words in italics indicate the frequent responses.

The Table 1 shows the physiological stigma in different time phases. Before the diagnosis of HIV in Blood, the intensity of stigmatization depends heavily on the perceived epidemiology of the illness (AIDS) and associated bodily experiences. A majority perceives AIDS to be responsible for an untimely death, having no idea on HIV neither by the abbreviation nor the meaning of the HIV as a situation and conditionality around. For this reason, people are unable to attach a well defined negativity to AIDS condition than mere illness led impairments. This phase also develops a state of

**Table 1. Physiological stigma in different time phases**

Time	Physiological Stigma
Before diagnosis of HIV in Blood	AIDS lead to untimely death but no idea on HIV A major disease or may lead to major illnesses Higher probability and easy to be transmitted Lower probability of getting infected, not clear about magnitude and route (A2 only) Probable Infection to family/ society members due to contagious nature of HIV Normal daily services should not be taken from PLH
Immediately when diagnosed with HIV	Life is very short, as HIV=AIDS = die very soon (no chance of survival for long) Thinness and Abomination (disfigured skin) Continuous degradation of life processes and sufferings before untimely death Sexual partner and acquaintances might have got infected
Post-diagnosis (after spending months or years with HIV)	Opportunistic infections Stigma reduce by sharing problems with PLH Although HIV infection does not mean AIDS and immediate death, but this infection leads to untimely and undesired death Over-consciousness about sexual behaviour, diet and lifestyle Less work efficiency



confusion among people regarding the probability of transmission of the virus or illness, which varies by the magnitude (depth) and quality of knowledge about HIV and AIDS and exposure to any live cases (HIV positive people).

During the phase persons immediately diagnosed with HIV, physiological stigma perceptions are extremely impulsive in nature and most people tend to get confused with HIV as AIDS and quickly decipher the later as immediate end of life. This phenomenon reflects a lower level (depth) of knowledge regarding epidemiology of the illness. The intensity of stigma also get aggravated by stereotype behaviour of health care workers (doctors, lab technician) such as non provision of clear and complete information on test results, denial of certain services or immediate referral to big hospitals, higher estimate of time and cost for treatment and so on. Based on frequent observations of respondents' perceptions, we strongly infer that, to a great extent, people at different domain are responsible for such confusions, since they present (written or verbally) the words HIV and AIDS together just putting a slash (/) in between which possibly recreate a me-

aning that HIV and AIDS are a single condition, in spite of the fact that a long time-gap exist between the two.

During the phase individuals already spent sometime with HIV, the negative valuing of life or stigmatization reduce steeply after a considerable departure of time, as with the passage of time, PLH get exposure to knowledge environment (counseling) from health system or mass media or service agencies. This brings down the level of stigma from perception of death to life, even if fear of untimely & undesired death and opportunistic infections continues to bother. Although people feel the importance of not stigmatizing about HIV and AIDS, at the same time they overemphasize the need of responsible sexual behaviour, better diet and lifestyle for possible prolonged and normal life.

The Table 2 shows the social stigma in different time phases. Before the diagnosis of HIV in blood, the intensity of stigmatization, stigma does not acquire a definite shape rather individuals develop vague impressions that infected person has got acquaintance with undesired people or situations thereby developing chances of being discriminated in social net-

**Table 2. Social stigma in different time phases**

Time	Social Stigma
<b>Before diagnosis of HIV in Blood</b>	Acquaintance with undesired people or situations (Immoral Characterization/ Character Blemish) Discrimination (Reduced or problematic) in social networking for self and family members
<b>Immediately when diagnosed with HIV</b>	Character blemish (Labeling and link with unappreciated high risk group) Blame and shame on self and people around (spouse, friends etc.) Loss of face Discrimination and prejudice towards self and family members (marriage/ engagement of daughter may break) Keep secret about own and family member's HIV infection Migration to keep away from known people Reduced / Poor social support
<b>Post-diagnosis (after spending months or years with HIV)</b>	Linked to undesirable behaviour or high risk group even if innocent Partial Discrimination/ separation within family and society Symbolic stigma/ Stereotype / ambiguous non-verbal cues towards self and family members Care and support with some blame and shame Labeled as black sheep in family / society Maintain concealability at self and by family members to unrelated people Loss of face Social distance to children by service providers and peers (school, playground) Bring bad name to family and society

working both for self as well as family members. During the phase persons immediately diagnosed with HIV, social stigma take a journey from a well defined form such as abomination (disfigured skin) to equivocal concepts like thinness or 'mind getting blocked and could not think further'. However, persons at this phase often stigmatize on continuous degradation of life processes and sufferings before untimely death as well as quite surely that sexual partner and acquaintances (may include offspring) to be infected.

During the phase individuals already spent sometime with HIV, social stigma appears to be stronger than before the detection of HIV. Persons face enacted stigma in terms of a clear blemish of character in the form of labeling. They also stigmatize in terms of devaluing of social life or fearing partial or increased discrimination within family or society in the form of blame, stereotype or isolation. The stigma is perceived in the form of spousal disharmony, care & support with some blame and shame, link with unappreciated high risk group and so on. People infected with HIV immediately perceive to have lost face in family and society and fear of getting no or reduced support.

The Table 3 shows the economic dimensions of social stigma in different time phases. Before the diagnosis of HIV in Blood, economic stigma perceptions does not offer a clear picture and vivid ideas sprout on very high expenses and poor income for the infected person and its family members. During

the phase persons immediately diagnosed with HIV, economic insecurity runs acute and persons stigmatize to the level of being thrown out from job by the employer or loss of face and discrimination leading to poor business (earning). Persons also stigmatize this phase as an economic disaster to the extent of visualizing family members on road in addition to a common fear of elevated family expense towards treatment.

During the phase individuals already spent sometime with HIV, the economic stigma declines slowly by intensity when supports are provided by service agencies in the form of free treatment, livelihood activities and so on. The PLH continue to stigmatize in terms of facing higher discrimination in skilled jobs category to the extent of job loss and reduced chance of new recruitment. It is perceived that the family of PLH continues to face some economic pressure due to reduction in family income attributed to HIV related illness and increased cost (travel and opportunity cost) towards care.

#### 4.2. Dynamic Process of Stigmatization

The current study decompose the stigma life-cycle into 3 time phases to understand possible effects of 'time lapse' on the intensity of HIV and AIDS related stigma.

- A. Life before the detection of HIV status
- B. Life during the immediate detection of HIV in blood
- C. Life after HIV detected in blood

The stigma perceptions from the respondents who have not yet got any information on, interaction with or clinical ex-

**Table 3. Economic stigma in different time phases**

Time	Economic Stigma
Before diagnosis of HIV in Blood	Family Expenses increase towards treatment Not able to lead healthy life hence earning declines
Immediately when diagnosed with HIV	Loss of job or earning Very high expense towards treatment Economic disaster to family (on road) Prolonged illness & burden to the fami
Post-diagnosis (after spending months or years with HIV)	Discrimination in skilled job category to the extent of job/ business loss No/ reduced chance of new recruitment Discriminated in job appraisal Lower contribution to family income Less economic stigma as service agencies provide free care and treatment Family continue to face economic pressure as total productivity reduce due to illness and increase in non-medicine costs (travel, time and opportunity cost) towards care



posure to HIV, present different kind of stigma with varying intensity. These perceptions are put into a hypothetical graphical representation. This took the form of an inverted J-shaped “stigma curve” (Figure 1). They have been explained in the figure and text through 3 broad phases A, B and C.

Phase A: Life before the detection of HIV status

The phase A represents the dynamics of stigma “before” the detection of HIV status (pre-diagnosis) and presents the changes in level of stigma at different points such as  $A^0$ ,  $A^1$ ,  $A^2$  and  $A^3$ . The point  $A^0$  illustrates the lowest level of stigma due to insignificant knowledge and ignorance about HIV and AIDS. This point could be hypothetical in nature given the situation of current-day general media exposure about HIV and AIDS. With the passage of time and acquaintance to situations (or cases) related to HIV or AIDS in the form of incidents, discussions or media communications, the individual may develop some impression, which in turn may elevate the stigma (denoted by the point  $A^1$ ). This is due to incomplete and incorrect information associated with a negative hype on HIV and AIDS. A person who has heard about HIV but not clinically infected with HIV says:

*I feel we can buy vegetables from a vendor who has HIV, but we should not buy things if there is any sickness. Because, HIV may pass to us through vegetable which s/he has hold.*

A PLH recalls about the past when he had not contracted HIV says:

*I had no such clear-cut information about HIV or AIDS. I used to read behind (about this) AMTS (local) bus. I had no prior knowledge. Vividh bharti radio program use to talk about this about 2 and half year ago when it ALSO started on TV. I had heard from people that it is the end of life, people are being discriminated.*

Contrast to this, when individuals are exposed further to real life HIV situations by virtue of face-to-face interactions with HIV positive persons (denoted by the point  $A^2$ ), the magnitude of stigma tends to weaken down little. This is because the interaction gives some option to know actual means of HIV transmission, its non-contagious nature and a realistic picture of day-to-day life with HIV.

*Sometimes back, I was not keeping well and lost weight. Doctors asked me a test but father refused saying that there is no need. Still I wanted to go for the test. I got it done in government hospital and found myself positive. I wanted to reconfirm so I changed my name and got tested in a private hospital paying Rs.600 and diagnosed positive.*

Associated with any reason, when the individual goes for blood test on HIV, the stigma continues to ascend up till the receipt of the result. If the result of the test comes out to be negative (denoted by point  $A^3$ ), the ascent of stigma curve takes a different turn rather than going to a peak. Then the person continues to live with some stigma till receiving suitable counseling further as shown in the point  $C^1$ . Total length of the Phase A may vary from a day to months or few years before the actual detection of HIV in the blood. Overall, this phase is characterized by three major constructs such as Ignorance about the AIDS process, Exposure to AIDS situations and Interaction with AIDS affected persons.

Phase B: Life during the immediate detection of HIV in blood

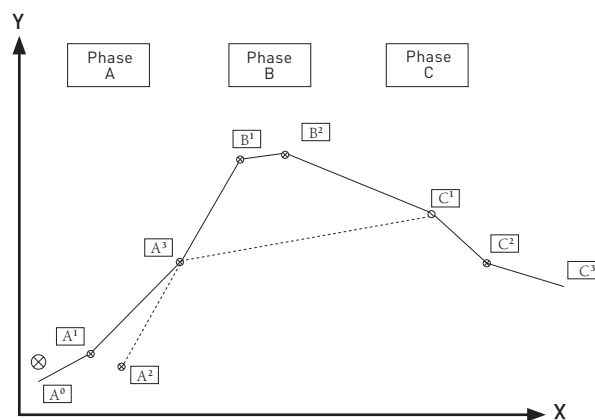
When the information (test or any relied information) is received that confirms the existence of virus in blood, stigma shoots northward to the peak (the point  $B^1$ ) immediately as an impulse.

*My (female) immediate reaction after knowing the HIV positive status was that I would die and there is no meaning to my life.*

The process of stigmatization continues further (the point  $B^2$ ) till the time when perceptions or experience of discrimi-

**Figure 1. A hypothetical model of Stigmatization on HIV and AIDS**

Phases → A. Pre-diagnosis, B. Diagnosed+ve, C. Post-diagnosis counseling and support



(Inverted J- shaped curve shows change in Level of Stigma by Knowledge and Support; Y-axis denotes Level of stigma and X- axis → Level of Knowledge and Support)

nation take more or less a definitive shape. The phase B may vary from an hour to a couple of days or a week. This phase is vital since some such HIV positive people take as stringent actions as suicide immediately (Times of India, Ahmedabad version, 23<sup>rd</sup> October 2008 page 10) or within few months (Times of India, Ahmedabad version, 19<sup>th</sup> November 2008 Page 3) or few years (Indian Express, supplement front page, 18th March 2009 Page 5). This shows the significance of research on stigma for working out proper interventions.

*...Before this infection (HIV), I (male) had never heard of this deadly virus. The thought of my family's well being made me worried as I am the prime earner around which the entire family's well being revolves. I thought after my death my family would be on roads; hence I was extremely depressed.*

This phase is reflected in terms of a kind of identity in Illusion.

Phase C: Life after HIV detected in blood

In the model, the phase C represents the life after HIV is detected in blood that starts with the process of coping with impulsive stigma and changes due to exposure to service system such as counseling, health care, support and so on. Immediate counseling after the detection of HIV in blood lowers down the stigma significantly (implied by the point C<sup>1</sup>) till the PLH gets anchored with any service agency providing humanizing benefits.

*I (female) was very depressed after knowing my status... the term AIDS triggered fear and anxiety in my mind as I thought of AIDS is the end of life, but later the counselor clarified my doubt. After being associated with the service agency (name undisclosed) and their livelihood program, life is somewhat comfortable. People around also do not show any explicit discrimination.*

With this arrangement, stigmatization further comes down (implied by the point C<sup>2</sup>) on the aspects in which the person perceives some normalization (adaptation) of life and receive supports. This phase may continue from 1-2 years to as long as 8-10 years or more till the period closer to death (denoted as point C<sup>n</sup> of Phase C). Overall, this phase is characterized by three major constructs such as counseling from PLH counselors, resilience by PHL to realities and supports available in terms of different stigma contexts.

The current study makes it clear that every individual irrespective of being affected or not, may not pass through all the points on the "stigma curve". Rather there may be departures at certain points such as A<sup>2</sup> (when there is no interaction with PLH).

#### 4.3. A Combined Perspective

Both PLH as well as general people are largely unaware that their attitude and actions are stigmatizing. They spoke of the importance of not stigmatizing about HIV/AIDS but at the same time talked on the need of "being responsible", "behave correctly", "discuss when necessary", "happened to self and others should not get" and so on. Although words look positive, they emerge out of negative feeling about the situation (life with HIV) in the form of self-stigmatization. There are no words for expressing stigma in some languages as opposed to discrimination; language is central to how stigma is expressed, through words used by individuals, the media and in educational materials (McKee et al 2004). For instance, people working with PLH are often referred to as *AIDS wale log* (persons with AIDS), *jindegii chota hey* (going to die very soon). Sometimes, stigma is expressed by avoidance added with non-verbal expression.

The complex interaction between knowledge and fear manifest in such an unexpected way that this allow stigma and discrimination to persist side-by-side. People maintain both correct and incorrect knowledge; for example, even when people know how HIV is transmitted, they still fear casual contacts. Irrespective of understanding the difference between HIV and AIDS, people equate HIV-positive test results with imminence death and shun HIV positive persons for this reason. Some of the close correlates of HIV-related stigma are sex, morality, shame and blame existing between the PLH and society around. HIV is usually associated with identified high-risk groups: sex workers, MSM, IDU and bar ladies etc. HIV positive people have often been wrongly perceived to have brought shame to their family and communities. Hence persons infected with HIV are stigmatized as members of high-risk category and through this they might have contracted the virus.

In an ideal condition, individuals living with HIV should feel able to disclose their status, but fear of being discriminated (meta-image) by society makes it difficult to do so. People often try to infer HIV status through changes in behaviour, symptoms and weight loss. Extensive care and support for HIV positive people coexist with stigma and discrimination. Love and care coexist with blame, separation, stereotype, or believing PLH are less worthy or worthless.

Overall observation of all phases present comparative picture of stigmatization processes at different phases of time and contexts, and this reveals a complex but interesting phenomenon. A simple observation on the number

of different stigma perceptions reported gives an impression that people develop more stigma related to their social aspects followed by physiological and economic aspects, although this may vary with different phases (A, B and C). Often observed the magnitude of stigma in physiological as well as economic contexts tends to peak during the immediate detection of HIV and comes down slowly with the access to knowledge and support on health and livelihood aspects. The stigma dips further when the PLH actually gets anchored with some definite programs from service agencies for humanizing benefits. In contrast, the stigma in social contexts become more pronounced with departure of some time after the actual detection of HIV, as the social realities come one by one as life proceeds with HIV. Again, decline in the intensity of stigma in social aspects is slower compared to other aspects. This is because societal components take much longer to change from an established shape, sometimes reported as *vehem* in Hindi language.

## 5. TO SUM UP

In the line of understanding the theoretical framework of stigma added with its importance for policy makers, current study is a modest attempt to unearth possible facets of stigma surrounding HIV and AIDS at different time and space. Evidence from live experience of PLH juxtaposed on theoretical understandings and critical analysis of earlier studies together brings out important insights.

A number of factors play significant role in developing stigma or altering its intensity or simply acting as a catalyst in the process without being explicit, also sometimes referred by Alonzo and Reynolds (1995) as stigma construction and management. In depth analysis of narratives from field study revealed a range of such important factors responsible for stigma in relation to person itself (as internalized stigma observed by Berger et al. 2001) and to society at large. However, the mechanism involved with effect of these factors on the contents and magnitude of stigma is so complex, that drawing a thin line between purely individual and social level factors is absolutely tricky.

It is observed by this study that at individual level, the quantity and quality of education and awareness about HIV

and AIDS emerged as a significant determinant of intensity and nature of stigma at different phases of time. Correct information particularly on the biophysical (epidemiology) nature of HIV as well as AIDS can help people reducing the stigma. Another significant factor is the prior history of marginalization- social, economic or physiological has a strong bearing on stigmatization. People coming from lower social (education) and economic section (standard of living) or with poor physical health (less immunity, weak, disable) are more vulnerable to stigmatization. The higher level of self-esteem often linked with higher socio-economic background are found to have a positive impact on the intensity of stigma as also observed in Lawrence and Arthur, 2008. Some of the distinct factors such as distal migration, longer period after divorce, apathy due to longer period of exposure to HIV have a reducing effect on the intensity of stigma. The study overall infers that that the nature and level of stigma are largely decided by personal and geo-cultural (social) background of persons living with HIV. Individual level knowledge and attitude towards life, and familial or societal interpretation on worthiness of life after infection emerged as major determinants of stigma. Finally, three most important variables such as depth of knowledge about the epidemiology of HIV and AIDS, personal or individual level resilience or adaptability and availability of support (Physiological, social and economic), their nature and magnitude are found responsible for the content and intensity of stigma.

The current study provides a strong theoretical base in new understanding of the stigmatization process. Results of this disaggregate analysis contribute some innovative approaches to HIV and AIDS stigma in not only giving a broad picture on its dynamics but also the variation in the level by different realistic contexts such as social (include cultural and political), economic and physiological. So this brings about wide-ranging implications to specific program managers working towards combating against social, economic and physiological stigma both at Indian and International level. The stigma curve developed by the study clearly implies that intensity and nature of stigma varies by different phases and contexts, and warrants the need of appropriate interventions.

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