A systematic review of HIV/AIDS-related stigma and discrimination in India: Current understanding and future needs

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Abstract

HIV/AIDS-related stigma is recognised as a major barrier to HIV prevention efforts and an impediment to mitigating its impact on individuals and communities. This paper reviews the existing research literature on AIDS stigma in India with the objective of documenting the current status of research, highlighting major findings and identifying key gaps remaining. Thirty publications were identified through a careful search of which a majority focused on stigma assessment and very few on stigma measurement, conceptual aspects of stigma or stigma reduction interventions. A few standardised stigma measures are available but more are required to assess causes of stigma among general population and compounded and internalised stigma among positive people. Research exploring linkages between stigma and HIV services uptake or the effect of HIV care and treatment programs on stigma levels are largely missing and need to be prioritised. In addition, more research is needed to advance conceptual understanding of stigma within the cultural context of the country including research on the neglected groups such as, transgender people. Context-specific (health care, community) interventions are needed to address various forms of stigma – enacted, perceived, internalised and layered – including structural approaches besides inter-personal and information-based approaches. A major gap relates to meager research on developing and evaluating stigma reduction interventions and needs priority focus. Overall, the review recommends developing a national agenda on AIDS stigma research and interventions to help realise the government's goal of stigma reduction.

Keywords: HIV/AIDS, stigma, discrimination, people with HIV/AIDS, attitudes, India.

Résumé

La stigmatisation associée au VIH/Sida est reconnu comme constituant un obstacle majeur aux efforts de prévention du VIH et une difficulté à l'atténuation de son impact sur les individus et les communautés. Cet article passe en revue les articles de recherche existant sur la stigmatisation du Sida en Inde, dans l'objectif de documenter l'état actuel de la recherche, de souligner les conclusions majeures et d'identifier les lacunes essentielles qui subsistent. Trente publications ont été identifiées par une recherche soigneusement conduite, la majorité de ces documents se concentrant sur l'étude de la stigmatisation, très peu portant sur la mesure, les aspects conceptuels ou les interventions de réduction de la stigmatisation. Quelques mesures de stigmatisation standardisées sont disponibles, mais davantage sont nécessaires afin d'évaluer les causes de la stigmatisation dans la population générale et la stigmatisation exacerbée et internalisée par les personnes séropositives. Les travaux de recherche étudiant les liens existant entre la stigmatisation et le recours aux services associés aux VIH ou l'effet des programmes de prise en charge et de traitement du VIH sur les niveaux de stigmatisation sont pour l'essentiel absents et doivent être initiés en priorité. De plus, des travaux de recherche supplémentaires sont nécessaires afin de pouvoir disposer d'une meilleure compréhension conceptuelle de la stigmatisation dans le contexte culturel du pays, et notamment des études sur les groupes négligés tels que les transsexuels. Des interventions spécifiques au contexte (santé, communauté) sont nécessaires afin de pouvoir gérer différentes formes de stigmatisation – affirmée, perçue, internalisée et à plusieurs couches et notamment des approches structurels, en plus des approches interpersonnelles et basées sur les informations. L'une des principales lacunes est constituée par le manque de recherches sur le développement et l'évaluation des interventions de réduction de la stigmatisation et doit être étudiée en priorité. Globalement, l'étude recommande le développement d'un programme national sur la recherche et les interventions en matière de stigmatisation du VIH afin d'aide le gouvernement à atteindre son objectif de réduction de la stigmatisation.

Mots clés: VIH/Sida, stigmatisation, discrimination, personnes vivant avec le VIH/Sida, attitudes, Inde.

Introduction

Substantial evidence from different parts of the world highlights HIV/AIDS-related stigma as a barrier in HIV prevention work and in mitigating its impact (Mahajan, Sayles, Patel, Remien, Sawires, Ortiz *et al.*, 2008). The National AIDS Control Program of India also recognises AIDS stigma as a significant barrier to HIV prevention efforts. Accordingly, addressing stigma and discrimination is a key guiding principle in phase 3 of India's national programme to prevent and control HIV (National AIDS Control Organisation-NACO a, 2006, pg. 6). A vast body of social science literature exists on stigma assessment (Mahajan *et al.*, 2008) and on its role in hampering uptake of voluntary

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HIV counselling and testing (Day, Miyamura, Grant, Leeuw, Munsamy, Baggaley *et al.*, 2003), adherence to antiretroviral treatment (Calin, Green, Hetherton & Brook, 2007), and delaying general health seeking among people with HIV (Dunn, Green, Hammond & Roberts, 2009). In the past two decades the concept of stigma as commonly applied to conditions of mental illness and epilepsy, for example, has been revisited resulting in a greater clarity of the concept, in relation to the HIV epidemic (Parker & Aggleton, 2003; Phelan, Link & Dovidio, 2008; Maluwa, Aggleton & Parker, 2002; Weiss, Ramakrishna & Somma, 2006; Steward, Herek, Ramakrishna, Bharat, Chandy, Wrubel, & Ekstrand, 2008). Despite recognising stigma as a roadblock to HIV prevention efforts much less attention has been paid to developing effective stigma reduction programmes and activities globally (Mahajan, *et al.*, 2008; Brown, MacIntyre & Trujillo, 2003). In India, research on this important topic is gaining momentum but is still limited in scope and intervention research is almost non-existent. This paper reviews existing empirical literature on HIV/AIDS-related stigma and discrimination in India with the objective of examining the status of research, summarising key findings, identifying gaps and discussing the way forward.

The concept of stigma is derived from the work of Goffman who referred to it as '…an attribute that is deeply discrediting' and that reduces the discredited 'from a whole and usual person to a tainted, discounted one' (Goffman, 1963). People discredit others based on 'differences' and the 'deviance' so labeled results in 'spoiled identity'. Scambler (1989) differentiated between forms of stigma, referring to personal experience of stigma as 'enacted stigma' and perception of stigma as 'felt stigma'. Although Goffman's work has been widely applied to examine HIV/AIDS stigma, several inadequacies have been identified in this application, most notably by Parker and Aggleton (2003). They maintain that stigma and the resulting discrimination are not individualised processes in which some individuals 'do' something to other individuals in a vacuum. Instead, stigma must be understood in relation to the structural dimensions of 'power' and 'domination' that underlie inequalities, whereby some groups are devalued and excluded in comparison to others who are more valued and more privileged. Thus, stigmatisation is a social process inherently linked to the production and reproduction of structural inequalities (pg. 19). Within this framework, preexisting power imbalances and inequalities can be expected to intensify the stigmatisation of some individuals and groups. Indeed, HIV/AIDS-related stigma builds upon and fuels existing prejudices and inequities of class, gender and sexualities (Parker & Aggleton, 2003; Maluwa, Aggleton & Parker, 2002). A related concept in the stigma literature is that of discrimination, defined as the acts/behaviours that arise from stigma and that disadvantage people in various ways (Deacon, 2006). AIDS stigma often results in social and economic marginalisation and withholding of treatment or denial of services amounting to violation of human rights of people with HIV (Maluwa *et al.*, 2002). Both stigma and discrimination may occur at family and community or at institutional levels such as workplace, school, or health care settings. In addition, both may take overt (visible) or covert (hidden) forms. Because the term 'discrimination' denotes the acts that targets of stigma experience, it is also referred to as 'enacted stigma' (Jacoby, 1994). In this paper empirical works on both stigma and discrimination are reviewed.

Methods

Search strategy and articles selection

The PubMed/JStor/ScienceDirect/PsychINFO data bases were searched employing six keywords: HIV/AIDS, stigma, discrimination, attitudes, people with HIV/AIDS, and India. These generic key terms allowed for a wide search without restricting it to any particular state in India or discipline of study. The 70 articles/abstracts initially identified this way were scrutinised for inclusion criteria, resulting in a list of 37 articles. Specifically, only empirical articles with HIV/AIDS stigma as a key objective of study, with relevance to India, employing qualitative and/or quantitative methods, published in English language periodicals up to April 2010, were included. Review articles, case studies, those on other non-HIV health conditions, were excluded. A further cross search was made on the websites of India's National AIDS Control Organisation (NACO) and the UNAIDS and WHO. A manual search was also made in the reference list of relevant review articles. This way a further 10 publications, a few of them non-peer reviewed but significant for this review, were identified taking the total to 47 articles. These 47 articles were carefully examined and finally 30 were retained after excluding those lacking in any meaningful analytic procedures (see Fig. 1 for selection process). For the purpose of this review these 30 articles were classified into four broad, though not entirely exclusive, categories: conceptual articles, articles on stigma assessment, on stigma measures; and those on stigma reduction interventions.

Four broad questions guide this review: What main AIDS-related stigma themes have been examined in India over time? What methods have been used to study AIDS stigma? What are the major findings? What is the status of stigma-reduction interventions in the country? Based on answers to these questions, gaps have been identified in the current literature followed by directions for future research and intervention.

Results and discussion

A total of 30 studies were reviewed and are summarised in Table 1. Broadly, two almost 'parallel' streams of HIV/AIDS-related stigma research can be identified in the Indian context. One stream represented by quantitative studies in the classic 'Knowledge-Attitude' pattern (N=14) has investigated 'attitudes' of select population groups of 'stigmatisers' such as, health staff and college students towards people living with HIV/AIDS (PLHA). The other, represented by a combination of quantitative and/or descriptive qualitative studies, has mainly explored in-depth the forms, contexts, manifestations and implications of AIDS-related stigma among those living with HIV, that is, the stigma 'victims' (N=10). Differing in their conceptualisation of stigma and methods the two sets of studies preclude a direct meaningful comparison and appraisal of study findings. Each set of studies is, therefore, reviewed separately with an attempt made to identify cross learning. Stigma assessment studies dominate the literature (N=24) with only a few articles reporting on development of reliable and valid stigma measures (N=5), stigma effects (N=2) or on stigma reduction interventions (N=3). Only two publications were found dealing with conceptual aspects; one that explored all stigma forms (Bharat, Aggleton, & Tyrer, 2001) and another a framework for understanding stigma in the Indian context (Steward *et al.*, 2008). In terms of geographical coverage, a
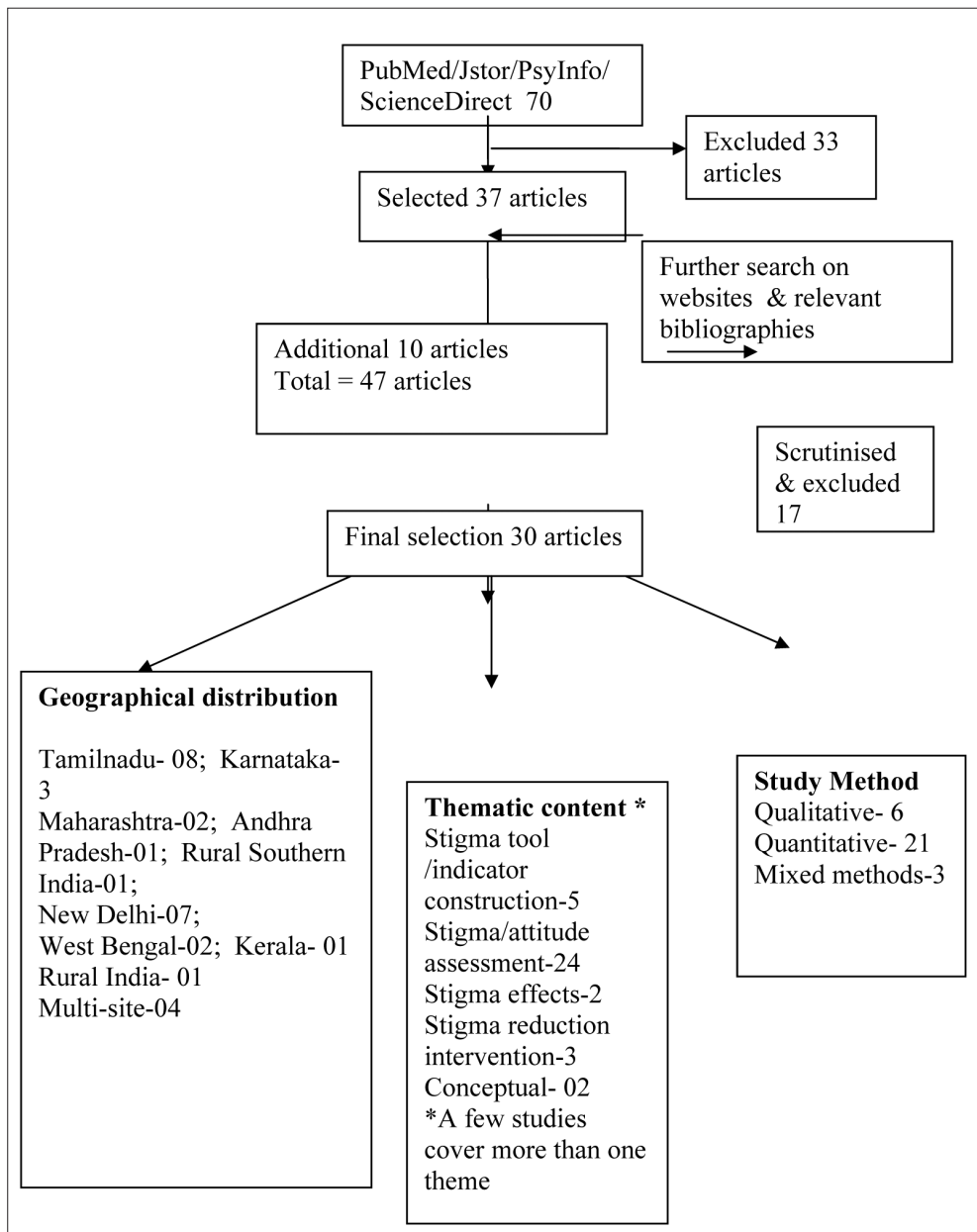
Fig. 1. Review/selection process and distribution of selected articles.

Sarma, & Thankappan, 2000; Pramanik, Chartier & Koopman, 2006), adults in general population (Porter, 1993) or health providers, mainly nursing staff (Lal, Kumar, Ingle & Gulati,1998; Datta & Bandopadhyay,1997; Kermonde, Holmes, Langkham, Thomas & Gifford, 2005; Kumar, Lal, Ingle & Gulati, 1999; Kumar, Mohan, Seenu, Kumar, Nandi & Sarma, 2002), and more recently among pregnant women (Rogers, Meundi, Amma, Rao, Shetty, Antony *et al.*, 2006; Rahbar, Garg, Tripathi, Gupta & Singh, 2007). The findings from these studies are fairly consistent with regard to attitudes towards PLHA. Between one third and half of the respondents including health providers, blame HIV-infected people for their infection, display fear of infection from casual contact with them, express intentions to avoid them in daily life, endorse denial of their right to marry, and support their isolation in health settings. More than one-third of respondents in the earliest study by Porter (1993) refused to dine and work with HIV-positive people and 50% supported their quarantine. Feelings of discomfort were reported among more than one fourth of the sampled nursing students in talking, hugging, shaking hand and sharing room with HIV-positive people, with about a tenth of them (11%) contemplating leaving the nursing profession due to fear of occupational exposure to HIV (Lal *et al.*, 1998). However, more than 58% among them expressed willingness to care for PLHA if provided relevant training. In a sample of educated youth 90% harboured at least one negative view towards PLHA, example, 'HIV-infected people should kill themselves', 42% supported quarantining them and 31% favoured their ban from attending classes (Ambati *et al.*, 1997). In a more recent study of school adolescents in New Delhi, 37% are reported to believe that HIV/AIDS is a punishment from God and 30% that PLHA deserve their condition but 84% were willing to talk to them while only 12% were comfortable shaking hands with them (Pramanik *et al.*, 2006). Among general population respondents of the National Behavioral Surveillance Survey-BSS (NACO, 2006b), 56% said they would allow PLHA to stay in the same village while a higher percentage (63%) supported a separate care center and only 44% would allow PLHA to be treated

majority of the studies are understandably carried out in regions with higher HIV prevalence (N=15): Tamil Nadu 8, Karnataka 3, Maharashtra 2 (1 rural site), Andhra Pradesh 1, rural Southern India 1. Four studies are designed as multisite studies in high, medium and low HIV prevalence states (Bharat et al, 2001; Paxton, Gonzales, Uppakaew, Abraham, Okta, Green *et al.*, 2005; National AIDS Control Organization NACO b, 2006; Kurien, Thomas, Ahuja, Patel, Shyla, Wig, Mangalani, *et al.*, 2007). Other study sites are located in lower HIV prevalence states of New Delhi (7), Kerala (1), and West Bengal (2), rural India (1). In all, only 3 studies were located in rural sites (see Table1 for details).

What do quantitative studies tell us?

Some of the earliest studies on AIDS in India were carried out in the 90s and a majority assessed knowledge about HIV/AIDS and attitudes towards HIV-infected people among the general public, mainly students (Ambati, Ambati & Rao, 1997; Lal, Vasan,

Table 1. Details of studies included for review (*N*=30)

Sl. No.	Authors/ year	Study site(s)	Type of study	Sample	Methods/measures
Studies with PLHA (victims of stigma)					
1.	Chakrapani et al. 2009	Chennai, Tamilnadu	Qualitative	19 HIV-positive FSWs	Key informant interview, focus group discussion
2.	Subramanian et al. 2009	Chennai, Tamilnadu	Quantitative	646 HIV+ 220 F/ 426 M	Stigma scale - 40 item (Actual, perceived, disclosure concerns, internalised stigma)
3.	Steward et al. 2008	Bangalore, Karnataka	Qualitative & Quantitative	16 HIV + (11 M/5 F) & 229 HIV + (159M/ 70F)	In-depth interview- phase 1 Scales to measure stigma types - phase 2
4.	Thomas et al. 2008	Chennai, Tamilnadu	Qualitative	60 HIV+ women	Focus group discussion
5.	Chakrapani et al. 2007	Chennai, Tamilnadu	Qualitative	10 HIV + *kothi* MSM	Interview
6.	Elamon 2005	Trivandrum district, Kerala	Qualitative	20 HIV + 12 F/ 8 M 12 key informants	Key informants interview, focus group discussion/ interview
7.	Thomas et al. 2005	Chennai, Tamilnadu	Quantitative	203 HIV + 102 F/ 101 M	Berger scale 40 item - 4pt scale (Actual, perceived, disclosure concerns, internalised stigma)
8.	Pallikadavath et al. 2005	Rural Maharashtra	Qualitative	19 HIV + 10 F/ 9 M	In-depth interview Focus group discussion
9.	Paxton et al. 2005	Manipur, Nagaland Tamilnadu Kerala Goa Karnataka Maharashtra	Quantitative	291 HIV + 126 F 159 M 02 Transgender	133-item questionnaire
10.	Bharat et al. 2001	Mumbai, Maharashtra Bangalore, Karnataka	Qualitative	45 HIV + men & women; Hospital staff; community members	In-depth interview Focus group discussion
Studies with general population and select sub-groups of health staff, students (perpetrators of stigma)					
11.	Unnikrishnan et al. 2010	Mangalore, Karnataka	Quantitative	630 adults aged 18 years and above	Semi-structured questionnaire
12.	Meundi et al. 2008	Dakshina Kannada district, Karnatak,	Quantitative	1669 adults aged 19-49	Survey instrument
13.	Kurien et al. 2007	Multisite study	Quantitative	2200 health providers	Interviewer administered questionnaire
14.	Rahbar et al. 2007	New Delhi	Quantitative	90 pregnant women	Questionnaire
15.	NACO, BSS 2006b	National- multisite	Quantitative	97 240 adults aged 15-49	Questionnaire
16.	Pramanik et al. 2006	New Delhi	Quantitative	186 school going adolescents	Questionnaire
17.	Rogers et al. 2006	Rural southern India	Quantitative	202 pregnant women antenatal clinic attendees	Survey instrument
18.	Kermonde et al. 2005	Rural India	Quantitative	Nurses, doctors, health workers	Attitude scale
19.	Kumar et al. 2002	New Delhi	Quantitative	Nurse staff	Attitude scale
20.	Kumar et al. 1999	New Delhi	Quantitative	Nursing students	Self-administered questionnaire

Table 1. Continued

Sl. No.	Authors/ year	Study site(s)	Type of study	Sample	Methods/measures
21.	Lal et al. 1998	New Delhi	Quantitative	233 diploma Nursing students	Survey instrument
22.	Ambati et al. 1997	Andhra Pradesh	Quantitative	College students and teachers	Attitude scale
23.	Datta & Bandyopadhyay 1997	Calcutta, West Bengal	Quantitative	In-service nurses	Attitude scale
24.	Porter 1993	Calcutta, West Bengal	Quantitative	153 adults- 78 women, 75 men	Survey instrument and attitude scale
Stigma measures					
25.	Zelaya et al. 2008	Chennai, Tamilnadu	Quantitative	200 men from general population	Stigma scale construction
26.	Green et al. 2007	Madurai, Tamilnadu	Quantitative	230 HIV + 102 F/128 M	Observation method
27.	Mahendra et al. 2007	New Delhi	Qualitative and quantitative	884 health staff	Key informants interview 21-item stigma index development
Stigma reduction intervention studies					
28.	Sivaram et al. 2009	Chennai, Tamilnadu	Quantitative	2369 men & women	Ethnographic interviews; survey questionnaire; Stigma scale – fear of transmission, shame & judgment, enacted, perceived stigma
29.	Pisal et al. 2007	Pune, Maharashtra	Qualitative/ Quantitative	3 focus groups; 480 nurses	Pre-post design focus group discussion Questionnaire
30.	Mahendra et al. 2004	New Delhi	Quantitative	Hospital staff	Pre-post design PLHA-friendly checklist Stigma index

with other patients. One study examined stigma in terms of denial of rights of PLHA to marry and have children. Nearly one third of the pregnant women (29%) attending a Prevention of Parent to Child Transmission (PPTCT) programme (Rahbar *et al.*, 2007) believed that PLHA should not marry, 31% that they should not have children and 39% supported mandatory testing for pregnant women and for premarital couples (Rahbar *et al.*,2007). Although it is difficult to assess trends in findings because of non-uniformity of study instruments across studies, the general observation is that negative attitudes, attribution of blame, fear of contagion due to casual contact with PLHA, and avoidance intentions towards PLHA have not declined significantly from the early 90s. These studies carried out on the 'stigmatisers' of PLHA and designed within the individual centric socio-cognitive framework, have led to the general demand for basic training on HIV for health staff and for HIV/AIDS 'awareness' programmes in schools and colleges (Lal *et al.*, 1998; 2000). The major weakness of these studies is their oversimplified approach to conceptualising attitudes towards AIDS in terms of fear of contact and its corollary avoidance intentions with lack of appreciation to contextual and structural factors underlying AIDS stigma. From the point of methodology the most critical gap is the absence of formative research to guide the study design and

tool construction for a 'new' stigmatised health condition strongly associated with sex and sexuality.

Stigma themes based on qualitative and mixed methods research

A majority of the studies included in this section are based on samples of PLHA, in other words the victims or targets of stigma.

Stigma and HIV status disclosure. HIV status disclosure forms an important theme in many stigma studies. Involuntary disclosure of a person's HIV status in the health setting through health staff is reported to be the beginning of the stigmatisation experience for most positive people in India (Bharat *et al.*, 2001; Elamon, 2005; Paxton et al, 2005; Mahendra, Gilborn, Bharat, Mudoi, Gupta, George *et al.*, 2007). See Box 1.

> Box 1. 'The society knew from the health inspector that I was HIV-positive. The situation became worse. All of them stopped coming to my home. I was mentally tortured…' (40-year-old male in Kerala, Elamon, 2005).

Disclosure worry about who knows, or will come to know about one's HIV infection and with what consequences is not contingent upon enacted stigma or discrimination alone. In other words, disclosure concerns are not limited to only those PLHA with personal experience of stigma. Maintaining secrecy or limiting disclosure of HIV status appears to be a protective response among both men and women regardless of actual experience of stigma. Further, it is associated with all forms of stigma, namely felt, internalised and vicarious stigma (Steward *et al.*, 2008). For example, the fear of mistreatment in health settings, potential loss of social status for self and family, possible loss of job and rejection from spouse, reported among men with HIV influence their disclosure decisions and form the basis for felt and self stigma (Bharat *et al.*, 2001; Pallikadavath, Garda, Apte, Freedman, & Stones, 2005). Similarly, the anticipated negative impact on children's school admission and likely rejection from spouse/in-laws, reported among HIV positive women affect their decisions to share information on HIV status with others (Thomas, Nyamathi & Swaminathan, 2008; Bharat *et al.,* 2001).. Managing information of one's own HIV status or of a close family member is thus important as a strategy to escape from enacted stigma and its social costs (Pallikadavath *et al.*, 2005; Steward *et al.*, 2008). High disclosure-related concerns are supported by quantitative studies of stigma (Subramanian, Gupte, Dorairaj, Periannan & Mathai, 2009; Thomas, Rehman, Suryanarayanan, Josephine, Dilip, Dorairaj *et al.*, 2005) with at least one study reporting significantly higher disclosure concerns among positive women (91%) than men (82%) (Subramanian *et al.,* 2009).

Blame and shame. One of the expected findings reported in literature is the blame attributed to people with HIV and the shaming process associated with blame attribution (Bharat *et al.*, 2001; Pallikadavath *et al.*, 2005). In the Indian context HIV infection in men is most commonly associated with 'immoral/ promiscuous' behaviour such as visits to sex workers (Pallikadavath *et al.*, 2005; Bharat *et al.*, 2001). Moral aspersions are cast on men with HIV and they are labeled as possessing 'loose moral character' (Bharat *et al.*, 2001). Women with HIV may be slotted as 'innocent victims' within society with their 'behavior vouched for positively' (Pallikadavath *et al.*, 2005), but within the household they are often blamed for bringing the infection into marriage (Bharat *et al.*, 2001). Shaming of positive people is commonly reported after HIV diagnosis in health settings and probing questions are often asked by health staff with the intention to shame them (Thomas *et al.*, 2008; Bharat *et al.*, 2001; Pallikadavath *et al.*, 2005). See Box 2.

> Box 2. 'I was asked very embarrassing questions when my little daughter was HIV-positive. The doctors accused my husband saying he must have been drunk and (must have) sexually abused my child' (a mother with HIV, Thomas *et al.*, 2008).

Enacted, perceived and internalised stigma. All three forms of stigma are reported in the Indian context. Descriptive studies (Bharat *et al.* 2001; Pallikadavath *et al.*, 2005; Thomas *et al.*, 2005) report personal experiences of men and women who are isolated in their homes, forced to use separate utensils, not allowed to cook, or refused treatment by health staff. See Box 3.

> Box 3. '…family members do not treat me well. They do not let me touch anything, mix with them, do not let me cook for my son' (positive woman aged 28, Pallikdavath *et al.*, 2005)

However, similar to the findings for other Asian countries (Thailand, Philippines, Indonesia), the proportion of positive people reporting enacted stigma (personal experience of stigma or discrimination) is not very high in India (Paxton *et al.*, 2005; Steward *et al.*, 2008). Between 5 and 30 per cent of HIV positive Indian respondents in Paxton's study of PLHA in Asia reported discrimination (enacted stigma): 30% experienced discrimination by health workers, 20% were refused treatment by a health worker because of HIV status, and 15% were forced to pay additional charges for medical services on account of HIV status. Similarly, in Chennai, Thomas *et al.* (2005) reported enacted stigma among 30% of women and 20% of men, while Subramanian *et al.* (2009) reported it among 33% of PLHA with significantly more HIV-positive women reporting perceived stigma (41%) than positive men (28%). In a Bangalore sample, 71% of positive people did not report any instance of discrimination (Steward *et al.*, 2008). By comparison, perceived or felt stigma is reported much higher. For example, more than 94% of men and women reported perceived stigma in two separate studies by Thomas *et al.* (2005) and Subramanian *et al.* (2009). Quality of life of those experiencing enacted stigma was found to be good in overall terms. Internalised stigma (or self-stigma) was also reported to be high (between 63% and 83%) in both the above studies with significantly negative correlation with quality of life in the psychological domain. In the Bangalore sample, perceived stigma was higher than internalised stigma and all three forms of stigma were associated with greater levels of depression (Steward *et al.*, 2008). Qualitative studies also support the presence of self or internalised stigma whereby those infected tend to accept stigmatisation from others, feel guilty and justify the discriminatory behavior of others towards them (Bharat *et al.*, 2001). The quote below illustrates this:

'*People are not to be blamed (for how they behave towards us). I think this was to happen – I mean nobody will tolerate "wrong' kinds" of behavior (galat kaam), and this is an incurable disease (lailaaj bimari) – so who wouldn't be afraid' (Bharat et al., 2001, p53)*

Courtesy stigma. Very few studies in India have reported on courtesy stigma or stigma by association. Bharat *et al.* (2001) reported on courtesy stigma experienced by doctors treating HIV-positive patients while Chakrapani, Newman, Shanmugam, McLuckie & Melwin (2007) have reported it for family members of HIV-positive *kothi*, identified men who have sex with men (MSM).

Layered stigma. Stigma associated with HIV is frequently layered over other forms of social disadvantage thereby accentuating the exclusion and devaluation of positive people. Bharat *et al.* (2001) reported stigma and discrimination among HIV-positive female sex workers (FSWs), MSM, and '*hijras*' (transgendered persons) to be compounded due to their being part of groups traditionally stigmatised in Indian society. Post HIV status disclosure, not only were they marginalised by the mainstream but sometimes also by

their own communities. HIV-positive female sex workers were isolated by other sex workers and thrown out of the brothels by the owner, and when sick, refused treatment at local hospitals because of dual stigmatised identities as HIV-positive and as '*dhandewali*' (sex-worker) (Bharat *et al.*, 2001). For HIV-positive MSM similarly, the two stigmatised identities of being HIV-positive and of being homosexual posed challenges. Some, therefore, chose to pass as positive heterosexual men rather than risk being found out to be homosexual (Bharat *et al.*, 2001). HIV-positive *Kothi* identified MSM in a study by Chakrapani *et al.* (2007) reported stigma, discrimination and violence in a variety of social and institutional contexts for example, the police, community, family and health care. The reality of double stigma is underscored by the following quote, 'My father told me that he could tolerate that I was HIV-positive but asked me not to tell others that I got it by having sex with men' (Chakrapani *et al.*, 2007, p. 355). In another study HIV-positive female sex workers reported experiencing dual stigma on account of their sex work and HIV status (Chakrapani, Newman, Shanmugam, Kurian & Dubrow, 2009). Groups vulnerable to HIV are commonly associated with HIV infection in India which predisposes them to discrimination. A little less than half of all health staff (43%) in a base line survey (Mahendra *et al.*, 2007) for instance, agreed with the statement, 'sex workers are the only women to worry about getting HIV' implying that sex workers are the only women who are vulnerable to HIV because of their risk behaviour.

Gender dimension of AIDS stigma. Diagnosis of HIV infection among women has been shown to result in attribution of blame and labelling in diverse contexts (Bharat *et al.*, 2001). In the case of married women, members of the husband's household tend to blame them for the disease and for the misery brought on the entire family. Women are also blamed for not being able to control their men from straying on the wrong path. Women with HIV are often denied shelter and the right to live in their matrimonial home, sometimes even while their HIV-positive husbands are alive . In some homes positive women are denied access to their children and the right to their share in the deceased husband's property (Bharat *et al.*, 2001; Thomas *et al.*, 2008; Pallikadavath *et al.*, 2005). Widows of HIV-positive men are rejected by the in-laws family and forced to return to their natal homes (Pallikadavath *et al.*, 2005; Bharat *et al.*, 2001). About 10% of HIV-positive women in the Indian sample of Paxton's study were forced into abortion or sterilisation (Paxton *et al.*, 2005). By contrast, studies show greater acceptance and support for HIV positive men as part of the family-oriented culture and ethos of India (Bharat & Aggleton, 1999). In health settings women with HIV are asked embarrassing questions which discourage them from seeking care for HIV-related treatment, as supported by this quote: 'When they (physicians) see our case record and see the (HIV) status they treat us differently….they probe further and ask sensitive questions' (Thomas *et al.*, 2008). Frequent visits to hospitals are a potential source of suspicion and stigma for some HIV-positive women (Thomas *et al.*, 2008) presumably because women are not expected to be seen in public spaces on their own and without apparent reasons. In quantitative assessments gender differences were not uniformly strong. In the Bangalore sample, for example, men scored higher on internalised stigma but no gender differences were observed on enacted and felt stigma (Steward *et al.*, 2008).

Multiple contexts of stigma and discrimination

Stigma in health care settings. Health care settings are reported to be the most significant contexts for stigma and discrimination in India (Bharat *et al.*, 2001; Thomas *et al.*, 2005; Mahendra *et al.*, 2007; Pisal, Sutar, Sastry, Kapadia-Kundu, Joshi, Leslie *et al.*, 2007; Elamon, 2005; Paxton *et al.*, 2005). Across staff levels attitudes towards positive patients are unfavourable and the basis for their discriminatory acts. In a base line survey conducted among hospital staff in Delhi, 68% agreed to the statement that 'HIV spreads due to immoral behaviour' and more than a third (37%) agreed that men with HIV deserve what they have got while this view was supported by comparatively fewer respondents for women with HIV (29%) (Mahendra *et al.*, 2007). Discriminatory practices towards PLHA by health staff include, identifying positive patients and minimising contact with them including denying assistance to pregnant positive women during delivery (Thomas *et al.*, 2008), delaying treatment or care and demanding additional payment for consultation or services (Bharat *et al.*, 2001; Elamon, 2005). Kurien *et al.* (2007) similarly reported discrimination of PLHA by doctors; 20% of doctors refused treatment to PLHA some of the times, 24% isolating them for care and 13% postponing or changing line of treatment, (Kurien *et al.*, 2007). Patient consent and confidentiality, the basic tenets of human rights, find little support within health settings in India. And this is even truer for HIV-positive patients. HIV testing is quite often done without seeking consent of patients or pre-test counselling and may not always be followed by post-test counselling either. Paxton *et al.* (2005) found that only 52% of positive respondents in India were explained about the HIV test prior to being tested and a similar percentage were provided counselling at the time of receiving the HIV test results. In the study by Mahendra *et al.* (2007) half of the health staff felt that the need for consent prior to testing was exaggerated and just 39% agreed that patients' blood should never be tested for HIV without their consent. Pisal *et al.* (2007) similarly reported high agreement among nursing staff of a government hospital on an attitudinal scale measuring agreement (100)/ disagreement (0) to statements related to themes of informed consent and patient confidentiality. For example, high mean agreement scores were obtained on statements that said testing for HIV of a surgery patient without his/her consent is not a problem (74.7) or that labelling the beds of HIV patients is a good practice (56.1). Another violation of rights occurs in the domain of reproductive health. About 10% of positive pregnant women reported being coerced into abortion or sterilisation (Paxton *et al.*, 2005). Eighty per cent of the health staff interviewed (N=884) felt HIV-positive women should not get pregnant and only 39% agreed that people with HIV should be allowed to marry (Mahendra *et al.*, 2007). Health staff were also supportive of mandatory testing of all patients before surgery (86%) and of all pregnant women (79%).

Stigma within community settings. Few studies have examined community-based stigma. The most common forms reported are labelling and shaming (Paxton *et al.*, 2005; Pallikadavath *et al.*, 2005; Bharat *et al.*, 2001). However, various instances of more extreme forms are also reported such as, exclusion from social functions, expulsion of children of positive parents from schools, boycotting social visits to homes, physical isolation, and denial of last rites and burial plot upon death (Bharat *et al.*, 2001; Pallikadavath *et al.*, 2005; Elamon, 2005). Visible signs and symptoms of AIDS seem to

enhance discrimination within the community due to increased fear of infection transmission (Pallikadavath *et al.*, 2005).

Stigma within family setting. About 20% of positive people in the study by Paxton *et al.* (2005) reported discrimination in their family. Most common forms of discrimination reported were separating eating utensils, preventing positive people from cooking or sharing food, and denying them the use of common spaces and toilets (Paxton *et al.*, 2005). In addition to these, qualitative studies also reported withholding resources for care and treatment, denying share in property and access to children (Thomas *et al.*, 2005; Bharat *et al.*, 2001; Pallikadavath *et al.*, 2005).

Stigma in other settings. Other settings for AIDS-related discrimination reported in India are employment and education setting. One in five positive respondents in Paxton's multisite study reported losing their job after HIV diagnosis (Paxton *et al.*, 2005).

Stigma impact on health seeking, HIV prevention and treatment

AIDS stigma (enacted or perceived) is reported to be a strong barrier to accessing services whether for HIV testing, treatment for opportunistic infections or for anti-retroviral treatment (Mahajan *et al.*, 2008). Very few studies in India have examined AIDS stigma as a barrier to accessing testing, care and treatment services. Among pregnant women seeking antenatal care in a rural setting, willingness to be tested for HIV was high (85%) but a majority were concerned about confidentiality and stigma from husband, parents and community (Rogers *et al.*, 2006) suggesting fear of stigma as a reason for low testing uptake. Perceived stigma discourages HIV-positive women from seeking care in public hospitals in Chennai (Thomas *et al.*, 2008). Among HIV-positive female sex workers, both enacted and perceived stigma are reported as barriers to accessing general care as well as ART services (Chakrapani, *et al.*, 2009).

Conceptual framework for understanding stigma

Qualitative studies provide rich insights into the cultural contexts of stigma and discrimination in India. One of the early insights gained was that perceived stigma is experienced more commonly than enacted stigma in India and that perceived stigma seriously impacts disclosure of sero-status to significant others including health care personnel (Bharat *et al.*, 2001). Other critical insights have been in relation to the internalisation of stigma by HIV-positive men; the gendered dimension of stigma; the multiple stigmas experienced by those already marginalised in society; and stigmatisation carried in death (Bharat *et al.*, 2001). More recently, Steward *et al.* (2008) examined the applicability of existing conceptual frameworks of stigma in Indian context, linking enacted, felt and internalised stigma with disclosure avoidance and psychological distress. A new form of stigma, namely vicarious stigma, was indentified to denote the channel for transmitting information about enacted stigma (Steward *et al.*, 2008). Vicarious stigma helps to explain how stories about enacted stigma and its consequences are communicated and form the basis for felt normative stigma (Steward *et al.*, 2008). For example, listening to stories of discrimination towards other positive people made the possibility of stigma highly salient for positive respondents, resulting in efforts to manage information about their HIV status.

Further, the conceptual distinctiveness established between felt stigma and internalised stigma with differential consequences for PLHA was reported to have important implications for stigma interventions. The study supported the theorisation of 'discredited' and 'discreditable' identities and their links with management of stigma and discrimination by affected individuals. Supporting PLHA for disclosure of HIV status was identified as an important aspect in stigma-reduction efforts.

Methodology of HIV/AIDS stigma research

Typically, the qualitative studies are based on numerically small (between 10 - 60), convenience samples of positive people drawn from clinics and PLHA support groups (Bharat *et al.*, 2001; Thomas *et al.*, 2008; Elamon, 2005; Pallikadavath *et al.*, 2005). Interview and focus group discussion are the main methods used. Quantitative studies are based on samples ranging in size from 200 to 97 240 respondents from the student, general population (NACO, BSS- 2006) and health staff (Mahendra *et al.*, 2007; Pisal *et al.*, 2007). Few studies have drawn samples from low income or rural communities (Bharat *et al.*, 2001; Pallikadavath *et al.*, 2005; Rogers, *et al.*, 2006). In all the qualitative studies, with the exception of Bharat *et al.* (2001), positive people are treated as a homogeneous group disregarding other identities they may have as sex worker or MSM. With regard to study design, nearly all studies are cross-sectional.

Stigma measurement

Quantitative measures used in early studies are largely attitude scales with statements pertaining to one or more of four broad domains: negative and hostile feelings towards people with HIV ('it is better for everybody if AIDS patients killed themselves'), attribution of HIV to vulnerable groups ('only prostitutes can get AIDS'), avoidance intention or social distancing ('I would not associate with people who have AIDS'), and support for punitive actions and denial of rights ('HIV-positive people should not marry'). Responses were obtained on 3 or 4 point scale (No/ Yes/ Maybe/ Don't Know). The early scales lacked standardisation and as such reliability and validity of these measures are not known.

Subsequent efforts in measuring AIDS stigma in India reflect the overall increase in better understanding of stigma (Zelaya, Sivaram, Johnson, Srikrishna, Solomon & Celentano, 2008; Green, Devi & Paulraj, 2007; Mahendra *et al.*, 2007; Paxton *et al.*, 2005; Steward *et al.*, 2008). Notably, most of these studies are grounded in qualitative-formative research. Zelaya *et al.* (2008) developed a 24-item stigma assessment scale based on a study of male population of unknown HIV status recruited by simple random selection from wine shops in Chennai, Tamil Nadu. The strength of this scale lies in its focus on perceived stigma and its standardisation complete with psychometric properties. The final tool contains 24 items in 4 domains: fear of transmission and disease, association with shame and blame, personal support of discriminatory actions towards people living with HIV, and perceived community support of discriminatory actions or policies towards HIV-infected people. Internal construct validity (discriminant and convergent) assessed by factor analysis and internal consistency was reported to be 0.81 for the full scale. Based on a highly select population of low-income, relatively high HIV-risk men, this scale may not be useful for the general population. Mahendra *et al.* (2007) report the

development and evaluation of a culturally appropriate index to measure AIDS stigma among health workers as part of a stigma intervention project in three Delhi hospitals. The final stigma index containing 21 items is based on formative research with hospital staff and measures, fear of personal contact with positive people ('willing to share a meal with an HIV-infected person'), blaming and judgmental attitude ('men who get HIV get what they deserve'), support for denial of rights of positive people ('HIV-positive women should not get pregnant'), and attitudes towards HIV/AIDS related hospital practices ('patients should be tested for HIV before surgery'). With a reliability coefficient of 0.74, the strength of this instrument is that in addition to assessing fear of contagion and moralistic attitudes, it taps the dimensions of human rights and health management practices as aspects of discrimination within health settings. And therein lies its utility for stigma assessment among health practitioners. Steward *et al.* (2008) developed four new and separate instruments for different stigma forms (enacted, felt, internalised and vicarious) each with acceptable reliability (0.92, 0.94, 0.83 & 0.88 respectively). Based on previous qualitative studies these scales tap context-specific and cultural aspects of stigma and have potential utility in future research work with PLHA.

Taking a human rights approach Paxton *et al.* (2005) developed a comprehensive questionnaire to measure discrimination in relation to denial of human rights of PLHA in eight dimensions as outlined in the Universal Declaration of Human Rights (right to health, privacy, security, freedom from degrading treatment, marry and found a family, employment, education and right to self determination and association). Based on previous research on the topic, discrimination was measured in five areas using a simple response format – Yes/ No/ Don't Know/ Not Applicable: health sector ('has a health care worker ever refused to treat you because of your HIV status?'), family, community ('have you ever been excluded from social functions because of your HIV status?'), employment and education. The strengths of this comprehensive measure are that it directly measures enacted stigma (discrimination) experienced by PLHA, has applicability in Asia and measures stigma/discrimination at institutional and structural levels. The instrument was reviewed by experts but does not provide psychometric properties and needs testing on subsets of PLHA. This limits its wider utility among the PLHA, a community that is by no means homogenous.

Green *et al.* (2007) report on an indirect approach to investigating stigma and discrimination within the cultural context of caregiving in India. Based on previous findings that caregivers experience courtesy stigma due to their association with positive patients resulting in their withdrawal from care giving tasks or neglect of care towards positive patients, the authors used the method of observation to record relationship of attendants at the time of admission of married positive patients in hospitals and of visitors closest to them. Novel and inexpensive in its approach, the method provides a simple indicator of AIDS stigma in a cultural setting where absence of caregivers is indicative of fears and strains in relationships. However, the method suffers from lack of standardisation and is reported for only the married population. Development of a pre-tested, standardised observation checklist for both married and unmarried populations would add to its utility

for wider use in care giving contexts. Elamon's (2005) approach of examining discrimination in legislation and written policy in addition to in practice represents a way forward in understanding structural aspects of enacted stigma or discrimination.

Interventions to reduce AIDS-related stigma

Stigma reduction interventions are beginning to grow in the country but very few have been tested for effectiveness and/or reported through publications. One of the earliest interventions was piloted with health care workers in 3 hospitals in New Delhi with the aim to reduce discriminatory practices and improve quality of care for PLHA in health settings (Mahendra & Gilborn, 2004). The multilevel intervention strategy went beyond the usual information/education strategy and included participatory staff – self-assessment, sensitisation training, communication material reinforcing infection control procedures and hospital policy reform. A stigma scale was developed to assess the impact of the intervention by comparing levels of stigma and discrimination before and after the intervention. A secondary output of the intervention was 'The Patient/PLHA Friendly Achievement Checklist' that helped hospital managers to assess how well their facility reaches, serves and treats HIV-positive patients (www.popcouncil.org/horizons/pfcheklst.html.). An end-line survey revealed significant improvements in HIV-related knowledge and respect for rights of positive people accompanied by better understanding of rights-based practices in relation to testing, confidentiality, and infection control as a result of intervention. Participants also showed positive attitude change.

In another stigma reduction intervention with nursing staff at a hospital in Pune (Pisal *et al.*, 2007), the training modules of the Horizons-Population Council/ Sharan intervention (Mahendra & Gilborn, 2004) were used to increase factual knowledge about HIV and AIDS, skills in clinical management and counseling of HIV patients, and influence attitudes towards care of positive patients. A pre-post intervention design was used to assess intervention impact through a 96-item questionnaire. A significant aspect of this intervention was the participatory nature of the training programme led by nurses specifically trained to deliver the training curriculum and the involvement of HIV-positive people and peer educators from a sex workers' organisation (Pisal *et al.*, 2007). The post-intervention data showed decrease in fear of HIV contagion, support for positive women's right to confidentiality of her status, greater disapproval of discriminatory practices such as, placing signs and symbols to indicate HIV status of patients, and decline in blaming positive people for their infection. However, no objective data were used to validate change in discriminatory practices with HIV patients in the wards. The intervention impact was also limited by the lack of a supportive environment for nurses to practice what they learned from the intervention training.

Both these stigma reduction interventions employ anti-discrimination, inter-personal approach with focus on increasing HIV-related information to reduce fear of contagion and thereby discriminatory practices in health settings. Internationally this is the most common strategy to reduce stigma (Heijnders & Van Der Meij, 2006). Mahendra *et al.* also aimed to influence hospital policy on AIDS and used a standardised stigma index to measure change in levels of stigma and discrimination. Pisal *et al.* (2007) conducted

the intervention in one hospital without using a standardised tool to measure impact. Although promising in showing immediate positive impact in terms of support for PLHA rights and reduction in negative attitudes, both interventions suffer from lack of demonstrated sustainability of impact. The more serious gap, however, is the lack of a systemic approach to addressing stigma within health settings.

Community mobilisation and involvement provide a more dynamic and structural approach to addressing stigma. In a recent publication social capital indicators namely, membership in formal groups, higher levels of collective action, high reciprocity norms among members of a community, and higher perception of safety are reported to be associated with lower levels of HIV stigma (Sivaram, Zelaya, Srikrishna, Latkin, Go, Solomon *et al.*, 2009). Although, the approach needs to be validated and tested for effcetiveness, it offers support for developing AIDS stigma reduction programmes that derive strength from community-based groups and networks, availability of local resources in the form of trusted health providers and address structural factors underlying stigma due to AIDS. Community empowerment and collective action strategies for HIV prevention involving sex workers, one of the most marginalised communities in India, are beginning to show some positive results by strengthening their agency to demand protection and freedom from police violence. (Biradavolu, Burris, George, Jena & Blankenship, 2009). Finally, mass media campaigns for spreading AIDS knowledge and awareness through popular media (radio, television), widely used in the country since the early years of the epidemic, have largely remained untested for their effectiveness in reducing stigma. One of the problems is that while a few studies have included knowledge-based outcome measures, none have used stigma reduction as an outcome. Mass media interventions can be effective in reducing stigma, as has been found in a study carried out in Botswana where a TV soap opera with a HIV story line led to significantly lower stigma levels among viewers than non-viewers (O'Leary, Kennedy, Pappas-DeLuca, Nkete, Beck & Galavotti, 2007).

Gaps and recommendations

The existing body of research on HIV/AIDS-related stigma in India is quite modest in numerical terms and limited by geographical coverage with most studies having been conducted in the high HIV-prevalence western or southern states. Yet, what exists provides some useful insight into the complex nature of stigma in India, its forms and contexts, and its negative impact particularly in relation to HIV status disclosure and consequences for mental health of PLHA. A few important observations are summarised here and some recommendations made for further work on this important theme. First, findings are consistent about the pervasiveness of enacted, perceived, internalised and layered stigma due to AIDS. Second, stigma continues to be reported by HIV-positive people even after nearly two decades of information and education campaigns and care and support programmes, highlighting the need to rethink strategies for dealing with stigma. Felt or perceived stigma is more commonplace and higher than enacted stigma or discrimination, which is in line with what is reported for other countries of the region (Paxton *et al.*, 2005) and globally (Bogart, Cowgill, Kenndy, Ryan, Murphy, Elijah & Schuster, 2008). Higher levels of perceived stigma negatively impact intentions to disclose

HIV status, which explains why enacted stigma levels may be low. Disclosure avoidance hampers or limits optimal and timely use of HIV services by both PLHA and 'risk groups', thereby minimising instances of discrimination or enacted stigma. Thus, more than enacted stigma, it is perceived stigma that appears to act as a barrier. In other words, the potential for stigma is more damaging and has higher psychological as well as health costs for PLHA. Steward *et al.*'s (2008) work in India explores the role of 'stories of stigma' or vicarious stigma in influencing perceived stigma and levels of depression with implications for HIV status disclosure avoidance. This work needs to be advanced further to study the role of AIDS-stigma stories in sustaining stigma in contexts of varying levels of HIV prevalence. More conceptual work is required to understand the role and functional value of different stigma forms, in particular, the correlates, causes and dynamics of perceived stigma. Research is also required to identify the drivers or motives underlying stigma – fear of infection, knowledge deficit or value judgments. Complete understanding of stigma will contribute to development of meaningful and comprehensive stigma reduction strategies.

Given the multifaceted nature of stigma it is also important to conceptually integrate individual level cognitive processes of labeling, shaming, and stereotyping of PLHA on the one hand, and fear of infection acquisition on the other, together with the social processes linked to the production of social inequalities and power hierarchies within the cultural context of India. For example, more work is required to understand how gender, class and sexual identities intersect and interact with cultural notions of sex, sexuality and sex-work on the one hand and with notions of infection transmission/acquisition on the other, in India. This latter aspect namely of infection acquisition and contact-avoidance is inadequately understood within qualitative research although the quantitative attitudinal studies report on intended avoidance behaviour in hypothetical situations involving varying levels of PLHA proximity. In terms of study populations, there is marked absence of research exploring stigma due to HIV among injecting drug users, transgender populations and among children who are HIV-positive or are born to HIV-positive parents. Future researches must address this gap.

Although stigma is considered a major barrier in uptake of HIV services, especially testing and ART, there is very little empirical evidence to support this linkage in India. Specifically, there is only one study so far demonstrating stigma as a barrier to accessing ART, and just a few that provide evidence for delays in seeking health services among HIV positive women. For programmatic purposes it is important to find out how stigma affects HIV services, for example, testing for HIV within the general population and the obverse, that is, how HIV services may exacerbate stigma. More research is required to identify the determinants of stigma and its consequences for the overall health and wellbeing of positive people in India.

Another gap relates to development of culturally appropriate standardised stigma assessment instruments essential for research as well as programmatic purposes, for example, to measure success of stigma reduction interventions. While a beginning has been made, more efforts are required. The few existing tools spell promise

in that there is an appreciable variety and a definite trend away from constructing simplistic stigma scales. This may be attributed to the conceptualisation of measures based on qualitative/formative research; a point that must be recognised. But there is a need to bring in more refinement in construction of items/statements in a tool, enhance their cultural relevance and expand their scope to cover all stigma domains and types. In general, stigma measures suffer from ambiguity in wording statements, social desirability and failure to identify the underlying cause of stigma. For example, the statement, 'I would be willing to work with a person with AIDS' could be interpreted as work in the same office, on the same floor or at the same desk, each of which denote different levels and type of proximity to the infected person. A negative response to an item related to 'eating' or 'drinking' would either reflect fear of infection transmission or hostility towards PLHA on moral grounds, or both. There is also a need to construct measures with culturally valid items. For instance, the statement 'I would be willing to shake hands with a person with HIV' may not be culturally appropriate in the context of India since hand shake is not a common social practice everywhere, particularly in rural India. Similarly, there is a need to avoid items that suffer from social desirability. Thus, an item 'I will not visit a relative who has AIDS' could elicit a more socially desirable response in India because of the relatively greater familistic orientation and family-based caregiving expected of people.

A vital gap in the existing stigma/discrimination measures is the lack of attention to assessing compounded or layered stigma, which is stigma experienced both on account of seropositive status and due to other forms of marginalisation. There is strong evidence that HIV-positive women, sex workers, MSM and transgender people experience multiple stigmas. Therefore measures are required that can tap the burden of multiple stigmas among diverse sub-groups. Other gaps include lack of items to capture courtesy stigma experienced by care givers including health providers that may explain some of the discriminatory care practices in health settings. While stigma measures are largely constructed to meet research objectives, Mahendra *et al.* (2007) developed the stigma index to measure impact of a stigma reduction intervention in hospital settings. There is a critical need for more such measures for programmatic use. Overall, there is a strong need in the country for comprehensive and standardised quantitative measures with psychometric properties, validated for use with diverse population groups, and in diverse contexts. Finally, more measures are required to assess the underlying structural and institutional dimensions of AIDS related stigma – for example, attitudes towards gender norms and values, gender roles, measures of social access and equity, social exclusion – with the objective of analysing and addressing HIV/AIDS stigma within the wider context of existing marginalisation, exclusion and inequities in society.

Lack of suitable and tested context specific stigma reduction interventions is a vital gap which needs urgent attention. Interventions need to move beyond education and interpersonal approaches to more structural approaches and besides addressing enacted stigma or discrimination need to also address internalised stigma. Steward *et al.* (2008), for example, suggest supporting PLHA in dealing with their own stigmatising beliefs to reduce internalised stigma. Based on collective action model involving affected community of PLHA and socially marginalised groups (Bartholomew *et al.*, 2006), structural interventions at community level must be collaborative activities between health promoters and other key actors from affected communities. Such approaches have the potential to address pre-existing stereotypes and prejudices against marginalised communities. Other strategies that need to be tested for stigma reduction are those of social inclusion and empowerment. Interventions are also needed for reducing stigma in key institutions of health, work and education. The few interventions currently available for the health system need to be further tested for wider usage. One of the drawbacks in most stigma reduction programs is the absence of suitable evaluation measures. Both process and effect evaluation measures are required to be developed (Bartholomew *et al.*, 2006). Equally important is the need to evaluate the impact of legal reform process, for example, the impact of the recent reading down of the regressive section 377 of the Indian Penal Code that criminalises same-sex behaviour, by the Delhi High Court, has been positive in empowering affected community of Lesbians-Gay-Bisexual-Transgender to demand protection from police and health promoting services. Finally, a robust national agenda is required to guide a comprehensive AIDS stigma research programme with the explicit aim to fill existing gaps in knowledge and develop evidence based stigma reduction interventions.

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