HIV/AIDS STIGMA AND DISCRIMINATION: A KERALA EXPERIENCE

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Background

It goes without saying that HIV/AIDS is as much about social phenomena as it is about biological and medical concerns. Across the world, the global pandemic of HIV/AIDS has shown itself capable of triggering responses of compassion, solidarity and support, bringing out the best in people, their families and communities. But the disease is also associated with stigma, ostracism, repression and discrimination as HIV affected individuals (or believed to be affected) have been rejected by their families, their loved ones and their communities. This rejection holds as true in the rich countries of the north as it does in the poorer and developing countries of the south. All over the world, ignorance, lack of knowledge, fear and denial have engendered serious and often tragic consequences, denying people living with HIV/AIDS access to treatments, services and support, as well as making it hard for prevention work to take place. The epidemic of fear, stigmatization and discrimination has undermined the ability of individuals, families and societies to protect themselves and provide support and reassurance to those infected

HIV positive/AIDS patients are forced to take asylum elsewhere as their family members refuse to take responsibility of care. Job, finance, family relationship are some of the major issues they are struggling with in addition to housing/accommodation and food problems. THRANI tries to resolve some of the issues of HIV positives by networking with St. Vincent's home, Muringoor and Bishop Markundukulam Memorial Research and Rehabilitation Center, Thrissur. Financial difficulties are one of the major problems faced by HIV patients, especially of lower social class. They do not even have enough money to fetch daily food. In this circumstance it is not possible for them to think about spending on medicines and treatment. A young couple, Mani & Raji was tested to be HIV infected. Their eldest son died of AIDS. Mani was a head load worker and now he is suffering from opportunistic infection of T.B. He is unable go for any heavy work. They were in a very hard situation to find money for treatment and to look after their child. Their relatives are reluctant to help them and refused to interact with them. They were in a severely depressed condition when they came to Thrani. They were counseled and were provided with medicines for T.B. To tackle their financial difficulties, THRANI is assisting them to start some small-scale business with the help of Panchayat authorities.

Jaya and her husband Raju is another HIV positive couple faced discrimination in hospital. Raju is suffering from T.B. and the doctors and the nurses at the T.B. sanatorium were reluctant to treat him, as he is HIV infected. He was forced to discharge from the sanatorium. When they reached THRANI for assistance, they were in a severely depressed and highly suicidal condition. They were counseled and Raju was admitted at general hospital and was given proper treatment. The authorities at the T.B center marked in Raju's treatment card as HIV positive with bold letters. This was preventing them to fetch medicines from shops or other hospitals. THRANI intervened and helped Raju to get a new card that does not reveal his HIV status.

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Her husband deserted Sumathy and her three-month-old female baby, three months ago. Both them were later found infected with HIV, and the baby was seriously suffering from pneumonia. The child was forcefully discharged from the Government run Mother & Child Care Hospital, when the staff came to know that the young baby is seropositive. With the help of THRANI team the child was readmitted at SAT hospital and given treatment. Further, THRANI team made the necessary arrangements for the rehabilitation and further treatment of the mother and child.

Above are a few of the harsh realities of HIV patients; in the context THRANI team ventured to explore the difficulties of more HIV patients and report the findings, as each and every one of the HIV clients had a bitter story to tell. THRANI team sincerely expects these revelations be an eye-opener to the society. HIV/AIDS clients coming to THRANI crisis control center were interviewed in depth and text-recorded, as a part of counseling and psychotherapeutics offered. All the five counselors at THRANI are specially trained in HIV/AIDS counseling apart from being well qualified mental health professionals. Later, professional translators of THRANI team translate these verbatim reports of the clients to English as far as possible keeping the meaning and context in tact. The study is structured into qualitative design and names of subjects were changed to preserve identity.

Verbatim Reports

While the focus of the fieldwork was on stigmatization and its consequences within the health care and employment settings, stigmatization and discrimination in intimate relationships at home, in the community and even after death (in relation to the disposal of bodies and funeral arrangements) were also discussed. In each of these settings, felt and enacted stigma were discerned, as well as HIV/AIDS-related stigmatization and discrimination in both overt and covert forms. The majority of people living with HIV/AIDS who were interviewed had learned about their serostatus either during an illness, surgery or pregnancy. Differential treatment was reported as occurring immediately after (and sometimes even before) disclosure was made.

Veena, wife of a HIV-positive truck driver was also tested HIV-positive recently. When they went to the hospital for treatment, some nurses and house surgeons in that hospital told them that the HIV spread through air so their sneezing or spitting may cause infection to other patients. It is embarrassing to note that even some of the medical staff does not have the basic information about HIV/AIDS.

> She recounted: *"The staff were looking after my husband well, but after they tested his blood for HIV their behavior changed and they separated our vessels, pushed him to a corner of the room and talked about us in hushed tones. I couldn't understand why their (doctors) behavior had become so cold and pathetic".*

Madhu was admitted in the hospital due to pneumonia, but in further test the doctors understood that he was HIV carrier and was immediately shifted from ward to an isolated

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room saying that the other patients in the ward may get in infected. His doctors also gave instruction to other paramedical staff not to visit the patient often.

> He says, *"My blood was tested and from that day they stopped giving me injections. They didn't tell me why."*

In Kerala, individuals diagnosed with HIV/AIDS in private hospitals were frequently transferred to government hospitals where conditions and the quality of care are often far worse.

> As a surgeon in a government hospital explained: *"In private hospitals the news of HIV-positive patients once detected is closely guarded and the patient is conveniently transferred to a government hospital."*

In an investigation by THRANI team about the attitude among doctors of various hospitals in Kerala, a physician attached to a private hospital said:

> *"We are not bound by any rule to give treatment to positive patients. Let the government hospitals take that responsibility. There is a great risk of infection to my staff, and I'm responsible for my staff's welfare and health."*

Elsewhere in the State, a few private hospitals were reported as accepting people living with HIV/AIDS as patients – although this acceptance came with a price. The costs of fumigating operating theatres and labor rooms, HIV/AIDS kit to all staff assisting in surgery, amounted in some medical professionals' eyes to an indirect form of discrimination against people living with HIV/AIDS.

During the course of the study, it was possible to identify some of the ways in which the identity of HIV-positive patients was marked. Medical files in the majority of hospitals in Thiruvananthapuram are theoretically kept in the safe custody of the ward nurse, but in some hospitals the identity of HIV-positive patients on the general ward for economically poorer patients was plain for all to see.

> An attendant explained: *"When the patient comes to our ward, it's written on the file 'HIV' in big letters. It's kept next to the patient. Anybody can see it."*

Numerous accounts were elicited of medical and nursing staff breaking the confidentiality of an HIV-positive diagnosis and telling family members and relatives before the patient him/herself. A couple came to the crisis control center revealed the following,

> Husband: *"The doctor didn't inform me. He informed my wife and asked her to inform me."*
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> Wife: *I took my husband to the lab and got his blood tested. After two days they called me and informed me that my husband's blood test result was positive. My husband*

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> *informed them that he had illegal relationships with a woman three years back. The doctor told me the news."*

Some doctors and nurses argued that this was done so as to protect the patient from shock and possible self-destructive behavior.

> As a nurse explained: *"The patient, as it is, is half-dead. If he is told of the test results, he might commit suicide."*

There was considerable evidence that once the news of HIV infection had reached relatives the outcomes were far from supportive. Young women in particular reported being blamed and rejected by other family members. Men were dealt with far more supportively and positively.

> As Susanna a 35-year-old HIV-positive woman from Ernakulam explained: *"My in-laws blame me for their son's death. They have severed all relationships with me. They never discriminated with their son but to me they say, 'you gave him AIDS through your bad deeds.' I took great care of their son – never felt dirty cleaning him up. But my in-laws used to say 'you married him and our son got bedridden'. I have lost faith in everybody."*

And as Gomathy of Kollam complained that her in-laws are forcing her husband to divorce her. They were blaming her that it was due to her infidelity she incurred this disease and infected their son.

> She recounted: *"My in-laws never had a good opinion about me. They say that my husband got this disease from me. I sometimes feel why should I live with the insult. It is better to die. But I am living for the sake of my children."*

Narayanan, an auto driver from Kollam was tested HIV-positive. He disclosed the first result to his family. But the consequence was frightening. His relatives, including his wife and children left him.

> He says: *"Even after having done everything to my family, I am dead for them."*

Another incident is of 7-year old boy, whose parents died due to HIV infection was tested HIV-positive. His relatives become reluctant to look after him, knowing his HIV-positive status and deserted him. Latha, 26-year old HIV-positive was wife of late Sudhakaran who died of AIDS. Knowing this, her parent's behavior towards her became so indifferent. This was because she had a younger sister who was unmarried. Thus her family started considering her as a burden.

> She asks: *"Will you be able to believe that I was cursed everyday by my own parents that I die in another 90 days?"*

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Conscious discrimination against young children at schools is more heart breaking. Raju, 9-year-old student was discriminated among the school friends and teachers. He was given a separate chair in the classroom knowing that he has a HIV positive patient.

> He was totally lonely in all matters at school atmosphere. *"I only know my parents got some disease… these people think I am also having the same illness"*.

HIV-positive interviewees reported experiencing strong pressures to keep their serostatus secret within the workplace. The shame of admitting to colleagues and friends that you have HIV, coupled with the perceived likelihood of being dismissed on discovery, combined to silence the majority of respondents. One HIV-positive bachelor from Thiruvananthapuram district was reluctant to disclose the test result even to his mother. He is working, as a supervisor in an ice factory. His fear was that he may lose his job and the people may isolate him. So he lost the chance to share his distress with others and to get support from them.

> As he put it: *"You know how the society is. They want your reputation to be sullied. I know if my HIV status comes to be known to them, they will call me names, laugh at me, jeer at me, and I'll have no other option than to commit suicide. I shudder at the very thought."*
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> And as Joy (a HIV-positive gay) explained: *"And who will give me a job? My health will not be good. What will I do for my living? So it is better not to tell anybody, and go on doing what I do to fetch my living."*

Joy left his home at a younger age in search of job, and was working as drug peddler in Bangalore city; he was infected thorough intravenous drug use. He also had homosexual and heterosexual relationships with many people in the city. Counseling helped him to cope with fear of death and he started pursuing his clients to use condoms, especially in anal sexual acts with him.

The experience of those few respondents who had revealed their serostatus at work were far from reassuring: Dr. Rajeevan is a doctor in a big hospital from Kanyakumari who was found HIV-positive. He said that the patients are afraid to consult him knowing his HIV-positive status.

> He says: *"My colleagues didn't openly say anything to me, but the environment was no longer the same. They avoided me. If I entered the room they would leave abruptly"*.

Alex was a 25-year-old smart executive who was loved by his parents, friends and other office staffs. But to his fate he happened to be HIV positive, through blood transfusion when he had an accident 5-years back. This was the only reason that Alex was isolated from social activities, friends and staff who neglected while he approached them. He was even forced to resign from his job.

> *"Those staff members who know about me talk about it. They secretly point at me and say 'Look, he is the HIV*

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> *fellow.' They keep their distance from me and remain aloof. I don't feel like coming to work. I remain absent for 10-15 days and then lose wages. Finally I decided to end that job."*

In the majority of businesses with whom contact was made, denial was the order of the day. Personnel managers and welfare officers refused to acknowledge either that HIV infection was a problem or that it might be so in the future.

> The human resource development officer in a software company at Thiruvananthapuram said that: *"Our staff is very highly paid. They are drawn from the most reputed institutes and we are quite sure they do not have behavior which makes them suspect for HIV. They are very well educated and have easy access to sources of information, so cannot easily fall for such things."*

Findings of the present investigation

People with HIV and AIDS face widespread discrimination from all sectors of society. The report from the Terence Higgins Trust, suggests that one in five people diagnosed with HIV/AIDS have experienced prejudice in the past 12 months. The report claims discrimination and, more importantly, fear of discrimination, is a problem in the workplace, at home and within the health care system itself. In the THRANI-team experience, such fears prevent many people from coming forward to be tested, and counseled. Immediate efforts are to be channeled for an extensive public awareness campaign for reducing discrimination against people living with HIV. It is important to recognize that people with HIV have just as much right to be treated properly as anyone else with a long-term illness.

There can be several factors strengthen the forms of stigmatization and discrimination against HIV/AIDS prevalent in the community. Many of these relate to the very real fear of HIV/AIDS that exists among both the general public and professionally qualified health care workers. The sources of these fears are complex and include lack of knowledge and understanding, as well as the manner in which AIDS has been reported in the national and local media (e.g. as being highly "contagious" when in fact it is not). Other causes of stigma and discrimination have their origins deep within Indian culture and the manner in which "sexual wrongdoing" is popularly understood.

Individuals, particularly those within the health care setting appear to relate both to lack of knowledge about HIV/AIDS, its routes of transmission and means of protection, as well as to local beliefs about infection through closeness and proximity. Long-standing ideologies of gender that result in women being blamed for the transmission of sexually transmitted infections – either directly as the supposed "vectors" of transmission or indirectly through failing to "satisfy" their husbands – influence the ways in which families and communities react to the seropositivity of their members. While seropositive men may be offered support and care, the same is unlikely to be true for women – many of whom are blamed for the illnesses from which they and their husbands may suffer.

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Processes of stigmatization, whereby people living with HIV/AIDS are rendered outsiders and "others", are also reinforced by the tendency for people living with HIV/AIDS to make themselves invisible and to disavow their condition. This enables employers and others to deny that there is a problem.

HIV/AIDS has evoked a variety of responses in Kerala context, some of them positive, others considerably less so. At the positive end of the spectrum are the reactions of households and families who agreed to provide care and support for affected members. These responses were relatively infrequent, but were more likely to occur when male household members rather than women were affected. Much more common were responses of ostracism and rejection. The predominant effects at the individual level were fear and withdrawal leading to secrecy about HIV status and self-imposed social isolation. In a few cases, suicidal tendencies were noted, and in a few other instances people living with HIV/AIDS sought to avoid stigmatization by denying their serostatus, thereby risking transmission of infection to others.

Negative responses in the health care setting lead people to conceal their HIV status in treatment facilities for fear of being denied care. Individuals who are sick may also delay seeking treatment until the last moment, harming their own health in the process. Within the workplace, widespread denial that HIV/AIDS is a problem means the majority of companies and employers have no policies and procedures with which to respond to seropositive employees. The belief that HIV only affects promiscuous people, and that "such types" are unlikely to work in a given location further contributes to institutional denial. Because of the social stigma associated with HIV/AIDS and in the absence of legislation and procedures stipulating how people living with HIV/AIDS should be treated at work, many prefer to keep their serostatus secret. This contributes to the invisibility of the epidemic and makes life more difficult for those individuals affected.

Occasionally, however, HIV/AIDS-related stigma may trigger more positive responses such as the altruistic actions of those who carve roles for themselves as educators, counselors and HIV/AIDS activists. Through their work, such individuals may develop a collective identity and mobilize group support that results in a greater awareness of the epidemic and more positive responses towards those affected.

Implications of the present investigation

- It is important to recognize that HIV/AIDS-related stigmatization and discrimination can appear in a variety of forms, at a variety of levels and in a variety of contexts. Mapping these forms is the first step towards being able to identify their determinants. It may be important theoretically as well as practically to differentiate between individual, family-level, community and institutional determinants.
- Pre-existing local cultural practices and beliefs are both determinants and legitimateness for HIV/AIDS-related stigmatization, discrimination and denial. These beliefs frequently establish categories of person or types of behavior that are likely to be stigmatized (e.g. sexually "promiscuous" individuals, sex workers, drug users and homosexuals). The advent of HIV/AIDS frequently reinforces

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these already existing types of stigma, imbuing them with new and potent legitimacy.

- There is an important distinction to be made between "felt" and "enacted" stigma. Felt stigma arises from the real or imagined stigmatizing responses of others. It has an important role to play in "policing" the behavior of people living with HIV/AIDS, causing some to deny their serostatus, others to conceal it, and all to experience anxiety about telling others and seeking care. The consequences of both felt and enacted stigma undermine efforts to challenge HIV/AIDS-related stigmatization, discrimination and denial. Both prevent people living with HIV/AIDS publicly acknowledging their serostatus and playing their full and proper role in prevention and care.
- Socioeconomic status and relative financial (and productive) security can influence the stigmatizing process. By enabling some families to "conceal" HIV/AIDS-affected members either within the home or in private medical facilities, some individuals are able to avoid being overtly stigmatized. At the same time, however, it may be especially shameful for wealthy individuals and their families to acknowledge being affected. More generally, socioeconomic status and wealth allow people to better manage the flow of information relating to HIV/AIDS and its impact upon family and household members.
- It is clear that there is a strong gender bias in HIV/AIDS-related stigmatization and discrimination. Women and men are not dealt with in the same way when they are infected by HIV/AIDS. There is evidence that men are more likely to be accepted by family and community. Women, on the other hand, are more likely to be blamed, even when they have been infected by their husbands in what for them have been monogamous relationships. This double standard exacts a terrible toll on women as mothers, as daughters, as caregivers and as people living with HIV/AIDS. HIV/AIDS-related stigma, and the discrimination to which it leads, therefore plays a key role in intensifying gender inequalities.
- It is not enough to spread awareness about HIV/AIDS, its transmission matters or even about legal rights. What is urgently needed is government anti-discrimination policy supported by a law that will ensure the protection of (HIV) positive people's rights.
- Even where such laws exist, or where governments make active efforts to combat HIV/AIDS-related discrimination, it is vital to challenge popular myths, stereotypes and judgments that provide the ground upon which HIV/AIDS-related stigma can grow. At the policy level, prevention programmes should foster tolerance and social solidarity using, wherever possible, an approach which is non-judgmental and not based on fear.
- In both employment and health care, discriminatory policy needs to be developed to protect and safeguard the employment and health care rights of people living with HIV/AIDS. Central to this must be principles of confidentiality and respect for human rights.

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- Interventions targeting discrimination need to take place concurrent with the establishment of a supportive legal framework that includes generic anti-discrimination laws covering health care, employment, education, housing and social security, as well as effective enforcement mechanisms. Other important and complementary activities must include efforts to change attitudes through communication campaigns in the media, education and training.

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