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The micropolitics of disclosure, stigma and (dis)trust surrounding HIV/AIDS in India¹

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Introduction

In this chapter, my main analytic focus is the interplay of stigma and dis(trust) which impacts upon the 'social self' in deciding upon acts of (non)disclosure, with particular reference to what Goffman (1968) calls 'a spoiled identity'. When the spoiled identity concerns an identification of HIV positive health status, a labelling of the individual ensues, both in medical and social terms. Focusing my discussion on the Indian context, I suggest that such a labelling is not confined to the individual alone: potential consequences are calculated at the family and community levels. As we will see, the potential negative consequences for the self and other family members are usually proffered as a reason for justification of nondisclosure. I shall argue that the social stigma attached to HIV/AIDS will play a significant part in how decisions about disclosure and nondisclosure are legitimated. Our understanding of such disclosure/nondisclosure will then need to be grounded in the prevailing sociocultural norms that regulate a community's everyday practices.

Even when ascribed a spoiled, discredited identity, the individual self has to retain a normative role in the family and community circles. Indirectly, therefore, concepts of trust and distrust with regard to third parties come to the fore. Decisions about who to disclose one's health status become mediated by social norms. In other words, a key issue concerns: how the information about health status can be contained in order to allow normality to continue in the eyes of significant third parties. Nondisclosure is one form of such containment so as to allow an 'as-if-

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normal' state-of-affairs to prevail. Acts of nondisclosure can then be justified in the face of social stigma attached to any form of deviance such as HIV positive status.

In examining the themes of 'disclosure' and 'nondisclosure', I draw attention to the multiple aspects of trust and distrust and point to some of the cultural assumptions such as the tradition of heterosexual marriage, the role of the individual in maintaining a family-community bond, the position of women in society etc that become invoked to legitimise decisions to disclose or not disclose one's HIV positive status. I draw on interview and observational data relating to HIV/AIDS from research sites in South India. The data are analysed from a broad discourse analytic perspective, focusing in particular on how accounts of actions and decisions are framed in language. Following Goffman (1974), a 'frame' can be conceptualised as a social element of the communication system: it consists of 'principles of organisation which govern events – at least social ones – and our subjective involvement in them' (Goffman 1974, p. 10). In a sense all communicative activities are framings of one kind or another in different degrees.

The notion of trust is commonplace in everyday mundane and institutional settings, and tensions in trust and distrust are perhaps mostly felt on the interface of lived experiences and institutional realities. In the public domain, trust and value are intricately interwoven. As Pendleton and King (2002, p. 1352) point out:

Values are deeply held views that act as guiding principles for individuals and organisations. When they are declared and followed they are the basis of trust. When they are left unstated they are inferred from observable behaviour. When they are stated and not followed trust is broken.

In the private sphere, values are often unstated, but are implicitly followed in order to maintain a given social order.

Cross-cultural differences in who to trust/distrust and how to manifest trusting/distrusting relations through communication have been topics of study across disciplinary boundaries. From a discourse analytical perspective, trust remains an abstract concept, not readily lexicalised, although viewed from the perspective of speech act pragmatics, trust can be formulated as a speech act, as in 'I trust you with X'. More commonly, trust is invoked to underlie authority, credibility and sincerity of speaker/writer positions. In linking linguistic realisation of sincerity with trustworthiness, Montgomery (1999) offers a comparative analysis of tributes offered by Tony Blair, the British Prime Minister, and the Queen on the eve of Princess

Diane's death. The conversational features, in addition to careful choice of words, in Blair's speech – lack of fluency, insertion of hesitation, patterning of pauses as in casual speech, not only at major boundaries, but also between smaller units – are characterised as emotional and hence sincere. By contrast, the Queen's speech is less hesitant, grammatically complex, containing multiple clauses resembling planned written speech, with long pause only occurring at sentence boundaries. Her speech seems 'measured' as far as choice of words is concerned – and hence lacks sincerity. Montgomery thus points to the use of clause structure and pausing as indicative of sincere feelings that can be trustworthy. Generally speaking, when it comes to claiming authority and credibility, the word 'trust' is very rarely explicitly used. In terms of communicative strategies, use of factual statements, direct reporting of other's words may be seen as markers of trustworthiness.

My point of departure in this chapter is that accounts of disclosure and nondisclosure offer an anchorage for exploring the abstract notion of trust and its cultural manifestations in a given societal context. I would like to explore the communicative dimension of trust and distrust by focusing on the topic of (non)disclosure from a cultural perspective. But there is another overriding context that is the central concern of this paper: the social stigma around HIV/AIDS which constrains the activity of disclosure of HIV positive status. In looking at the Indian setting, specifically dealing with the HIV positive people and associated non-government organisations (NGOs), the aim is to explore ways in which (non)disclosure and (dis)trust are mediated by drawing upon existing social norms characteristic of Indian family and community system.

Background: HIV/AIDS and the Indian scene

HIV continues to be seen as a disease of 4 Hs: homosexuals, heroin users, Haitians and hemophiliacs (Shapiro, 2002). To this 'H' list, heterosexual has been added, but in the public domain homosexuals remain stigmatised. As we will see with reference to the Indian scene, both the heterosexual and homosexual dimensions become problematic when it comes to disclosing one's positive status in light of potential consequences. Religion has played a part in defining what sexual conduct is morally acceptable, which was medicalised in Britain in the 1950s with a view to legitimising treatments to change it. 'Homosexuals, formerly considered to be sinners, were labelled as ill – not bad, but mad' (Hart and Wellings, 2002, p. 897).

While HIV/AIDS is framed – in terms of cause, prevention and treatment – as a global phenomenon and a cosmopolitan disease, the experience of HIV/AIDS at the individual, family and community level retains a local character that aligns with situated socio-cultural value systems. Many of the countries that have been affected by the HIV/AIDS have steered different pathways to tackle the epidemic. From a globalisation perspective, the spread and prevalence of HIV/AIDS can be regarded as an extension of the late modern ‘risk society’ (Beck, 1992), whereby risk is no longer seen as an individual responsibility, but as a consequence of socio-political transformations. As Shapiro (2002, p. 2189) remarks: ‘Viruses create a unique (if unpleasant) genetic bond between us all, and our ability to pass viruses connects us across space and time, across race, religion, and social class’. The globalisation of risk has led to the emergence of new communities such as HIV positive groups based on anxiety, and a common appreciation of uncertainty and hazard.

Among the developing countries, India stands at the forefront of the HIV/AIDS epidemic, although controversies continue about causes and patterns of prevalence. Following from the reporting of the first case in 1980s, a national programme titled National AIDS Control Organisation (NACO) was set up in 1987 under the auspices of the Ministry of Health and Family Welfare, Government of India. NACO operates its programme with the help of state-level branches which are registered societies operating outside of state bureaucracies, with state health minister as chairperson – mainly oriented towards targeted intervention. The prevention drive partly explains why the management of the potential epidemic is in the hands of state level bureaucracies and their structural organisation. It is also evident from the role NGOs are expected to play in containing the epidemic – i.e., many NGOs framing their actions in a prevention discourse. The primary focus continues to be on targeted intervention with high risk groups, with some exception (Mooney and Sarangi, 2005).

According to government sources, numbers affected so far are below two per cent, which is routinely disputed in the public sphere. Various stakeholders, including NGOs, claim that the government systematically refuses to recognise specific risk groups, because such recognition would have resource implications. More importantly, high risk groups such as the homosexuals have gone unnoticed for a long time because of the social taboo surrounding their sexual orientations. From a disclosure perspective, the government’s reluctance to acknowledge the existence of this group (whether or not as a high risk group) is indicative of the stigma attached to

expression of sexuality in the public domain. As far as the homosexuals are concerned, disclosure brings with it the fear of consequences which may amount to social exclusion. In this respect, the prevention ideology may seem to work as a disincentive at the individual level. One can here think of a scale as to how different target groups position themselves when it comes to disclosure and its consequences against the backdrop of social stigma.

A struggle against stigma: the individual, family and community nexus

Goffman (1968) defines stigma as ‘an attribute that is significantly discrediting’ and goes on to suggest that the stigmatised individual is characterised as a person who possesses ‘an undesirable difference’ which leads to ‘a spoiled identity’. There is an overtone here of social norms because the ‘differentness’ is conceptualised as deviance which falls outside of social acceptance. One may characterise deviance in terms of visibility and invisibility. If the ‘differentness’ is invisible then disclosure is optional, unlike visible deviance which is hard to conceal. As Goffman (1968, p. 152) points out: ‘The fully and visibly stigmatised, in turn, must suffer the special indignity of knowing that they wear their situation on their sleeve, that almost anyone will be able to see into the heart of their predicament’. One communicative strategy that can arise in the case of the visibly stigmatised in terms of ‘stigma management’ is alienation or the avoidance of contact. For those with an invisible condition, as is the case with many genetic disorders before the onset stage, the strategies available are those of adjustment, including ‘passing as normal’, something that Goffman captures as ‘the normal deviant’. Davis (1963), in his study of childhood polio, describes two of the strategies that parents use to sustain their definition of the child as normal: ‘normalisation’ where parents seek validation from others; and ‘disassociation’ where parents avoid audiences which might invalidate their definition. These strategies point to the fact that stigma is embarrassing – not just for the stigmatised person but also for those who are confronted with it and have to react to it. The notion of ‘face’ (Goffman, 1955) becomes relevant for all concerned.

A key dimension here is the notion of self and the action of disclosure/nondisclosure. Mead’s (1934) characterisation of the ‘social self’ in relation to the ‘generalised other’ is relevant for our purposes. ‘The “other”, for Mead, is not only the other person, but another *perspective*: another way in which the world is judged or appreciated’ (Natanson 1956, p.64). Individuals can take the role of

others which is facilitated through language, i.e., they can anticipate the responses that others will have to their actions. Niebuhr (1999, p. 65) captures this response-orientation in his conceptualisation of 'responsibility' as 'an agent's action as response to an action upon him in accordance with his interpretation of the latter action and with his expectation of response to his response, and all of this in a continuing community of agents'.

Following Mead, the self thus becomes 'an object' that anticipates the generalised other's projected responses and the community norms. Individual actions are then quintessentially 'social acts' with potential third parties involved.

Stigma, in its extended sense, is to be seen in social-relational terms, with a high potential for devaluation of relationships in a given sociocultural order that includes the immediate family and the community (Kleinman 1988). Social psychological literature has contributed to our understanding of how individuals construct categories and incorporate these categories in stereotypical beliefs. The main thrust has been on the perceptions of individuals and the consequences of these perceptions for social interaction (Oliver, 1992; Link and Phelan, 2001). In this regard, stigma comes to be seen as something *in* the person stigmatised, rather than as a designation that others attach *to* that individual (Link and Phelan, 2001). Green (1995), among others, explores the extent to which public attitudes may contribute to what she calls 'felt stigma', although the public's attitudes to HIV may not be as 'stigmatising as those infected believe them to be' (Green 1995, p.566). Stigma thus manifests at the individual, interpersonal and societal level.

Parker and Aggleton (2003) make a strong case for conceptualising the notion of stigma in relation to the structural conditions that produce exclusion from social and economic life. They call for a need to 'reframe our understandings of stigmatisation and discrimination to conceptualise them as social processes that can only be understood in relation to broader notions of *power* and *domination*' (2003, p. 16). For them, stigma is inevitably linked to the workings of social inequality, as it plays a key role in the production and reproduction of relations of power and control. They complement Goffman's insights with those of Foucault and Bourdieu in drawing attention to how stigma is a social and cultural phenomenon linked to the actions of whole groups of people, and are not simply the consequences of individual behaviour.

Foucault's work more clearly emphasises the cultural production of difference in the service of power. While Goffman's work on stigma hardly even mentions the notion of power, and Foucault's work on power seems altogether unconcerned with stigma in and of itself, when read together, their two bodies of work offer a compelling case for the role of culturally constituted stigmatisation (i.e., the production of negatively valued difference) as central to the establishment and maintenance of the social order (Parker and Aggleton, 2003, p.17).

This argument is taken further with the help of Bourdieu's notion of 'symbolic violence' which describes the process whereby symbolic systems (words, images, practices) are strategically, and hegemonically, deployed to promote the interests of dominant groups as a way of legitimising existing hierarchies. As Parker and Aggleton (2003, p.18) conclude:

Stigma and discrimination therefore operate not merely in relation to difference (as our readings of both Goffman and Foucault would tend to emphasise), but even more clearly in relation to social and structural inequalities ... Put even more concretely, stigma is deployed by concrete and identifiable social actors seeking to legitimise their own dominant status within the existing structures of social inequality.

Returning to our research context, stigma begins with HIV/AIDS itself being seen as a taboo word. Even within Africa, where HIV prevalence is most acute, HIV remains highly stigmatised: '[in Botswana,] the disease is never mentioned as the cause of death at the funerals every family now attends each weekend. HIV is called "today's illness" or "the radio disease", as if the very name cannot be spoken' (Shapiro 2002, p. 2189). Such euphemistic categorisation of HIV is mainly due to fear of the baggage of meaning attributed to HIV/AIDS which has the lethal consequence of social exclusion. Stigma even continues beyond life unto death. In some communities in India, as one respondent put it, 'people still don't allow bodies of HIV positive people to be burnt within the village' (W, 405-06).

Disclosure and nondisclosure of HIV positive status: taking a closer look

One of the main sources of social stigma is ignorance. By extension, one strategy to fight stigma is to remove the veil of ignorance through raising awareness. Let us begin by looking at the following leaflet issued by NACO, India, which plays

on the theme of family as well as that of ignorance about AIDS, resulting in stigma and stereotyping.

Figure 1

[TO BE INSERTED ABOUT HERE]

The first heading – Stay away from AIDS – suggests an inclusive readership, but the next heading – Not the person with AIDS – is specifically addressed to those who know people with HIV/AIDS, urging them not to isolate the latter. It anticipates the theme of touch (see the heading later – Should HIV patients be kept in isolation?) and the lack of factual knowledge in the community as a whole. This is made obvious by the headings that follow, emphasising both how HIV is transmitted and how it is NOT transmitted. Getting in to such informational details signals the level of ignorance, which may lie at the heart of stigma, thus making nondisclosure a preferred action for people who are HIV positive. The visuals that accompany the text are a persuasive means to foster trust, which is the climate that could then facilitate disclosure. Implicitly, then, it coerces those who are HIV positive to trust their relatives and friends and disclose their status as the normality of everyday life can still be guaranteed. Overall, the promotional leaflet assumes that disclosure is a normal, responsible act to undertake if only one can fight the stigma associated with ignorance. Touch becomes a symbolic force: if the general public believed that HIV can be transmitted through touch, then isolation of the HIV positive person becomes a logical option. It plays on the popular belief that touch and proximity cause and spread diseases.

In sum, the leaflet is informational in how facts and beliefs are presented – explicitly and implicitly. It brings to the surface the myths of ignorance as it highlights the significance of factual knowledge. It also underscores the circumstances which force people who test positive not to opt for disclosure. It tries to promote a notion of normality in social encounters both within the family and in the community. There are several references made to the need for actual physical contact, especially manifest in the rhythm-like contrast made between ‘stay away from AIDS’ ... [but] not the person with HIV/AIDS’; ‘know AIDS’ ... [to ensure] no AIDS’.

The social stigma about ‘touch’ is of particular significance in the Indian context, especially concerning the lower classes (often referred to as backward classes). There is the fear that the HIV/AIDS epidemic is creating a new

‘untouchable’ class in a society which is already torn with a complex caste system. Touch plays a crucial role in the caring of sick people (Autton, 1989). In the context of HIV/AIDS and because of myths attached to its contagious character, they are not touched, even by the medical profession. This seems to be a new ‘untouchable’ class in the Indian caste system.

Given that the advertisement campaign embodies the prevention discourse, one would expect ‘volunteered disclosure’ and ‘elicited disclosures’ to be key issues. It is important to draw a distinction between right to disclose and duty to disclose – the former bordering on moral and the latter on legal (e.g., regulations governing HIV testing). The duty to disclose includes the following: many government initiatives call for HIV testing, which is the gateway to disclosure. For instance, The Health Ministry’s announcement that blood donors found to be HIV positive would be told of their infection and asked to seek tests and counselling. Also worth noting the Indian Supreme Court’s ruling that people with HIV positive status should inform their spouses before marriage. As we shall see later, such a ruling, however, does not extend to declaration of homosexual orientations. As far as the medical profession is concerned, they are, however, bound by law to disclose their HIV positive status so as to prevent transmission through contact.

The fear of consequences of disclosure

Trust and fear are the two sides of the same coin when it comes to decisions about disclosure of HIV positive status against the backdrop of social stigma. In what follows I focus on how the fear of consequences of disclosure for the individual as well as for the family and the outside community is worked up as a major reason for nondisclosure. In this sense, potential consequences are not only future-oriented, but are also inherently other-oriented where the third parties have to be taken into consideration as a premise for nondisclosure.

Let me recount here the following social scenario based on my fieldwork in Southern India. The site is the Red Cross Day Care Hospital in Chennai, sponsored by the Health India Foundation. Because of the continuing stigma attached to sexual health, leave alone HIV/AIDS, the character and remit of the clinic were to be masked with a signboard hanging outside which read ‘Integrated Allopathic-Siddha Clinic for Family Health’. However, the clinic operated in an isolated building which carried a sense of alienation, although the sign posting, according to the Director of the clinic,

allowed people to visit the clinic without feeling stigmatised. This may partly explain why it was not easy for the patients to disclose their concerns to the outside researcher. The language barrier, as well as the lack of private space, contributed to an impasse. I was finally introduced to a young woman who was sitting in the waiting room. Mediated through one of the clinic staff, the woman confided her HIV positive status, and went on to narrate how she was infected by her husband some years ago, how her HIV positive status came to be known during routine check-ups at pregnancy rather than via disclosure by her husband, and why she now wanted to test her son's status. In her account, the test was mainly to give her peace of mind. She was fairly certain about her son's 'normal' status: if there were any fear of uncertainty or doubt about infection, she would not be undertaking the test procedure. This prompted me to ask questions about her own coping strategies and how she had gone about disclosing or not her HIV positive status. It emerged that only her mother, not father, was trusted with this information, which raises questions about nondisclosure of vital information between a couple, in this case the woman's parents, in the same way that the woman's husband had chosen not to disclose his HIV positive status in their married sexual life. She also confirmed that no disclosure was made to either of her husband's parents, as they would not accept her version of events (i.e., her husband is the perpetrator and she is the victim), and it is most likely that fingers will be pointed at her as being responsible for infecting the husband. This can be explained by the position of the daughter-in-law, and more generally women, in the Indian family system. A disclosure will have resulted in the woman being discriminated and stigmatised. While disclosure to her own mother was motivated by practicalities such as child-care arrangements as she had to keep to her regular clinic appointments, nondisclosure to her parents-in-law was motivated by the fear of being accused as a loose woman and consequently thrown out of the safe family haven.

During this period of fieldwork, which included a visit to the large Government Hospital of Thoracic Medicine², it emerged that the doctors in the ward chose not to disclose the patient's HIV positive status on the grounds of poor literacy of patients and the possible stigma attached to such labels. Here one can see a form of collusion at the level of disclosing diagnosis. Especially with relation to children who were diagnosed as HIV positive, the 'illiterate' carers, mostly women, were

experiencing a normal hospitalisation routine, optimistic of cure without even knowing the diagnosis. This is based on the trust that carers of patients have in the expertise of the doctor and the integrity of the hospital as an institution.

The above examples are a good illustration of the positioning of women in Indian family life, and by extension, in the community – as a surrogate self who has to fulfil a set of predetermined tasks. In a more general sense, the provision of antiretroviral drugs for preventing mother child transmission shows how the protection of child is undertaken without any notice of the mother's life.

I shall return to this theme of disclosure surrounding women in a later section (engendering discrimination). But let me focus more generally on the fear of consequences of disclosure against the prevailing social stigma. I shall draw on accounts given in interviews with members of locally based non-government organisations (NGOs)³.

The following extract captures the consequences of disclosing one's HIV positive status. Of particular interest here is the vulnerability of family members, especially women, as third parties. In what follows we can see that the interviewee is talking about the circumstances that followed after a disclosure was actually made by the founder of one of the NGOs, W:

His own family, at least the problem is he is a single person. It's more like, a woman who comes forward with her status declared will face more problems than a male because the stigma is more there. But then in his case what happened was his family also suffered a lot along the way and in that anger they isolated him completely. This is one place, just one street away from here. So this is actually his grandma's place. At that time he was totally isolated sent to this place, the stigma part is something that he experienced. He was even put through windows. When he gave a gift a tape recorder as a gift to his brother's child he actually washed it with dettol [antiseptic], wiped it clean with dettol and then gave it but even now they have this stigma. See ??? you now have declared your status you don't have to declare your status you declared your status see what's happening here. So his sister was actually an advocate so she had a lot of problems in her own field her his brother, his

² . Just like the spatial marginalisation of the Integrated clinic in the Red Cross hospital site, this hospital was located in the outskirts of Chennai.

³ . The names of all participants and the NGOs have been changed to ensure confidentiality.

brother's friends all of them faced a lot of problems. His mother was a teacher and just imagine the kind of stigma that she faced in the school is that your own son is like that what are you going to teach our children in the school. It's more like that. So it was really difficult, very very difficult for him to come out.

The isolation that ensues from disclosure forces the self to be categorised as 'other'. The trajectories of touch, including its absence, bring to the fore the distancing of the self-as-other. Note that the touch dimension is explicitly mentioned, which stands out as a discursive expression of social stigma (see earlier the discussion of the NACO leaflet). Social stigma is characterised as a responsive act, with allusion to the normative gender-divide in the Indian culture. More importantly, for our analytic purposes, appeal to consequences of disclosure to others is made explicit. This 'otherness' is articulated with family members being conceptualised as the third party who are implicated in the disclosure and for whom there are real consequences. It is useful to distinguish between post-disclosure consequences for 'self' and for 'others'. The family as a coherent and single entity is presupposed when worst scenarios for various family members are laid out, like a set of chain reactions. The sister in her professional advocate role cannot continue; the brother may lose his friends; the mother will be faced with double-standards in her role as a teacher. The implicit moral here is that one should avoid disclosure of HIV positive status so as to protect other family members from being stigmatised or humiliated. Nonetheless, we see that stigma and discrimination can start at home, and then like ripples, spread wider into the community.

Consider the following extract (also taken from the same interview setting, W):

Because social pressure it's a lot higher in India than anywhere else, I don't know why it is that way but the thing is social acceptance is also very important for Indians so what a neighbour thinks of you is clearly high priority here so I think that even if you are willing to allow a person to stay, the rest of the people in the neighbourhood or in the building flats or whatever they might put pressure on this person so this person is evicted; I want to keep you but I can't. That kind of thing. It can also be a ventilation of his own fears but just putting it onto someone and saying, I'm OK but they're not OK about it. And discrimination happens also with in the family it's not just about

landlords throwing tenants out. A lot of people are afraid. If you talk to ??? they will tell you more of these things.

We have here a clear exposition of the third party perspective, which is invoked to legitimise present action/decision. Eviction can amount to social exclusion, so the individual who wants to give shelter to a person with HIV positive status needs to be very careful. In the event of a disclosure of HIV positive status, the uncompromising attitude of the neighbours is stressed, especially by using direct self-reported speech: 'I want to keep you but I can't', 'I'm OK but they're not OK'.

Engendering discrimination

A related dimension here is discrimination, which is gender-related. The scenario becomes more stigmatised when it involves a woman who is diagnosed as HIV positive. Many of the consequences that follow at the family level reflect the social positioning of women in the community. It also brings to the fore the fact that culture, in the traditional sense, can be a barrier to trust. Rao Gupta (2002) draws our attention to how men's power over women fuels the HIV epidemic in India: women, because of their low status, are not able to ask questions about their husbands' sexual lives, nor do husbands feel obliged to disclose their sexual activities (see earlier extract). The family relationship, and its manifestation at the sexual level, is built upon compulsive trust, that is, unconditional trust: you obey your husband at all times. This of course amounts to a form of silencing. Consider the following interview account, taken from another NGO setting, Y:

Like a country, like India, there is always gender problem traditionally we think everything is the men preference and women come last and with HIV also wife has been sick, but they prefer to bring their men or sons rather than their daughter-in-law – these are the problems ah so they and then very important problem, most of the women who are infected are infected from the spouse. They still support their husbands they are not sick. But they are still very good supporting the husbands taking the children to school all these things they are doing. And still they support, the family may not touch may not come in the house and this woman is struggling and struggling. If this man dies, family is taken to throw her out and get the property and lots of big issues. But she also has the children. Gender issues are big issues here. Even food, the lady will eat last. Talking about quality of life so many women are

anaemic, all the best food is eaten by the other people, how they get good food, these are traditions, they will serve to everybody and eat last. Simple things but it's like that. So these are the big issues. So also I suppose like sex also, they know the husband is exposed to so many other people they know the husband is having sex with other people but they cannot make the husband to wear a condom the moment she opens her mouth that he has to wear a condom he's going to ask, who are you to question my morality? And then she is out from the house. And Indians, Indian woman is just divorced or discarded so woman has no power to ask things. I don't deny that there are gender issues. The same thing for treatments, the wife will say let my husband get the cure first, but she also has to come for one.

This account resembles the points made earlier in the fieldwork setting. It offers a vivid description of the experience of discrimination that befalls women more generally. The situation only worsens when the woman in question is identified as HIV positive, although she may have been the victim. As far as normal sexual relations are concerned, the woman cannot ask her husband to disclose his sexual past for fear of consequences that might follow. Nor can she ask her husband to practice safe sex by wearing a condom as that would amount to challenging the man's moral integrity. We also hear that the women, in their illness phase, do not attract any sympathy and care as they are expected to carry on doing the usual chores of daily life.

Not only that the wives cannot insist on their husbands wearing condoms because of existing power relationships, they may also become suspicious if husbands did wear condoms. In the words of one doctor associated with the NGO, W:

For many of them also have bisexual behaviour and most of them are already married so talking about these issues also, so not just about male to male sexual behaviour but also bisexual behaviour. And sometimes how to negotiate condom use with wife, because sometimes it can be quite difficult. Usually we think that women cannot negotiate condom use but for example, the wife ??? if the husband is going to insist on condom use she will ask why you want to use condoms because I've already been sterilised. That's very difficult. But some of them, most of them, their wives are housewives, what they call housewives, they are there only in the house, maybe their education level is also not that much good otherwise they'll be asking so many

questions. So if the husband is going to say no this is to make sure that you don't get pregnant and sometimes that might fail, the sterilisation might fail, something like that. And they would like to tell I don't want to pass the heat to you. I want to prevent that by using condoms so something like that whatever in your local cultural context. They will tell, they have their own way of telling or convincing their wife, but sometimes not always possible.

Sometimes people are even afraid to talk about this issue about condoms because their wife will think that they are around with many women.

Practicing safe sex, which may be seen as a preventive measure, is not a simple matter to negotiate in normal marital life. In this intimate sphere of husband-wife relationship, it seems disclosure cannot be demanded. Even when men choose to wear condom to prevent transmission, they still do not disclose their HIV positive status. Instead they tend to 'pass' this as precaution for preventing unwanted pregnancies. When we apply this to the family situation in the HIV/AIDS context, the family values (no sex outside of the marital relation) act as a principle for wives not to insist on condom use, or even ask their husbands about their sexual life. Either of these would imply suspicion. In other words, wives cannot demand disclosure. This may give substance to the widely held view that HIV/AIDS is being spread through 'normal' patterns of family life.

The overall position of married women in society becomes pronounced when a diagnosis of HIV is made. The data extract below is taken from another organisational setting (I+). According to the interviewee:

Many of the women they are diagnosed with HIV either during pregnancy or when their husband is dying so they are like, the thing in India is once a woman gets married she is kind of packed off to her husband's house and she's their problem after that. When her husband died, her parents are not keen on taking her back because it is like, you don't actually care for your daughter after she's married. And the in-laws really don't even want her around because they blame her for the husband having died for their son having died. And she basically gets thrown out on the streets. And if she has children and she has a male child then maybe they keep the male child at home and kick the rest of them out or. That way discrimination happens also in the family and I somehow feel women bear the brunt of it, most of them. So jobs also, many people get kicked out of jobs because once the HIV status is disclosed. And

legally it's very very rare to have somebody file a lawsuit or anything because again it becomes an issue of the larger public knowing about your status. Once you're already been hurt you're afraid to like get hurt again. (I+)

Here we have an intriguing account of potential consequences that can follow a disclosure, if it involves a married woman. The social stigma associated with HIV/AIDS becomes conflated with traditional views about the place of women in family and society. The family's maltreatment of the widowed daughter-in-law can only partly be explained by this social stigma surrounding HIV/AIDS. What we also see is the rigid family traditions about responsibilities and patterns of inheritance. Family relations following the death of a husband with AIDS become strained. This is particularly so when it involves parents-in-law, as the widowed wife is left stranded in a 'no man's land', both literally and metaphorically. At the time of marriage, the woman is 'given away' to her husband's family, so it is logical not to take her back when things go wrong. What is intriguing here is the fact that a woman is still believed to be getting married into a family rather than to a person, but the social stigma (attached to widowhood and to HIV/AIDS) creates the situation whereby the widow has to be positioned as 'other' with no participation in normal family life. We see here a reconfiguration of the self/other in terms of belonging.

It is worth noting how widows, following the death of their HIV positive husbands, have to protect themselves against social discrimination. As one of the participants pointed out: 'Protection means, in this area they know me very well. I am going wearing all these things [glass bangles, ornaments] they think I am married woman' (S, K+). So, this works as more than social protection. It is also a way of economic gains, of remaining employable. This is a strategy of 'stigma management' in the Goffmanian sense, i.e., which affords one to pass 'as if married' when widowed so as to normalise everyday activities.

The societal compass of stigma and the imperative of nondisclosure

The tensions surrounding disclosure and nondisclosure are not confined to the existing marital relationships and their termination when one of the partners dies. The tensions extend to young people of marriageable age, and to people with 'nontraditional' sexual orientations.

There seems to be enormous social pressure on normal role taking behaviour on the interface of the family and the community. Young men and women of

marriageable age are expected to enter formalised marital relations. Failure to do so is treated with suspicion. If a person is infected with HIV, the fear is three-fold: nondisclosure in fear of consequences of not getting married; getting married to prove that nothing is wrong (this also covers homosexuality); in the marital relationship no disclosure is made. Behaving trustworthily at one level one could spread distrust. Consider the following extract from the interview (W):

They [parents] strongly believe that women mean they have to get married here. So it's something like in India whether men or women they should get married to their opposite sex partners, and whatever they do other than that it is up to them if they are not talking about that. They should not talk about that. That would be behaviour they should not talk about.

As we can see traditional 'norm following' as far as marriage is concerned is tied up with a vow of nondisclosure of sexual orientation. There is an appeal to the 'as-if-normal' status quo, which compels these young people with homosexual or lesbian sexual orientation to adopt a strategy of 'passing'. The same strategy of passing is also evident when we consider young people who already have a HIV positive status. The following account (Y) underlines this point:

There are people who want to get married, the HIV persons, because of family pressure they want to get married. Because in the Indian community, a young man who has finished his studies he is not getting married, there is a question why you are not getting married, the parents will have, these are big issues are the pressure comes. So they won't say anything they just get married and they infect their wife and the parents don't know. Even parents who know that their son is positive, but sometimes because society say he has finished studies doing well why is he not married, so they can't take that pressure so they make their son get married and then they are infecting somebody. These are big issues in our place. So like what we are trying to do through counselling to these people, how to disclose their status to family, rather the parents know first than the third person comes to the parents and says, your son has HIV so we are trying to make them understand how to disclose so we try to build their skills to disclose. These are very important issues because if things don't work, they can break the family. And the people like somebody wants to get married, we try to do HIV positive and HIV positive what do you call, matchmaking, for the positive mostly young, when they get married in one or

two years husband dies, but they are still very young and they are sexual and they still have life to go, so some young boys we come across we try to encourage them and if they like each other they can get married also. So no pressure to get married to a negative and not disclosing. That's what we do. The 'other'/'third-party' perspective is drawn upon to justify decisions about marriage and family life. One instance of nondisclosure leads to another and becomes compounded. Transmission of the HIV virus to unsuspecting, trustful sexual partners can be seen to be the result of nondisclosure. The family pressure puts a lid on disclosure not only within the intimacy of marital life but also within the community. It is also stressed that one's HIV positive status should not be disclosed via a third person 'other' as that would threaten the family entity. What is also interesting in the above extract is the encouragement of 'matchmaking' based on disclosure, and therefore trust, when both partners have a positive status. The traditional notion of matchmaking, which continues to be the basis of arranged marriages, still applies to the HIV/AIDS setting.

With regard to gay and lesbian communities, nondisclosure of sexual orientation is rather complex because of social stigma. This leads to covert practices that privileges nondisclosure as can be seen from the following extract:

There is always the thing where people say no I am a heterosexual I like to have sex with a female but it is he who after ??? Sometimes or many times what happens is people use men who are actually heterosexuals use these kothis⁴ as a mode of getting cheaper sex. If they go to a female you have to pay for the lodge, you have to stay in the lodge you have to pay the female a very high price. Whereas if it's a kothi nobody's going to suspect two people two boys in one room for one or something. Most of the time you don't even have to go to a room itself, either a bush or a local toilet or the beach it's very cheap 10 rupees for a kothi. It's very easy to have sex for 10 rupees, whereas if you go to a female you have to pay a minimum of 100 and the lodge fees.

The economics of cheaper sex aside, here we have evidence of how homosexuality and bisexuality is normalised in the public domain.

⁴ . 'Kothi' is a local term to refer to 'male' transvestites, who practice cross-dressing and adopt a feminine way of life.

On a larger scale, social stigma is capable of obstructing intervention activities such as distribution of condoms as a prevention measure. NGOs such as W have to carry out their everyday prevention activities without being seen as doing so.

Consider the following account:

And apart from that, we also have free condom distribution and we have set up outlets, nontraditional forms of outlets in each of these cruising areas. I say cruising area, it's usually a public space, an isolated space from any kind of, it won't have shops it will be a bush, it will be a seaside something like that. So having outlets at that point, having traditional outlets at that point, is a very problematic issue for us and the whole point is that stigma is also there. No shopkeeper was willing to accommodate condoms and when people, most of the people that we deal with are effeminate people, so when they dance and when they move like a female, dresses up like a female, the shopkeepers, they are getting affected by these and people and don't want them to come to his shop. So I do not accommodate your condoms, I mean I won't allow my shop to be used to as outlet. So therefore we have small no traditional outlets like a tree trunk or public tank like that. Or in certain areas where it is a residential area then we have a kothi volunteer who comes to that area, who has a house at that area, that accommodates the condom outlet in his place. So that way we have the outlet. We also have a drop-in centre that operates almost every day.

One has to operate with chain-like reasoning to follow the argument presented above. The effeminate people are a taboo, and they are the ones who are suspected of homosexual relationships, which is a major source of HIV transmission. If a shop were to dispense condoms, on behalf of an NGO, to such a target group, then their normal business stands to lose. The so-called 'normal' customers, as third parties, will not want to be associated with such an outlet.

Here we have reference to homosexual people seeking social acceptance. Most people believe that the transmission is through sex, and especially a particular form of sexual practice, although other routes of transmission (mother-child transmission, intravenous drug use, blood transfusion) are widely acknowledged. Homosexual conduct does become identified as a root cause because it easily feeds into available social knowledge schemas. Conventional, heterogeneous marriages under social pressure provide a social shield for the family's face in the community. The marriage

itself becomes a reason for not to disclose one's homosexual orientation. In a sense, cultural practices become a barrier to trust and disclosure.

So what happens I cannot if I am an MSM (Men Having Sex with Men) I cannot go to my parents and say I don't want to get married because I'm an MSM so when the parents say no you have to get married at least for the sake of name, I want an heir for my family things like that then they ultimately get married and they live as that. So there is general confusion between people, these people are married, how can they call themselves as gay, how they can they call them kothi it's something a lot of people don't understand. (W)

Homosexuality (referred to as 'Men having Sex with Men', MSM in short) poses a double stigma when it becomes associated with HIV/AIDS. What is equally interesting here is the fact that MSM is gaining wider recognition in the Indian context because of the potential threat it poses in spreading the virus; thus MSM need to be identified and worked with.

Nondisclosure of HIV positive status to healthcare professionals is also premised upon the fear of consequences at the societal level. In a recent study, Jones, Candlin and Yu (2000) discuss the different attitudes to disclosure between Chinese PHAs (Persons living with HIV/AIDS) and expatriates in Hong Kong. They conclude that the Chinese PHAs talk about disclosure more often than expatriates (with expatriates focusing more on disclosure in the workplace and Chinese focusing more on disclosure within the family). The decisions for disclosure or non-disclosure are influenced by the utility of the disclosure (on a cost-benefit scale), the identity of the target of disclosure (including other PHAs, family, social and workplace etc) and the timing of disclosure (in relation to testing positive). It is worth noting that the difference found in Jones et al study, showing that expatriates are more concerned with workplace rather than family, can be explained by the fact that most expatriates were detached from a 'normal' family setting and mainly occupied a workplace identity – the very reason for being in Hong Kong. A striking feature of the Jones et al study is that Chinese PHAs did not feel comfortable in disclosing relevant details to professional care givers, which borders on matters of trust; it also meant that the caregivers had limited scope to intervene. Many Chinese PHAs saw disclosure of information to professional caregivers as part of a problem rather than solution.

These differences can be partly explained by appealing to the sociocultural context. What is considered a family unit is a social/cultural construct – both locally

accomplished and historically embedded – and how information is generally shared or not shared within a family unit will influence decisions about whether to disclose or not disclose one's health status. This is parallel to findings from studies on transmission of genetic information within the family, whereby one can use the notion of disclosure/nondisclosure of information as a defining feature of ideal/dysfunctional family relations and kinship systems in contemporary societies (Featherstone et al 2005, Sarangi et al 2004). It is equally important to recognise that nondisclosure can have a social function in keeping family solidarity.

The conditions of disclosure

Much of my discussion so far has been the societal grounds of nondisclosure, because of fear of consequences. In this final section I wish to consider briefly when and how disclosure occurs, by ensuring a minimisation of consequences. Disclosure or 'coming out' is facilitated by a sense of belonging, in finding a family and a community outside of the traditional family and neighbourhood community which fails to provide a supportive environment. As we have seen, the option of coming out is less available in the context of normal family relationships. A disclosure is threatened with the act of being thrown out of the family as well as being abandoned by the society at large. The alternative strategy is based on a notion of normality rather than deviance per se. In the following example, an NGO (I+) representative paints a positive image for the HIV positive people:

What we do is we have something on the positive speaker's bureau. We try to positively show HIV AIDS and say you know this is a person with HIV and he's not dying, he's perfectly healthy, and he's very articulate, he knows what he's saying and and he does he's smiling and he's cheerful. And he does have a life you know, like he's not sitting in one corner waiting to die. So when you put somebody in front of an audience, a bunch of farmers or somebody and you tell them this is what a person with HIV looks like. So then they sit up and take notice and they say, OK what happened to the skeleton which we were shown on the poster? Because TANSACS ministry started off like this, they had this coffin and a funny looking skeleton laid out on it and it was like this is what HIV will do to you, this is what AIDS can do to you, AIDS kills and then a condom in the corner. Really weird stuff, but then it really sticks you know, something that terrifies you is something that sticks in your mind

whether you like it or not. So when you put somebody up in front of an audience and this person talks about how his life, how he discovered he had HIV and the stages he went through after that and how he finally managed to you know get a grip on himself and move on with life, what he's doing now with his life and things that he's doing. And when he talks about how to prevent AIDS, how you can safeguard yourself, how you can prevent it, it makes a lot more sense to at least to us to send it that way. Because what happens is a lot of people don't believe that HIV exists in this country. They say everybody says there's AIDS, and HIV and AIDS, but you don't see anybody with HIV.

We have here an example of disclosing/displaying a HIV positive person to society in a constructive way, as a move toward de-stigmatisation, which may help to minimise the 'felt stigma' (Green 1995), and thus encourage disclosure. In a sense, this is an attempt to counter directly the stigma and stereotype that is spread via scary advertisements, such as the one alluded to here from TANSACS, one of the regional centres of NACO. This activity of 'coming out' goes beyond disclosure in the everyday sense; it not only helps in relating to people but also in getting across a message of prevention. Trust is brought about by a process of demystification of the scare communicated through advertising. Trust is also premised upon a display of normal conduct of life. The very final sentence reminds us of the invisible nature of the stigmatised self, in the Goffmanian sense.

The discussion above connects with the tensions surrounding the 'risks of knowing' one's genetic status, although not for reasons of social stigma (Sarangi et al 2003). In the context of genetic counselling, clients tend to oscillate between knowledge about their at-risk status, including the possible consequences associated with the risk of taking the predictive test (R^1) as well as the risk/likelihood of developing the condition (R^2). The risks of knowing one's genetic status are made experiential, in the counselling setting, by making what is to be known as possible consequences of such knowledge available prior to the giving of the test result. In the HIV/AIDS context, what we find is the risk of disclosure, which may be called R^3 , on the face of social stigma.

Conclusion: Mutations in individual, family and societal role-relationships

The focus of my discussion in this paper concerning disclosure/nondisclosure can be situated at the interface between the public and private spheres with regard to notions of social acceptance and stigma. I have argued that the individual is caught up in maintaining relations with the family network as well as the community. Family- and community-based values, especially in terms of potential consequences, take priority over individual preferences. As we have seen, the community works as another layer of family – as an extended network – where a family’s corporate ‘face’ has to be preserved. Decisions therefore about disclosure and who to trust are based on the values attached to self-other relationships at both family and community levels. The influential role of third parties as recipients of sensitive information and their responsibility toward further non-disclosure is recognised. The global nature of HIV/AIDS has not altered the family/community relations with regard to disclosure/trust. Indeed the traditional concepts of marriage, matchmaking, role of women, extended family are drawn upon strategically to justify decisions about nondisclosure. As we have seen, in the Indian context, the situation becomes particularly complex when it involves disclosure of HIV positive status by women and homosexuals.

In the Parsonian model (Parsons 1951), the sick person relinquishes his/her normal social responsibilities until they recover. Within this framework, the society via its medical establishment is trusted to help the individual to return to normal. In the case of HIV/AIDS, however, the society-as-other becomes a player in the suffering process with a heightened sense of stigma and discrimination. Trust and normal social order are somehow interwoven.

As I have shown, trust and fear of disclosure are two sides of the same coin: one discloses information to someone trusted; trust is built upon shared information. Distrust and non-disclosure likewise go hand-in-hand. The cultural context, especially networks of information exchange, necessarily mediates the trust-disclosure dynamics. How close-knit a society is and how information flows upstream and downstream will no doubt affect what gets communicated.

Some fifteen years ago, Susan Sontag wrote:

It seems that societies need to have one illness which becomes identified with evil, and attaches blame to its ‘victims’, but it is hard to be obsessed with more than one. (Sontag 1991, p. 101)

Cancer has occupied such a position for some time and in recent years AIDS appears to be a strong candidate for such social obsession. Sontag's argument is that too much is read into illnesses such as cancer and HIV/AIDS, thus taking such experiences into the metaphorical and mythical levels. On the one hand, experience of – and responses to – chronic illnesses is rooted in socio-culturally available meaning systems along the lines of symbolic/constructionist interactionism (Blumer 1969, Berger and Luckmann 1967, Douglas 1971) and medical anthropology (Good 1994). On the other hand, such meaning systems are often based on ignorance about aetiology leading to stigmatisation of the individual patient. Myths and metaphors abound, which has immediate consequences for disclosing one's disease status in fear of social exclusion. Suffering is more from thinking about illness and how people respond than from the illness itself.

Against this backdrop, Sontag pleads for 'against interpretation' which will amount to depriving AIDS of its meaning, especially the moral overtones. Reflecting on her own cancer experience she writes:

For it was my doleful observation, repeated again and again, that the metaphoric trappings that deform the experience of having cancer have very real consequences: they inhibit people from seeking treatment early enough, or from making a greater effort to get competent treatment. The metaphors and myths, I was convinced, kill. (Sontag 1991, p. 99)

There are two inter-related points I would like to conclude with. Firstly, if social stigma acquires a mythical status, as we have seen in this paper, nondisclosure of HIV/AIDS positive status will continue to threaten not only the societal fabric but also the very quintessential inter-personal relationships in a given society. Secondly, the routine activity of nondisclosure of HIV positive status in fact 'discloses' the deep-rooted asymmetries and tensions that characterise the traditions of Indian social life.

Figure 1

Leaflet – front cover


STAY AWAY FROM AIDS



Not the person with
HIV/AIDS

AIDS
KNOW AIDS FOR NO AIDS

For more information contact :
National AIDS Control Organisation
Ministry of Health & Family Welfare
Nirman Bhawan, New Delhi - 110011

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AIDS

AIDS poses one of the biggest threats to mankind ever, in order to lead an AIDS-free life one must know all about HIV, (the AIDS causing virus) for knowledge is the best defence against AIDS.

HOW IS HUMAN IMMUNODEFICIENCY VIRUS TRANSMITTED ?

The Human Immunodeficiency Virus (HIV) gets transmitted through :

- Unprotected sex with an infected partner.
- Transfusion of infected blood and blood products.
- Use of contaminated needles and syringes.
- From an infected mother to her baby before, during or soon after birth.



You can befriend a person with HIV/AIDS without brewing doubts. Social contact does not spread the infection.

HOW IS HIV NOT TRANSMITTED?

- i) By casual contact such as touching,

holding hands,
body contact in
crowded places,
shaking hands,
working or
playing together.



- ii) HIV also does not spread by sharing food, vessels and clothes, eating food cooked by an infected person, mosquito and other insect bites, swimming pools and toilets.

SHOULD HIV PATIENTS BE KEPT IN-ISOLATION ?

No. HIV positive persons can live a normal healthy life for years provided they adopt a healthy life style. A person infected with HIV should be treated with the same warmth and affection as one would treat any other person suffering from an incurable disease. AIDS is just like any other disease and support from family and friends can only make the patient feel better.

AIDS patients need your friendship and concern, reach out to them, for emotional proximity does not cause AIDS.

KNOW AIDS FOR NO AIDS

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