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RESEARCH COMPENDIUM

HIV-related Stigma Research in India:
Current Knowledge, Gaps, and
Recommendations

June, 2014

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ACRONYMS AND ABBREVIATIONS

AIDS – Acquired immunodeficiency syndrome
 ARV – Antiretrovirals
 ART – Antiretroviral therapy or treatment
 CBO – Community-based organisation
 DAC – Department of AIDS Control
 FSW – Female Sex Workers
 GIPA – Greater Involvement of People Living with and affected by HIV/AIDS
 HIV – Human Immunodeficiency Virus
 IDUs – Injecting Drug Users
 ICTC – Integrated [HIV] Counselling and Testing Centre
 IEC – Information, Education and Communication
 MSM – Men who have Sex with Men
 NACO – National AIDS Control Organisation
 NACP – National AIDS Control Programme
 NGO – Non-governmental organisation
 PLHIV – People living with HIV
 PPTCT – Prevention of Parent to Child Transmission [of HIV]
 PMTCT – Prevention of Mother to Child Transmission [of HIV]
 TG – Transgender people
 SACS – State AIDS Control Society
 UNDP – United Nations Development Programme

EXECUTIVE SUMMARY

INTRODUCTION

In India, like elsewhere in the world, HIV-related stigma poses major challenge to the national efforts on HIV prevention, treatment and care, and accordingly, addressing stigma was identified as a key guiding principle in the third phase of the National AIDS Control Programme. Currently, there is a growing body of India-specific research on stigma and discrimination towards people living with HIV and marginalised groups associated with the epidemic, but its use for drawing policy and programme implications is negligible due to a lack of synthesis of available evidence.

This compendium will help in:

- a. Serving as an evidence-base to inform effective national response to stigma and discrimination against people living with HIV and various marginalized communities such as men who have sex with men, transgender people, sex workers and drug users
- b. Guiding future research on this subject based on existing gaps
- c. Providing directions and lessons for stigma reduction programmes of the future
- d. Influencing national policy on addressing HIV-related stigma and discrimination

METHODOLOGY

Published and unpublished literature on HIV-related stigma and discrimination in India was systematically searched through multiple data sources such as journal articles and global academic databases – Medline, PsychINFO and Sociological Abstracts. Grey literature search included data and reports from the national government, UN agencies, PLHIV networks, and other non-governmental organisations and community-based organisations. Application of exclusion criteria yielded 53 original peer-reviewed articles and 16 grey literature articles screened for their quality using quality assessment tools and then critically evaluated.

DISCUSSION

Key themes identified from research synthesis include:

1. There is limited research towards conceptualising HIV-related stigma (including stigma related to sex work, same-sex sexualities and drug use) from a cultural perspective
2. All forms of stigma and discrimination towards PLHIV and marginalised groups are reported in multiple settings (health care settings, family and the broader society) and at various levels (individual, community or group)
3. Gender dimension is critical to understand HIV-related stigma faced by Indian women and by feminine MSM and hijras
4. There is limited evidence on the impact of stigma on health outcomes (access to HIV prevention and treatment, quality of life, sexual risk behaviours and mental health)
5. There is limited research on developing and testing culturally-relevant stigma scales for use in India
6. Limited studies have tested and evaluated stigma reduction interventions among health care providers, general public, people living with HIV and marginalised groups

RECOMMENDATIONS

1. Need for development and testing of theoretical models and constructs for use in India
2. Need for well-designed single and multi-level interventions that measure both stigma reduction and their impact
3. Need for studies that capture the experiences of people in rural settings, marginalised communities, and various subgroups of people living with HIV
4. Evidence-based effective interventions or promising practices in the health care settings can be scaled-up and evaluated
5. Evidence-based effective interventions among women living with HIV, couples, family members, and youth need to be scaled-up
6. Need for structural interventions to protect the human and legal rights of PLHIV and marginalised communities

A. INTRODUCTION

Even 30 years after the first few HIV cases were reported in the world, stigma and discrimination against people living with HIV and populations most associated with the epidemic¹ remain unabated. Stigma and discrimination are universally reported and there is evidence that stigma prevents people from getting tested for HIV, and hinder access to and use of appropriate health care services. In India too, HIV-related stigma poses major challenge to the national efforts on HIV prevention and care, and accordingly, addressing stigma was identified as a key guiding principle in the third phase of the National AIDS Control Programme.

Globally there have been limited efforts to address the challenge of stigma and reduce its impact on individuals and families in multiple domains that include the general community, health and family settings, government departments, and public and private work settings. Recognising the importance of tackling stigma and discrimination to prevent new infections and provide care for people living with HIV, the UNAIDS recently released its strategy to bring down HIV-related discrimination to zero.²

In India, tackling stigma is yet to receive major impetus in HIV prevention and care programmes. Only a few locally developed small-scale interventions are reported so far. While some of the interventions developed in other countries may also be adapted in India, there is lack of easy access to India-specific information on stigma and discrimination, especially what interventions work or not in which situations.

Lack of a national HIV-related stigma research agenda, lack of synthesis on what have been done so far on stigma research in India, and absence of mechanisms to translate stigma research evidence into programmatic actions mean that the available research evidence on HIV-related stigma are not being used to design and test effective stigma reduction interventions in India.

This research compendium fills some of these gaps. This compendium compiles the research work done on HIV-related stigma in India and will serve as a resource material for various stakeholders including researchers, practitioners, policymakers and civil society especially the networks of people living with HIV and vulnerable populations.

In particular, this compendium will help in:

- e. Serving as an evidence-base to inform effective national response to stigma and discrimination against people living with HIV and various marginalized communities such as men who have sex with men, transgender people, sex workers and drug users
- f. Guiding future research on this subject based on existing gaps
- g. Providing directions and lessons for stigma reduction programmes of the future
- h. Influencing national policy on addressing HIV-related stigma and discrimination

¹ such as sex workers, men who have sex with men, transgender people and injecting drug users

² UNAIDS (2010). 2011–2015 Strategy. Getting to Zero.

Box 1. Glossary of stigma-related terms

HIV-related stigma refers to the devaluing of people who are HIV-positive or associated with HIV and AIDS, and may result in discrimination based on actual or perceived HIV-positive serostatus (UNAIDS, 2007). HIV-related stigma interacts with structural inequities and may be exacerbated for populations marginalized due to risk behaviour (e.g., injection drug use), demographic characteristics (e.g., socio-economic status) and identity (e.g., sexual orientation) (Campbell & Deacon, 2006; Herek & Capitanio, 1999; Parker & Aggleton, 2003; Van Brakel, 2006).

Discrimination typically refers to less favourable treatment, such as the denial of goods or services to a person, based on a real or perceived characteristic of that person. While some researchers include **discrimination** in conceptualizations of stigma (e.g., 'enacted stigma') (Link & Phelan, 2001; Nyblade, 2006) others differentiate discrimination (a behaviour) from stigma (an attitude) (Deacon, 2006; Herek, 2002).

Perceived/felt stigma refers to awareness of negative societal attitudes, fear of discrimination and feelings of shame (Berger et al., 2001; Herek, 2002; Herek, 2007).

Self-stigma or Internalized stigma refers to a stigmatized individual's acceptance of negative beliefs, views and feelings towards the stigmatized group and oneself (Herek, 2007; Mak et al., 2007; Steward et al., 2008).

Enacted stigma encompasses overt acts of discrimination, such as violence and exclusion (Herek et al., 2002; Nyblade, 2006).

Symbolic stigma refers to othering, blaming and shaming of a marginalized group (e.g. PLHIV) and people associated with this stigmatized group (e.g. sex workers, gay/bisexual men) (Herek & Capitanio, 1999; Herek et al., 2003).

Courtesy stigma ('stigma by association) refers to stigma based on one's association or affiliation with a stigmatized person/group and may impact family, friends, and health care providers (Herek, 2002; Brown, Macintyre & Trujillo, 2003).

Layered stigma, Intersecting stigma or Compound(ed) stigma refers to multiple, interrelated stigmatizing attitudes that mutually reinforce one another and often act to further marginalize vulnerable groups. For example, a gay person living with HIV faces stigma associated with HIV as well as sexual orientation (Nyblade, 2006; Reidpath & Chan, 2005).

Sexual stigma refers to the devaluing of sexual minorities and the negative attitudes and lower levels of status and power afforded to non-heterosexual behaviours, identities, relationships and communities (Herek, 2007). Sexual stigma processes are embedded within power relations and may result in multiple levels of social and institutional discrimination towards sexual minorities.

B. METHODOLOGY

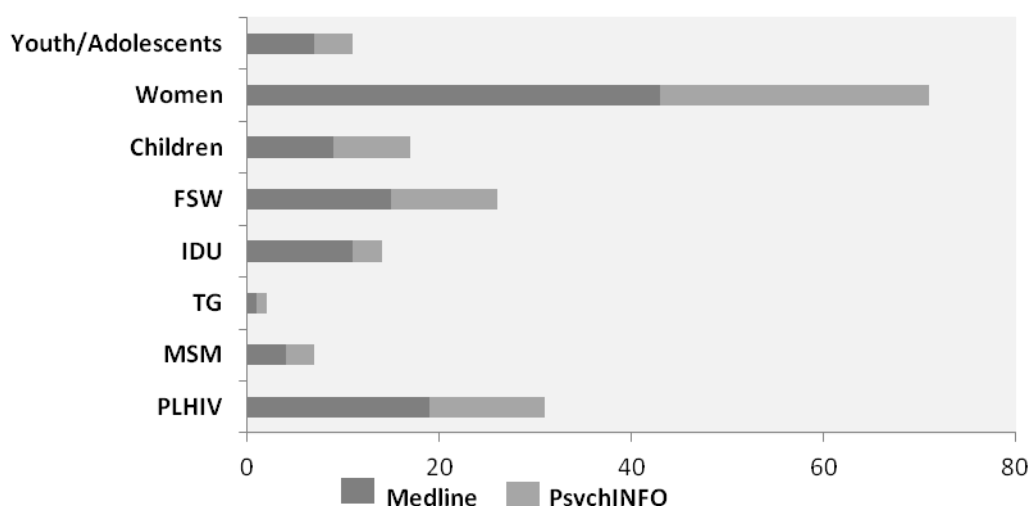
Published and unpublished literature on HIV-related stigma and discrimination in India was systematically searched through multiple data sources such as journal articles and global academic databases; data and reports from the national government, UN agencies, networks of people living with HIV, and other non-governmental organisations and community-based organisations in the country.

Criteria for inclusion were that the article or report should significantly focus on any or all of these aspects namely: 1) prevalence of HIV-related stigma and discrimination; 2) the types of stigma experienced by people living with HIV and marginalized groups at risk for HIV; 3) stigma measurement tools; 4) stigma conceptualization, and 5) description or evaluation/assessment of interventions to reduce stigma and discrimination.

We excluded literature that was directed at measuring knowledge, attitude and practices (KAP studies) towards HIV or towards people living with HIV if they had no major input on stigma conceptualisation and measurement; and descriptive anecdotal articles on stigma faced by people living with HIV. Additional exclusion criteria included: newspaper articles, letters to editor in peer-reviewed journals, other country-based stigma literature, articles not in the English language, articles not related to the above-mentioned focus topics, and conference abstracts.

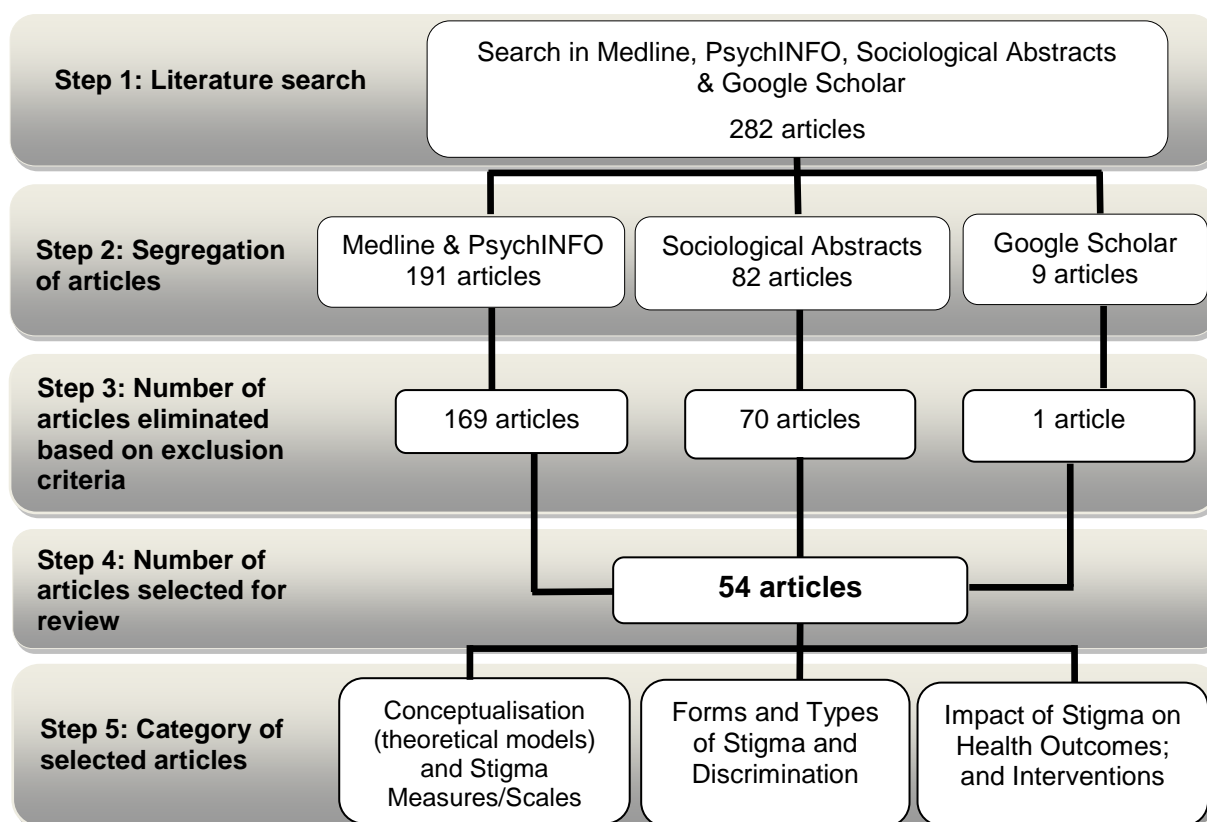
Peer-reviewed journals were searched in databases such as Medline/PubMed, PsychINFO and Sociological abstracts through Ovid interface. Furthermore, specific online searches were conducted in relevant international and Indian journal online archives³. General search engines such as Google and Google Scholar were also used.

Figure 1: Category of peer-reviewed articles accessed through Medline and PsychINFO databases



³ AIDS, AIDS and Behavior, AIDS Care, AIDS Education and Prevention, American Journal of Public Health, International Journal of STD & AIDS, Journal of Acquired Immune Deficiency Syndromes, AIDS Patient Care and STDs, Indian Journal for Social Work, Indian Journal of Medical Ethics

Figure 2: Flowchart of the search results for peer-reviewed articles



Starting date was not specified for searches conducted through databases such as Medline,⁴ PsychINFO, and Sociological abstracts. In Medline and PsychINFO, a first research using the search terms “Stigma or Discrimination” and “HIV or AIDS” and “People living with HIV” and “India” gave access to 42 relevant articles, of which 30 articles came from Medline and 12 from PsychINFO.

We also combined some of the above-mentioned search terms such as “Stigma or Discrimination” and “HIV or AIDS” and “India” with specific search terms such as, men who have sex with men, hijras or transgender, injecting drug users or drug users, female sex workers or sex workers, children, women and youth or adolescents. A total of 191 articles were accessed through Medline and PsychINFO (without filtering duplicates), of which 112 came from Medline and 79 came from PsychINFO. Furthermore, searches in Sociological Abstracts database and general search engines such as Google and Google Scholar resulted in retrieving 91 articles. Thus, a total of 282 articles were retrieved from the above-mentioned sources.

From the 282 articles, articles relevant to the aim of this review were selected on the basis of the available abstracts after reconciling uncertainties through discussion with the research team. The reference lists of selected articles were checked to further identify relevant articles. Application of exclusion criteria yielded 54 original articles screened for their quality⁵ using quality assessment tools (See Box 1) and then critically evaluated.

⁴ Medline and PsychINFO databases that we accessed had collections from 1948 and 1967, respectively.

⁵ according to the standards for their specific study types – quantitative and qualitative

Box 2. Criteria used to assess the quality of peer-reviewed articles

Quantitative studies

- Was the sampling method representative of the population?
- Does the study report appropriate statistical tests (such as correlations and regressions)?
- Did the study use any appropriate conceptual model or defined key concepts or used hypotheses (that were tested)?
- Did the study use standardized or properly developed tools/scales?
- Did the study report having obtained ethics committee approval?

Qualitative studies

- Was the research methodology appropriate to answer the stated research objective/questions?
- Did the study use any appropriate conceptual model/framework or defined key concepts?
- Did the researchers explain and justify the sample (type of sampling and adequacy of sample size) adequately?
- Did the researchers provide sufficient details about how the qualitative data analysis was conducted?
- Were adequate illustrative quotes provided?

We created a database in excel for storing data extracted from selected peer-reviewed articles and research reports (grey literature). Data extraction was done for multiple variables such as domain(s)/category, author name, year of publication, type of study (qualitative or quantitative or mixed methods; or theoretical or other review articles), study design, methods, tools/scales, sample size, study site details (name of the site, study location, name of the state), study population, data collection period, study objectives, original journal abstract, key findings, conclusion or implications, and funding details.

Grey literature was searched and collected from the websites⁶ of National AIDS Control Organization (NACO), Joint United Nations Programme on HIV/AIDS (UNAIDS), Stigma Action Network, The People Living with HIV Stigma Index, International Center for Research on Women, Engender Health, Asia Pacific Network of People Living with HIV/AIDS (APN), Asia Pacific Council of AIDS Service Organisations (APCASO), Indian Network for People Living with HIV/AIDS and Family Planning Association of India. Unpublished and published reports were collected from researchers, service providers, nongovernmental agencies and individual experts. A total of **15 grey literature reports** were selected for inclusion.

The following key research questions were used in the synthesis of the findings from both peer-reviewed (54) and grey literature (15), that is, a **total of 69 articles/reports**.

1. What are the major focus areas and populations for the research studies on HIV-related stigma in Indian context? What have been the gaps in the research knowledge?
2. What are the various types/categories of HIV-related stigma and discrimination reported in the literature in relation to various populations and settings in Indian context?
3. What kind of research and programmatic evidence are available in relation to: 'Causes' of various types of HIV-related stigma and stigma related to marginalized communities (sex work, injecting drug use, same-sex/bi-sexualities)?

⁶ www.apnplus.org; www.inpplus.net; www.nacoonline.org; www.unaids.org; www.stigmaactionnetwork.org; www.stigmaindex.org; www.icrw.org; www.engenderhealth.org; www.apcaso.org; www.indianLGBThealth.info

4. What are the theoretical and practical frameworks that have been developed or being developed in relation to HIV-related stigma in India? What are their implications for policy and program formulation?
5. What interventions, if any, are found to be effective and show promise for scaling up? And among whom and which settings they were conducted?
6. What are the recommendations provided by the current evidence-base to:
 - a. Remove or reduce the impact of causes of HIV-related stigma/discrimination
 - b. Better capture the different types of stigma to identify the trend
 - c. Combat the stigma/discrimination faced by marginalized communities
 - d. Employ effective interventions among various groups and at various levels
 - e. Design policies and programs on to HIV-related stigma and discrimination

C. DISCUSSION / SYNTHESIS

Six key themes were identified in this literature review.

1. There is limited research towards conceptualising HIV-related stigma (including stigma related to sex work, same-sex sexualities and drug use) from a cultural perspective

Stigma conceptualisation from cultural perspective has received little attention in India. Most studies have conceptualised stigma in Goffman's terms (i.e., seeing stigma as an attribute of an individual) with very few using the structural approach that includes power, gender, and socioeconomic class, etc. to examine stigma. However, a few recent studies have tried to develop or extend existing theoretical frameworks to understand stigma from the Indian perspective. For example, Steward *et al* (2008) extended the existing theoretical framework consisting of enacted, felt and internalised stigma to include a new component namely, vicarious stigma to explain stigma experience among PLHIV in Southern India [11]. An earlier study [55] examined the gender dimension of stigma within the patriarchal Indian context.

Among MSM, one study [47] has used 'structural violence' as the organizing framework for explaining the stigma and discrimination faced by kothi-identified MSM in various settings (family, health care setting and society) and another study has provided a 'medical anthropological perspective' of self-stigma experienced by kothis, emphasising how social, cultural and moral processes lead to negative attitudes towards self [52]. A quantitative study [53] included 'sexual stigma' (stigma of being a same-sex attracted person) construct and another new construct labelled as 'gender non-conformity stigma' to draw attention for the first time to stigma experienced by feminine MSM as often the femininity among males is seen as a proxy for their same-sex sexual attraction. The 'minority stress model' of Meyer is has been adapted to examine the impact of HIV-related stigma, sexual stigma and transgender identity-related stigma on the mental health and HIV-related sexual risk behaviours among MSM and transgender populations [52, 65].

Among sex workers, at least one study [38] has employed the structural factors approach including structural violence to explain the challenges faced by sex workers. Among drug users, one qualitative study [67] conducted among injecting drug users in Manipur showed how existing drug control policies and laws, police harassment, and stigma related to HIV and drug use, prevent injecting drug users from accessing HIV prevention and treatment services. Thus, it is one of the studies to show how existing laws and drug use stigma can lead to negative health outcomes.

In general, even though there has been a recent increase in the studies that use and test conceptual models of stigma faced by PLHIV and communities at risk for HIV, studies that use and test conceptual models of multiple stigmas (layered stigma or compounded stigma) and the impact of stigma on the health outcomes are lacking.

2. All forms of stigma and discrimination towards PLHIV and marginalised groups are reported in multiple settings (health care settings, family and the broader society) and at various levels (individual, community or group)

A large number of studies [1, 6, 8, 10, 11, 14, 17, 41, 43] have documented both perceived (felt) stigma and enacted stigma experienced by PLHIV and marginalised groups, the latter reported less frequently compared with the former.

Discrimination in the health care settings experienced by PLHIV and marginalised groups is commonly reported in several studies [2, 7, 8, 23, 33, 49, 55, 60, 61]. Discrimination ranged from policy level factors such as ambiguous law that favour the right to denial of treatment by health care provider to institutional level discrimination (e.g., absence of gender-sensitive procedures for registering a hijra client as an outpatient or in-patient) to verbal harassment by hospital staff and co-patients, and suboptimal care or delayed care by health care providers. Published studies that documented the discrimination faced by PLHIV and marginalised groups in the workplace, and schools and colleges are notably absent even though a lot of anecdotal evidence and media reports are available on the same.

Various forms of discrimination are reported [1, 6, 7, 47, 55, 56] from the immediate family members (husbands, in-laws and parents), and extended family members, which prevent many from disclosing their HIV status. At least one study [5] have explained the stigma faced by the families of PLHIV (stigma by association or 'courtesy stigma') and how the family members cope up with it, thus pointing out the need for interventions among family members not only to accept PLHIV but also how to take care of one's mental health.

3. Gender dimension is critical to understand the stigma faced by Indian women and by feminine MSM and hijras

Compared to HIV-positive men, HIV-positive women face high levels of stigma (both perceived and enacted) [17]. One study [4] showed that HIV-positive women admitted in hospitals are less likely to have many visitors from their husband's side, and even from their parents' side. Women who are diagnosed first as HIV-positive are often blamed for bringing HIV to the family and face rejection and separation from their husbands. HIV-positive women in rural settings fear being suspected for illness and negatively judged in their mother role for not breast-feeding their newborn infants [27]. Mothers living with HIV are especially concerned about the negative reactions of disclosure to their children and fear adverse consequences to children, which prevent them from disclosing their HIV status [13].

Studies [44, 46, 47, 52, 60] among feminine (kothi-identified) MSM, hijras and sex workers have documented rejection and physical violence faced from their families, and physical and sexual violence from police and ruffians.

Patriarchal values, unequal gender norms (whereby men's sexual behaviour is judged less harshly than women's), misogyny (considering women as inferior to men) and lack of economic independence among women could explain the additional stigma faced by women living with HIV, with stigma of widowhood adding to the existing HIV stigma. Stigma faced by feminine MSM [47, 48, 52] and hijras [60] can also be seen as related to misogyny because of the gender non-conformity or gender-variant behaviour among biological males and such a transgression is not tolerated by families and society, and it is seen then as legitimate to discriminate and unleash violence up on them.

4. There is limited evidence on the impact of stigma on health outcomes (access to HIV prevention and treatment, quality of life, sexual risk behaviours and mental health)

Only very few qualitative studies have documented how the stigma and discrimination in health care settings act as a barrier to HIV testing (for marginalised groups [61] and pregnant women [8]) and antiretroviral treatment for people living with HIV (that includes marginalised groups such as MSM, transgender people, sex workers and IDUs) [42, 49, 66].

Fear of negative consequences of being diagnosed HIV-positive prevents some marginalised communities to test themselves for HIV, even though they are aware about their HIV risk. Lack of confidentiality of HIV status within one's own community and fear of

loss of income among sex workers (whether kothi, hijra or female sex worker) prevented people from testing or from revealing their HIV-positive status to others [42, 48, 60, 61].

Non-disclosure of HIV status due to fear of negative consequences (such as rejection and shame) and consequent non-use of condoms with spouse and steady partners have been reported among heterosexual men⁷, MSM (kothi-identified and non-self-identified MSM), male injecting drug users, hijras, and sex workers⁸. Thus, fear of potential discriminatory acts prevented PLHIV from adapting safer sex practices within steady partnerships posing risk of HIV transmission to their steady partners (and to their unborn children). Non-disclosure of HIV status is emerging as a major casualty due to high levels of perceived stigma.

Mental health consequences of stigma among PLHIV have been reported in at least one clinic-based study. Studies have found that high level of HIV-related stigma and MSM-related stigma, among people living with HIV and MSM, respectively, are associated with poor quality of life and depression. A study among MSM [53] found that rural MSM are more likely to have high level of HIV-related stigma possibly because of lack of adequate HIV treatment services and misconceptions that are prevalent in the rural settings.

5. There is limited research on developing and testing culturally-relevant stigma scales for use in India

At least one study has developed and tested stigma scales among the general population for various constructs of HIV-related stigma, including a new construct 'vicarious stigma'[11]. Some other studies too have developed HIV/AIDS stigma scale among populations such as relatively high risk men [31] and health care providers [23].

One quantitative study [53] among urban and rural MSM in Tamil Nadu, tested 'sexual stigma' scale adapted from 'MSM stigma scale' used among MSM in China⁹, and developed and a new scale called 'gender non-conformity scale' for the first time in India to measure stigma faced by feminine MSM. These scales were found to be reliable and valid.

A study [43] among sex workers has developed and tested 'sex work stigma' index that has been found to be reliable and valid. Among drug users, a study [54] tested a drug use stigma scale and concluded that because drug use stigma is associated with HIV risk, drug use stigma need to be addressed in HIV prevention interventions among injecting drug users.

No scale is available to measure the stigma faced by transgender women (male-to-female transgender people) while one current study is testing a 'transgender identity stigma scale'.

Thus, in general, a limited number of culturally-adapted and tested scales are available to measure particular constructs of HIV-related stigma, sex work stigma, drug use stigma, and 'MSM stigma' and 'gender non-conformity stigma'. Usefulness of these scales among various subgroups of the populations and in different regions, however, needs to be tested.

⁷ Chakrapani, V, Newman, PA, Shunmugam, M, Dubrow, R. (2010). Prevalence and Contexts of Inconsistent Condom Use Among Heterosexual Men and Women Living With HIV in India: Implications for Prevention. *AIDS Patient Care and STDs*. 24(1):49-58.

⁸ Chakrapani, V, Shunmugam, M, Newman, PA, Dubrow, R, Satpathy, A, Kurian, AK. (2007). Sexual and Reproductive Health of People Living with HIV/AIDS in India: A Mixed Methods Study. Report Indian Network for People living with HIV.

http://www.icw.org/files/SRH_PLHA_Study_Report_INP_May_07_FINAL_RefRev.pdf

⁹ Neilands, T.B., Steward, W.T., & Choi, K. (2008). Assessment of stigma towards homosexuality in China: A study of men who have sex with men. *Arch Sex Behav*, 37, 838-844.

6. Limited studies have tested and evaluated stigma reduction interventions among health care providers, general public, people living with HIV and marginalised groups

In general, there is a lack of studies that tested HIV-related stigma interventions. And almost no studies reported testing interventions to reduce the stigma (internal and perceived) faced by MSM, transgender people or injecting drug users. Multi-level interventions that target individuals, communities, institutions and society are absent. Available interventions focus on improving short-term outcomes such as improvement in the knowledge, attitude and practices of health providers [23, 25, 69]. Improvement in the health outcomes such as uptake of HIV testing and HIV treatment services, and improvement in the mental health and social support are absent. Recently ICRW released a summary report that highlighted the outcomes from five short-term stigma reduction interventions among health care providers, panchayat leaders, FSWs and MSM [69]. The experiences gained and lessons learnt from these pilot interventions might help in refining and scaling up of stigma reduction interventions among diverse populations.

One intervention [23] in the health care setting that focused on changing both institutional policies, and attitude and practices of health care providers was found to be effective. Based on this study, a PLHIV-friendly checklist has been prepared to help in assessing and improving PLHIV-friendliness (or HIV-related stigma) in health care settings.

An intervention among nurses [25] found that a short course on HIV education and attitude change resulted in reduction of self-reported discriminatory practices. Other than these two interventions, there are barely any published articles on effective interventions in health care settings, even though most studies conducted among diverse populations have documented discrimination in the health care settings.

Some studies [38, 39, 41, 40, 69] have documented promising practices from interventions among female sex workers. These studies provide evidence for the effectiveness of community level interventions that empower communities by assisting in the formation of community-based organisations and providing support to confront police harassment and society's negative attitude towards sex workers. These interventions include the community-led structural intervention in which sex workers were empowered to challenge police harassment [39], and two other interventions in which sex workers' collectivisation was shown to be helpful to fight power structures (especially police in one case and stigmatising messages from the government in another case) both in a brothel-based sex work setting (Sonagachi project [41]) and in a predominantly street-based sex work setting [38, 40].

D. RECOMMENDATIONS

Need for development and testing of theoretical models and constructs for use in India

An India-specific conceptual framework for understanding HIV-related stigma among general populations has been developed but more research is needed to further validate it and expand to multiple settings. Conceptual frameworks for stigma related to same-sex sexualities (except structural violence framework and adaptation of Meyer's minority stress model), gender non-conformity, sex work, and drug use seem to be limited or absent. Such frameworks are needed for understanding the causes of the various types of stigma, their manifestations, and effects; and how to effectively tackle those causes and minimise or abolish harmful or negative consequences.

Need for well-designed single and multi-level interventions that measure both stigma reduction and their impact

When designing stigma reduction interventions, formative research among target populations will be helpful to design the components of the interventions and to fine-tune the tools. To measure HIV stigma (or other stigmas), an internally validated (i.e., psychometrically analysed) tool that also contains more than one construct or concept of stigma (perceived, enacted, internalized, or compounded stigma) is recommended. Interventions should not only show effectiveness in stigma reduction but, where possible, need to study the impact of interventions on improvement, if any, on health outcomes (such as HIV testing and ART uptake, HIV prevention,¹⁰ and improved mental health and social support)

Need for studies that capture the experiences of people in rural settings, marginalised communities, and various subgroups of people living with HIV

There is a need to understand variations in the nature and extent of stigma in relation to geographical areas (e.g., north-east India) and to capture differences in urban and rural settings. Such information will be useful to design interventions tailored to these settings.

Often studies are conducted among one or more particular subgroups of marginalised communities. Future HIV-related stigma studies, depending on the resources, need to be conducted among the various subgroups of MSM (kothis, double-deckers, gay- and bisexual-identified men, etc.); sex workers (street-based and non-street-based sex workers, brothel-based sex workers, 'mobile' sex workers, etc.); and drug users (injecting and non-injecting; male and female IDUs).

Studies are also needed to understand the multiple stigmas associated with individuals. For example, a HIV-positive hijra sex worker may be discriminated for being a hijra or HIV-positive or for engaging in sex work. Understanding the interactions of these multiple stigmas and their impact on the individuals will help us to design better interventions to reduce these stigmas and improve health outcomes.

¹⁰ For example, fear of negative consequences of HIV status disclosure may prevent a person living with HIV from using condoms with his/her spouse and thereby increasing risk of transmission of HIV.

Evidence-based effective interventions or promising practices in the health care settings need to be scaled-up and evaluated

In health care settings, to avoid stigma and discrimination faced by PLHIV and marginalised groups (such as FSWs, MSM, TG people and IDUs), the following evidence-based interventions – preferably in combination – need to be scaled up.

- Sensitization and training of all cadres of health care providers – to start with, at least in all the government centres where HIV-related services are being provided.
- Providing medical kits for universal precautions and post-exposure (occupational) prophylaxis for health care providers to reduce denial of care.
- PLHIV-friendly checklist can be used to improve the acceptance of PLHIV within health care settings. Similar checklists are needed to create a welcoming environment in the health care settings for the various marginalised groups (such as FSWs, MSM, TG people and IDUs).

In addition to sensitising and training health care providers, sensitization of co-patients and their caregivers are needed to prevent discrimination of PLHIV and marginalised groups on the basis of their HIV status, gender identity, sexuality and engagement in sex work.

Evidence-based effective interventions among women living with HIV, couples, family members, and youth need to be scaled-up

When testing pregnant women for HIV, couple testing can be offered; both husband and wife can be tested together after providing proper pre-test counselling. Couple testing may decrease (but may not eliminate) the chances of others blaming women for bringing HIV into the families that often lead to rejection by husbands or parents-in-law.

For mothers (or parents) living with HIV, support should be available for whether or not, when, and how to disclose their HIV-positive status to their children (who may or may not be HIV-positive), as often parents are worried about the possible rejection from their children if their HIV status is revealed. Counselling for parents living with HIV, thus, also needs to address coping up with the stress associated with non-disclosure and to deal with the consequences of disclosure, if the parents choose to do so.

In rural settings, when advising women living with HIV about breast-feeding, the local cultural practices of long-term breast feeding of children (even after four months of age) need to be taken into consideration. This is because the stigma attached to not breast-feeding one's child may compel some HIV-positive mothers to continue breast-feeding even after the recommended exclusive breast-feeding for four months. Thus, there is an increased chance of transmission of HIV to babies if the stigma of not breast-feeding the baby is not addressed.

In schools and colleges, sensitisation is needed for management, teaching staff, and parents of school/college youth on the issues faced by families of people living with HIV. Age-appropriate sexual health education and HIV information also might help the students to understand and accept co-students who are HIV-positive. Interventions among school and college youth need to focus not only on improving the knowledge on HIV but also on clarifying values related to sexuality and marginalised groups at risk for HIV.

Need for structural interventions to protect the human and legal rights of PLHIV and marginalised communities (legal protection, legal redressal mechanisms, and legal reforms)

Studies have documented that the following structural interventions among female sex workers are helpful and can be adapted in other geographical settings as well.

- Empowering sex workers by acknowledging their agency and assist them in forming collectives, and building their capacity to fight against the power structures such as police
- Improving the material conditions of sex workers that increase their self-esteem and decrease self-stigma

By reading down the criminal law Section-377 that was used against consensual adult same-sex relationships, the rights of the same-sex attracted adults are now ensured. Such legal reforms are needed in the area of sex work and drug use as well to protect the human rights of sex workers and drug users as these groups are often seen as criminals by the general public, which further exacerbates the stigma against these populations.

Legal redressal mechanisms need to be available for discrimination against people living with HIV and marginalised groups. To protect the rights of PLHIV, passing the HIV/AIDS bill that contains anti-discrimination clauses might both prevent discrimination and provide redressal for PLHIV who experienced discrimination. Similar anti-discrimination laws are needed to protect marginalised groups such as sex workers, MSM, transgender people and injecting drug users.

E. ANNOTATED BIBLIOGRAPHY

In this section, for all the peer-reviewed articles, the original journal abstract is followed by annotation. For grey literature reports, either executive summary, where available, is provided as such, or a brief summary is provided on the content and importance.

PEER-REVIEWED ARTICLES

I. People Living with HIV

1. Title: Chandra, P.S., Deepthivarma, S., & Manjula, V. (2003). Disclosure of HIV infection in South India: Patterns, reasons and reactions. *AIDS Care*, 15:2, 207-215. Retrieved from <http://dx.doi.org/10.1080/0954012031000068353>

Journal Abstract: The aim of this study was to examine aspects related to self-disclosure of their seropositive status among 68 persons (35 men and 33 women) infected with HIV. Data was collected through in-depth interviews to assess ways in which HIV-related disclosure took place and factors that influenced disclosure. The data was subjected to both qualitative and quantitative analysis. Voluntary disclosure was noted in 44 subjects (65%), while in other 24 (35%) subjects disclosure occurred without consent. Of those who disclosed, 78% of the subjects reported self-disclosure to family members, 7% to friends and 15% exclusively to health professionals. Expectations of emotional and material support from the family members were one of the commonly cited reasons for voluntary disclosure. Only half of the subjects disclosed complete and truthful information while in the rest, disclosure was partial or disguised as a less stigmatizing illness. Stigma, fear of discrimination, disgrace to family and self and futility were reported as the main reasons for non-disclosure. The majority of the subjects (73%) reported anticipation of negative societal reaction as the main concern following disclosure. In India, where HIV-related counselling services are still not freely available, there continue to be non-uniform practices related to confidentiality and disclosure. The findings of this study are important in identifying cultural factors related to disclosure in HIV infection and highlight the need to examine the varying patterns and concerns related to disclosure among HIV-infected individuals.

Annotation: This article reports multiple reasons for non-disclosure of one's HIV-positive status: 1) fear of discrimination; 2) futility (i.e., no hope of others helping them); and 3) disgrace to self or family. The reasons stated for disclosure included getting emotional and financial support, self-responsibility. The study findings indicate that disclosure by people living with HIV is a complex process and is often moderated by perceived stigma, anticipated negative or positive behaviour from others, and the possibility of gaining access to care. The findings suggest that multiple factors need to be taken into account when counselling a person on disclosure issues and counselling needs to address - whether or not, whom, and when to disclose; and to impart skills for safe disclosure of HIV status.

2. Title: Elamon, J. (2005). A situational analysis of HIV/AIDS-related discrimination in Kerala, India. *AIDS Care*, 17(Suppl2), S141-S151. doi:<http://dx.doi.org/10.1080/09540120500120070>

Journal Abstract: Due to its large population, India has a substantial proportion of the world's HIV infections. Recent evidence suggests that the virus is moving into the general population from high-risk groups. Despite this, a mentality of 'us' and 'them' continues to prevail, where PLWHA are marginalised from mainstream society. Focusing on the area of health care, this study, through an analysis of legislative policy, written regulations and interviews with key informants and direct witnesses aims to map the forms of structural

discrimination that inform the lives of PLWHA. Study findings indicate that a lack of clearly enunciated and enforced legislation (which is in some instances clearly discriminatory), coupled with an absence of written internal policy, leaves room for selective interpretation, which in turn creates the opportunities for discriminatory behaviours to be perpetuated against PLWHA. The paper concludes with a call for better educational training of medical staff and the improvement of existing legislature.

Annotation: The study provides insight into the impact of current legislation and policies in the health care sector on providing care to PLHIV. The study uses the UNAIDS Protocol for the Identification of Discrimination against People Living with HIV with focus on health care. It identifies ambiguity in the health care-related laws and policies that increase the scope for arbitrary discrimination, refusal to provide treatment, differential treatment, mandatory testing, withholding of test results, divulging of test results to family and communities, quarantining and segregation, and lack of confidentiality and privacy of PLHIV. The author points out that even though the UNGASS declaration of commitment on HIV/AIDS states that all PLHIV will be treated without discrimination, under the Practitioners of Indian Medicine (Standards of Professional Conduct, Etiquette and Code of Ethics) Regulations [regulation 5 (1)], medical practitioners are not bound to treat each and every person requesting their services. The author recommends training health care providers to increase sensitivity towards PLHIV; and to enact PLHIV-sensitive legislations.

3. Title: Finn, M., & Sarangi, S. (2009). Humanizing HIV/AIDS and its (re) stigmatizing effects: HIV public 'positive' speaking in India. *Health*, 13(1), 47-65. doi:10.1177/1363459308097360

Journal Abstract: Social stigma has been inextricably linked with HIV and AIDS since the epidemic erupted in the early 1980s. The stigma that has built up around HIV and AIDS is generally regarded as having a negative impact on the quality of life of HIV-positive people and on general prevention efforts. Current attempts to combat HIV-related stigma focus on increasing the acceptance of HIV among the stigmatizing public and stigmatized individuals alike. In this, the global HIV-positive community is being increasingly called upon to 'humanize' the virus, not least through public displays of HIV 'positive' health and public 'positive' speaking. This article critically explores the constitutive effects and inherent power relations of HIV Positive Speakers' Bureaus (PSBs) as a platform for such a display. Adopting a post-structuralist discourse analytic approach, we explore accounts of positive-speaking and HIV health from HIV-related non-government organizations in India and in PSB training manuals. In particular, we highlight ways in which positives speaking in India can be seen to have significant (re)stigmatizing effects by way of ambivalent and hyper-real configurations of HIV 'positive' identity and life.

Annotation: The findings critique the purported benefits of the positive speakers' bureau. The author claims that on the one hand positive speaking aims at reducing stigma, but on the other hand it also poses dilemma in terms of re-stigmatizing HIV-positive identity. Derived from the interviews conducted among NGO workers in India, the findings reveals that even though positive speaking reduces stigma and discrimination faced by PLHIV, the prevalence of societal barriers such as gender-inequality, poverty and homophobia deters greater involvement and visibility of marginalised populations. The findings also show how PLHIV (positive speakers) are merely seen as infectious and responsible for their infection, and hence are responsible for spreading the message on behaviour change and prevention. The author argues that seeing oneself as infectious can only increase the stigma rather than reducing it even though some positive speakers speak of 'collective responsibility' – putting the responsibility of HIV prevention on all people irrespective of their HIV status and the government.

4. Title: Green, D. A., Devi, S., & Paulraj, L. S. (2007). Care centre visits to married people living with HIV: An indicator for measuring AIDS-related stigma & discrimination. *AIDS Care*, 19(7), 910-915.

Journal Abstract: We tested whether observation of the presence and relationship of attendants (i.e. those that accompany upon admission) and visitors to a sample of 230 (128 male, 102 female) married HIV-positive people in an HIV care centre provides an indicator of caregiving, AIDS-related stigma and discrimination. Sensitivity to gender, location (urban vs. rural), age (<35 yrs vs. >35) and source of infection (spouse vs. non-spouse) were factors considered to modulate AIDS-related stigma and assess discrimination. HIV-positive people were accompanied by their spouse (53%), mother (14%), father (7%), with only 7% attending alone. Immediate family most commonly accompanied on admission (80%), but visitors were mainly from the 'extended' family (32%) with many receiving no visitors (48%). Females (11%) were more likely than males to attend alone (11% vs. 4%; $p < 0.05$). No effect of location, age or infector was obtained. Females were more likely to be visited by their mother (14% vs. 6%; $p < 0.01$) and non-immediate family (39% vs. 27%; $p < 0.05$) than males were. In contrast, fathers (0% vs. 6%; $p < 0.05$) and spouses were less likely (3% vs. 10%; $p < 0.05$) to visit females than males. No effect of location or age upon visitation was obtained. Non-spouse infected persons were less likely than spouse-infected to be visited by their spouse (3% vs. 10%; $p < 0.05$) but more likely to receive 'extended' family visitation (43% vs. 24%; $p < 0.01$). Spouse-infected persons had a higher rate of no visitors than persons not infected by their spouse (54% vs. 40%; $p < 0.05$). Observation of the presence and relationship of attendants and visitors to HIV-positive people has potential as an indicator of caregiving AIDS-related stigma and discrimination. The measure appears particularly sensitive to the gender of the HIV-positive person. Such a measure may aid healthcare professionals to focus resources such as relational counselling upon the family and close friends of people experiencing AIDS-related stigma and discrimination, with the aim of improving the provision of care within the community.

Annotation: This study used observation of the presence and relationship of attendants and visitors to HIV-positive people and reported that the findings from such an observation can be used as an indicator of care-giving AIDS-related stigma and discrimination. Gender and source of infection (spouse v/s non-spouse) impacted visitation and care-giver presence; positive females and non-spouse-infected persons receiving fewer visitors and having fewer attendants than males and spouse-infected persons. The limitations acknowledged by the author include lack of a structured stigma assessment questionnaire to validate the observational data and lack of attention to factors impacting care giving for HIV-positive patients. The author recommends that the observation measure can be used for interventions such as relational counselling that involves family and friends of HIV-positive people to reduce stigma and discrimination.

5. Title: Krishna, V. A. S., Bhatti, R. S., Chandra, P. S., & Juvva, S. (2005). Unheard voices: Experiences of families living with HIV/AIDS in India. *Contemporary Family Therapy*, 27(4), 483-506. doi:10.1007/s10591-005-8235-9

Journal Abstract: This study was aimed at understanding the impact of HIV on the family system in the Indian context. A sample of 20 families caring for a relative living with HIV/AIDS (PLWHAs) was recruited from a HIV counseling clinic at the National Institute for Mental Health and Neuro Sciences and a respite home for PLWHAs in Bangalore City in southern India. Qualitative data were collected from these families using a semi-structured interview guide and recorded in the form of narratives. Analysis of these data revealed the following themes: Stigma and discrimination; disclosure; changes in family functioning; financial difficulties; fears of the family; and helplessness. Each theme was presented in detail and implications for intervention to help these families and their PLWHAs discussed.

Annotation: This article narrates the feelings of families caring for relatives living with HIV on fear of being stigmatized or discriminated by extended family members and health care providers. The findings also provide evidence on how these families consider or take extreme measures (such as wanting to commit suicide and vacating their homes) to deal with the consequences of stigma by association.

The study findings provide reasons for why families chose to disclose their relatives' HIV status to neighbours. Reasons for such disclosure include the inability to tolerate the tension all alone and wanting to unburden themselves by sharing. The findings also show that disclosure, consented or not by the PLHIV, does not happen all of a sudden and families disclose the HIV status of their member only after understanding the possible consequences of the action. The family members felt supported and understood when they disclosed the HIV status of their relatives to others. Thus, this article highlights the need for tailored interventions for caregivers to reduce fear related to HIV and to develop strategies to cope up with the stigma they face from others.

6. Title: Mulye, R., Raja, T., Menon, M., Pereira, J., & Barnes, B. L. (2005). "Confidentiality, Stigma, Discrimination and Voluntary Disclosures." *The Indian Journal of Social Work* 66(3): 310-322.

Journal Abstract: The present study attempted to analyse the prevalence and experiences of stigma, discrimination and confidentiality issues, as well as voluntary disclosure and partner notification in HIV-infected patients. The sample consisted of 43 people living with HIV/AIDS receiving treatment and follow-up services at the Vasai Regional AIDS Control Society, a home-based care facility run by Kripa Rehabilitation Centre, Mumbai. They were evaluated on a questionnaire tapping key areas of health, employment, family and reproductive life, and social living, along with an interview schedule to tap various issues of partner notification and disclosure. The obtained results showed that the patients mainly experienced discrimination in health care settings. Discrimination at the workplace and in areas of family and reproductive life and social living was minimal. Incidence of tension/anxiety/fear/sadness/despair and other psychological symptoms were predominantly experienced by all the patients. An overwhelming majority did not want to disclose their serostatus for fear of judgmental attitude, ridicule and insult from friends, co-workers, and relatives. The status was revealed only to the spouse or to the doctors. It is the fear of stigma and discrimination that had impacted these patients in availing the health care facility and support from their significant others.

Annotation: The findings from this article suggests that people living with HIV experience high level of discrimination in health care settings when compared with other settings such as family and workplace. Forms of discrimination include: 1) HIV testing without explicit consent; 2) Segregation in the hospitals; and 3) Refusal of medical treatment. Furthermore this article shows the reasons for disclosure/non-disclosure of HIV status to others. Reasons for non-disclosure included: 1) Fear of being disowned by family or social discrimination; 2) Isolation; 3) Fear of being avoided and shunned; 4) Fear of being ridiculed/insulted and 5) Loss of trust. Reasons for disclosure included: 1) Need for emotional support; and 2) Need for sharing their feelings with others. Thus, the study highlights the need to address these concerns of PLHIV during counselling to help them in deciding whether or not to, to whom, and how to disclose their HIV status to others.

7. Title: Paxton, S., Gonzales, G., Uppakaew, K., Abraham, K. K., Okta, S., Green, C., . . . Quesada, A. (2005). AIDS-related discrimination in Asia. *AIDS Care*, 17(4), 413-424.

Journal Abstract: The Asia Pacific Network of People Living with HIV/AIDS (APN+) conducted the first regional documentation of AIDS-related discrimination in Asia. This

project was an action-based, peer implemented study that aimed to develop an understanding of the nature, pattern and extent of AIDS-related discrimination in several Asian countries. Trained HIV-positive people interviewed 764 positive people in four countries (India 302; Indonesia 42; Thailand 338; the Philippines 82) using a structured questionnaire. Findings indicate that the major area of discrimination in each country is within the health sector, where over half of those surveyed experienced some form of discrimination. In all countries, the majority of people did not receive pre-test counselling before being tested for HIV. People who reported coerced testing were significantly more likely than other respondents to face subsequent AIDS-related discrimination. A considerable number of respondents were refused treatment after being diagnosed with HIV and many experienced delayed provision of treatment or health services. Breaches of confidentiality by health workers were common. Within the family and the community, women were significantly more likely to experience discrimination than men, including ridicule and harassment, physical assault and being forced to change their place of residence because of their HIV status. These findings have serious implications, particularly in light of the increasing trend in many countries to test all pregnant women in order to prevent transmission of HIV to their unborn children.

Annotation: This is among the first few stigma studies to be carried out with HIV-positive people in four Asian countries including India thereby enhancing the understanding of stigma in different cultural settings. The study highlights health sector as a key context in which most PLHIV experience stigma and discrimination followed by community, family, educational and workplace settings. The most common forms of discrimination reported were treatment refusal and delayed care. Gender was found to be associated with experiences of discrimination; women more than men were discriminated within community, family, health care and educational settings.

8. Title: Rahangdale, L., Banandur, P., Sreenivas, A., Turan, J., Washington, R., & Cohen, C. (2010). Stigma as experienced by women accessing prevention of parent-to-child transmission of HIV services in Karnataka, India. *AIDS Care*, 22(7), 836-842. doi:10.1080/09540120903499212

Journal Abstract: In Karnataka, India only one-third of HIV-infected pregnant women received antiretroviral prophylaxis at delivery in 2007 through the state government's prevention of parent-to-child HIV transmission program. The current qualitative study explored the role of HIV-associated stigma as a barrier to access PPTCT services in the rural northern Karnataka district of Bagalkot using in-depth interviews and focus group discussions with HIV-infected women who had participated in the PPTCT program, male and female family members, and HIV service providers. Participants discussed personal experiences, community perceptions of HIV, and decision-making related to accessing PPTCT services. They described stigma toward HIV-infected individuals from multiple sources: healthcare workers; community members; family; and self. Stigma-related behaviors were based on fears of HIV transmission through personal contact and moral judgment. Experience and/or fears of discrimination led pregnant women to avoid using PPTCT interventions. Government, cultural, and historical factors are described as the roots of much the stigma-related behavior in this setting. Based on these formative data, PPTCT program planners should consider further research and interventions aimed at diminishing institutional and interpersonal HIV-associated stigma experienced by pregnant women

Annotation: Adapting the theoretical framework of Steward et al. (2008), this article shows a model of how the root causes of stigma and various types of stigma (enacted, felt normative and internalized stigma) prevent HIV-positive women from accessing PPTCT services. Thus, this article shows that not only the proximate agents of stigma (healthcare providers, family, etc.) need to be targeted in anti-discrimination campaigns, but there is also a need to focus on distal agents such as the deep-rooted cultural norms and gender inequalities.

9. Title: Souza, R. d. (2010). Women living with HIV: Stories of powerlessness and agency. *Women's Studies International Forum*, 33(3), 244-252. doi:10.1016/j.wsif.2010.01.006

Journal Abstract: Married monogamous women in India are now considered to be at higher risk from HIV/AIDS than previously considered. Gender inequalities rooted in an inherently patriarchal social system serves to marginalize women within the family unit, making them more susceptible to infection. Guided by postcolonial feminist theory, the study uses narrative methodologies to tell the stories of two women living with HIV/AIDS in India who were infected by their husbands. In particular, the study explores how culture and power inequities shape their unique experiences of stigma and how women demonstrate agency in their lives in a context of seeming powerlessness. The analysis reveals that stigma is inextricably linked to systemic patriarchy, but women demonstrate agency by articulating their own understanding of disease and illness, reflexively contesting cultural assumptions, and appropriating the courage to speak out for themselves and others.

Annotation: This article narrates the lived experiences of two HIV-positive widows. The findings show how gender-inequities, HIV-related social stigma and assumed relationships between sexual immorality and HIV marginalize women living with HIV. The findings reveal that women living with HIV also face stigma of widowhood which is as bad as, if not more than, the HIV-related stigma faced by them. This article also acknowledges the role of external agents such as non-governmental organisations in enabling marginalized individuals to empower themselves.

10. Title: Subramanian, T., Gupte, M. D., Dorairaj, V. S., Periannan, V., & Mathai, A. K. (2009). Psycho-social impact and quality of life of people living with HIV/AIDS in South India. *AIDS Care*, 21(4), 473-481.

Journal Abstract: This study examines psycho-social impact of HIV and quality of life of 646 HIV-infected persons from a major government sexually transmitted disease (STD) clinic in South India. In this cross-sectional study, data was collected using interview schedule and scales. Nearly 70% had problems in parenting their children after acquiring the infection. Most (88%) of the respondents reported of seeking help from their family members, relatives or close friends at the time of their illness. Among the four categories of stigma, most of them (96%) reported perceived stigma whereas actual stigma was mentioned by only 33%. All four categories of stigma were experienced on a higher proportion by females than males ($p < 0.05$). Each type of stigma was significantly associated with each domain of quality of life of the respondents ($p < 0.005$). Respondents who reported of actual stigma (33%) had significantly good quality of life in their physical domain (49%), psychological domain (48%) and environmental domain (44%). Multivariate analysis showed that gender and marital status had significant association with quality of life. The findings of the study underscore the need for enabling environment through "human force" to uplift their social status and to have a better quality of life.

Annotation: The study indicated higher prevalence of perceived stigma than enacted stigma among people living with HIV attending antiretroviral treatment centres. The study reports gender-wise differences in all four categories of stigma, with women reporting a high level of stigma in all categories. It reports poor quality of life in the social domain, particularly among women, and shows its association with stigma. The study recommends gender-sensitive approaches, considering the lack of equal treatment and acceptance, and, disadvantaged status of women. The study recommends that fear-based messages and biased social attitudes need to be confronted to reduce stigma and discrimination against PLHIV.

11. Title: Steward, W. T., Herek, G. M., Ramakrishna, J., Bharat, S., Chandy, S., Wrubel, J., & Ekstrand, M. L. (2008). HIV-related stigma: Adapting a theoretical framework for use in India. *Social Science & Medicine*, 67(8), 1225-1235.

Journal Abstract: Stigma complicates the treatment of HIV worldwide. We examined whether a multicomponent framework, initially consisting of enacted, felt normative, and internalized forms of individual stigma experiences, could be used to understand HIV-related stigma in Southern India. In Study 1, qualitative interviews with a convenience sample of 16 people living with HIV revealed instances of all three types of stigma. Experiences of discrimination (enacted stigma) were reported relatively infrequently. Rather, perceptions of high levels of stigma (felt normative stigma) motivated people to avoid disclosing their HIV status. These perceptions often were shaped by stories of discrimination against other HIV-infected individuals, which we adapted as an additional component of our framework (vicarious stigma). Participants also varied in their acceptance of HIV stigma as legitimate (internalized stigma). In Study 2, newly developed measures of the stigma components were administered in a survey to 229 people living with HIV. Findings suggested that enacted and vicarious stigma influenced felt normative stigma; that enacted, felt normative, and internalized stigma were associated with higher levels of depression; and that the associations of depression with felt normative and internalized forms of stigma were mediated by the use of coping strategies designed to avoid disclosure of one's HIV serostatus.

Annotation: This study was conducted in two phases (qualitative and quantitative), and 'vicarious stigma', hearing stories about enacted stigma, emerged as a construct in the qualitative phase. Based on the finding of the first phase, the second phase of the study developed and validated four new instruments, to measure four forms of stigma (including vicarious stigma). Perceived stigma was found to be higher than enacted stigma. Identification of the vicarious stigma construct is an important addition to the conceptual framework of stigma.

12. Title: Suhadev, M., Mahadevan, U., Dilip, M., Suryanarayanan, D., Sikhamani, R., and Thomas, B. (2011). Percentages, Process, and Patterns of HIV Disclosure Among the Spouses of HIV-Infected Men in South India. *Journal of the International Association of Physicians in AIDS Care*, 10: 26. DOI: 10.1177/1545109710369027

Journal Abstract: Most studies have described the outcome of HIV status disclosure rather than the process of disclosure. Hence, a study was conducted among 201 women who accompanied their spouses and children to 3 hospitals at Chennai and Vellore, Tamil Nadu, India, during January to June 2007. Majority of the respondents were sero-positive (69%) and marriage was the only risk factor for them. Of 201 women, 49% did not know the reason for their husbands' HIV infection. Confidentiality of the patient was often breached during disclosure as family members were drawn into the process without consulting the patient. Only for 117 (50%) respondents, HIV diagnosis was disclosed directly by the health providers. There was a considerable delay for men in disclosing their HIV status to their spouses. Apart from the spouses, 122 (61%) shared their diagnosis with other family members. Disgrace to self and family (54%), fear of discrimination (27%), and fear of rejection (9%) were reported for nondisclosure.

Annotation: Unlike other studies, the findings from this study highlight the process of disclosure – when and where the disclosure happens, who discloses to whom, consequences of disclosure and reasons for non-disclosure. The study findings show that the disclosure of one's HIV status was usually made by the doctors either directly to the HIV-positive persons or to their spouses, siblings, parents or in-laws. Among those respondents who disclosed their/spouses HIV status to others, a majority had disclosed the status to their natal families. Reasons for non-disclosure to others included: 1) disgrace to self and family;

2) fear of discrimination; and 3) fear of rejection. Thus this article suggests that HIV counselling should be gender-sensitive and there is need to focus on assisting the clients in disclosure issues.

13. Title: Thomas, B., Nyamathi, A., & Swaminathan, S. (2009). Impact of HIV/AIDS on mothers in Southern India: A qualitative study. *AIDS and Behavior*, 13(5), 989-996. doi:10.1007/s10461-008-9478-x

Journal Abstract: The purpose of this study is to explore the perceptions and needs of mothers living with HIV to gain greater insights into the challenges they face in relation to their health seeking behavior, fears around disclosure, and issues related to stigma and discrimination. This qualitative study utilized focus groups consisting of a sample of 60 HIV-infected mothers recruited from a large maternity hospital and STD clinic in Chennai, India. Discrimination by physicians and other health care workers has been a major impediment expressed by mothers living with HIV in accessing quality health care. Mothers living with HIV are increasingly concerned about how and when to disclose their HIV status to their children and the repercussions which could result from disclosure. The findings of this study call for urgent intervention strategies taking into consideration these various concerns and needs of mothers living with HIV and their children.

Annotation: The article shows that while some forms of stigma and discrimination faced by mothers living with HIV are similar (e.g., stigmatization by health care providers) to that of any other women living with HIV, certain unique issues include dilemma faced by mothers living with HIV in disclosure of their HIV status to children (because of fear of rejection) and concerns about potential negative consequences of disclosure to their children. The findings recommend the need to take into account the specific concerns of mothers living with HIV when designing psychosocial interventions and the need for sensitisation and training for health care providers.

14. Title: Thomas, B. E., Rehman, F., Suryanarayanan, D., Josephine, K., Dilip, M., Dorairaj, V. S., & Swaminathan, S. (2005). How stigmatizing is stigma in the life of people living with HIV: A study on HIV positive individuals from Chennai, South India. *AIDS Care*, 17(7), 795-801.

Journal Abstract: The nature and intensity of AIDS stigma are shaped by the social construction of the epidemic in different locales. Stigma therefore needs to be discussed in its cultural context. This clinic-based study aims at understanding stigma among 203 HIV positive individuals from Chennai, South India. The study throws light on the impact of stigma on the quality of life among these individuals. It also discusses the gender implications of stigma. This study brings out the findings that actual stigma experienced among those infected with HIV is much less (26%) as compared to the fear of being stigmatized or perceived stigma (97%). Internalizing of stigma was found to have a highly significant negative correlation with quality of life in the psychological domain and a significant negative correlation in the environmental domain. However individuals who did experience actual stigma seemed more determined to live and experience an above moderate quality of life. The implication of this study encourages HIV infected individuals to rise above stigma, avoid internalizing their stigmatized feelings and work toward a better quality of life. Health providers need to address these issues in their care for HIV infected individuals.

Annotation: The study found higher levels of 'actual stigma' (referring to enacted stigma) among women than men and an overall high level of perceived stigma than actual stigma. The study recommends psychosocial counselling for PLHIV, their care-givers, and wider family, and avoidance of fear-based messages about AIDS that emphasize fatality and moral decay.

15. Title: Tarakeshwar, N., Srikrishnan, A. K., Johnson, S., Vasu, C., Solomon, S., Merson, M., & Sikkema, K. (2007). A social cognitive model of health for HIV-positive adults receiving care in India. *AIDS & Behavior*, 11(3), 491-504.

Journal Abstract: In-depth interviews were conducted with 50 HIV-positive adults (23 women, 27 men) with access to care at a non-governmental organisation in Chennai, India to gain a broad understanding of how they managed their HIV infection. Using a Social Cognitive Model of Health, we identified factors within the model's three domains—Personal, Environmental, and Behavioural—that are applicable to this socio-cultural context. The Personal domain's factors were a positive self-concept, family-focused goals, and treatment optimism; the Environmental domain comprised family-based support, treatment availability, access and quality, and HIV stigma and discrimination; and the Behaviour domain's factors were medication adherence and health habits, sexual behaviour, and social relationships and emotional well-being. Significant differences for many of the factors within the three domains were observed across married men and women, widowed women, unmarried men, and female sex workers. Implications for an enhanced intervention for HIV- infected individuals in similar treatment settings are discussed.

Annotation: The study uses social cognitive model to understand the management of health needs of PLHIV, as the model accommodated factors that were applicable to particular socio-cultural context and situations. Disclosure concerns affected the emotional well-being and stigma in the form of losing business, shifting residence, negative reputation, shame, and isolation. As the study is from the perspective of PLHIV, further research is recommended to understand the perspectives of family members as care givers. The study recommends the clinicians and counsellors to conduct a detailed assessment of family and social networks to identify sources of support, and assess the structural barriers to access HIV treatment.

16. Title: Van Hollen, C. (2010). HIV/AIDS and the gendering of stigma in Tamil Nadu, South India. *Culture, Medicine and Psychiatry*, 34(4), 633-657. doi:10.1007/s11013-010-9192-9

Journal Abstract: Drawing on the seminal theoretical work on stigma by Goffman, this article analyzes stigma through the lens of Parker and Aggleton, who call for the joining of Goffman and Foucault to better grasp relationships among stigma, power and social inequality. Studies on the social impact of HIV/AIDS globally have demonstrated that women tend to be blamed for the spread of HIV/AIDS, and as a result, HIV-positive women face greater stigma and discrimination than HIV-positive men. Based on ethnographic research among 50 HIV-positive women in South India in 2002–2003 and 2004, my research supports this standard argument. However, my findings suggest that the gendering of stigma and discrimination is more complex and context specific. The gendering of stigma varies depending on the social context of private versus public spheres. The tendency to stigmatize women is due in part to cultural constructions of gendered bodies and not only to a gendered double standard of sexual morality, as has been previously reported. Even when a cultural argument about women's wayward sexuality is evoked, this rhetoric must be understood in part as a strategy to mask economically motivated responses, rather simply being attributed to sexist ideology per se.

Annotation: The study findings (self-narratives by HIV-positive women) provide evidence on why women living with HIV are more stigmatized when compared with HIV-positive men. The presence of double standard of sexual mores, and presence of general belief in the society that HIV is a women's disease (a disease that one gets from women in sex work) are considered as reasons for high burden of HIV-related stigma faced by women living with HIV. The findings also show how HIV-positive married women are being blamed by their in-laws and husbands for bringing HIV into family, even if they were infected by their husbands.

Thus, the findings are important in highlighting the specific issues faced by women living with HIV and the need for individual level and group-level interventions that take into consideration the gendered nature of HIV-related stigma.

17. Title: Malavé, S., Ramakrishna, J., Heylen, E., Bharat, S., & Ekstrand, M. L. (2014). Differences in testing, stigma, and perceived consequences of stigmatization among heterosexual men and women living with HIV in Bengaluru, India. *AIDS Care*, 26 (3), 396-403. doi:10.1080/09540121.2013.819409

Journal Abstract: Approximately 2.4 million people in India are living with HIV. Gender inequality affects HIV prevention, detection, and management. The purpose of this paper was to describe gender differences in the experience of living with HIV in Bengaluru, India. A subsample of n=313 (159 men and 154 women) from a larger cohort was used for these analyses. Participants were recruited through AIDS service organizations. They completed an interviewer-administered survey assessing HIV testing experience, types of stigma, and perceived consequences of stigmatization. The majority of men (67%) reported getting HIV tested because of illness, while women were more likely to be tested after learning their spouse's HIV-positive status (42%). More men (59%) than women (45%, p<0.05) were tested in private care settings. Men reported significantly higher mean levels of internalized stigma (men: M=0.71, SD=0.63; women: M=0.46, SD=0.55; p<0.001), whereas the women reported significantly higher scores for enacted stigma (men: M=1.30, SD=1.69; women: M=2.10, SD=2.17; p<0.001). These differences remained significant after controlling for potential socio-demographic covariates. Following their diagnosis, more women reported moving out of their homes (men: 16%; women: 26%; p<0.05). More men (89%) than women (66%; p<0.001) reported to have modified their sexual behavior after being diagnosed. These findings suggest that the experience of living with HIV and HIV stigma varies by gender in this population. Suggestions for a gender-based approach to HIV prevention and stigma reduction are provided.

Annotation: This paper examined the differences in the experiences of men and women living with HIV in an urban setting. The study found gender differences in relation to HIV testing, forms of stigma and consequences of stigma. While men were tested for HIV once they become ill, women were tested for HIV after their husbands were diagnosed with HIV. Men experienced higher levels of internalized stigma than women (as men are more likely to bring HIV infection into their family), while women reported higher levels of discrimination than men (as women are traditionally looked down upon and blamed by others even if their husband is the source of infection). Also, the paper reported that, when compared to men, more women moved out of their homes or neighborhood after HIV diagnosis, possibly reflecting the differences in the way the general public treats men and women living with HIV. These point out that in addition to taking measures to prevent stigma and discrimination, there is also a need to address internalized stigma among PLHIV, especially among men, and the need to enhance skills among women living with HIV to cope up with discrimination. As the participants in this study were primarily recruited from AIDS service organizations (ASOs), the findings may not be representative of PLHIV, in general. However, if this sample that had access to services and psychosocial support (as they were connected to agencies) reported high levels of internalized stigma and discrimination, then it is possible that those PLHIV who are not part of the ASOs are more likely to face even higher stigma and discrimination.

18. Title: Charles, B., Jeyaseelan, L., Pandian, A. K., Sam, A. S., Thenmozhi, M., & Jayaseelan, V. (2012). Association between stigma, depression and quality of life of people living with HIV/AIDS (PLHA) in South India - a community based cross sectional study. *BMC Public Health*, 12:463. doi:10.1186/1471-2458-12-463

Journal Abstract:

Background: India has around 2.27 million adults living with HIV/AIDS who face several challenges in the medical management of their disease. Stigma, discrimination and psychosocial issues are prevalent. The objective of the study was to determine the prevalence of severe stigma and to study the association between this, depression and the quality of life (QOL) of people living with HIV/AIDS (PLHA) in Tamil Nadu.

Methods: This was a community based cross sectional study carried out in seven districts of Tamil Nadu, India, among 400 PLHA in the year 2009. The following scales were used for stigma, depression and quality of life, Berger scale, Major Depression Inventory (MDI) scale and the WHO BREF scale. Both Stigma and QOL were classified as none, moderate or severe/poor based on the tertile cut off values of the scale scores. Depression was classified as none, mild, moderate and severe. Logistic regression analyses were performed to study the risk factors.

Results: Twenty seven per cent of PLHA had experienced severe forms of stigma. These were severe forms of personalized stigma (28.8%), negative self-image (30.3%), perceived public attitude (18.2%) and disclosure concerns (26%). PLHA experiencing severe depression were 12% and those experiencing poor quality of life were 34%. Poor QOL reported in the physical, psychological, social and environmental domains was 42.5%, 40%, 51.2% and 34% respectively. PLHA who had severe personalized stigma and negative self-image had 3.4 (1.6-7.0) and 2.1 (1.0-4.1) times higher risk of severe depression respectively ($p < .001$). PLHA who had severe depression had experienced 2.7 (1.1-7.7) times significantly poorer QOL.

Conclusions: Severe forms of stigma were equivalently prevalent among all the categories of PLHA. However, PLHA who had experienced severe depression had only developed poor QOL. A high level of social support was associated with a high level of QOL.

Annotation:

The study was conducted among people living with HIV (PLHIV) registered in antiretroviral treatment (ART) centres, PLHIV networks and non-governmental agencies in seven intensive HIV intervention districts of Tamil Nadu. The study found a relatively high prevalence of severe degree of stigma and depression, and low quality of life. The significant predictors of severe depression reported among PLHIV were being married and having self-stigma and negative self-image. Similarly, the significant predictors of poor quality of life were being from lower income group, having low or moderate social support, and having severe depression. The findings suggest the need of interventions that facilitate PLHIV to effectively cope with both self-stigma and discrimination; and screen for and address depression among PLHIV. Also, the authors suggest improving social support networks of PLHIV as that might then offer the necessary emotional and psychological support to tackle depression.

19. Title: Jeyaseelan, L., Kumar, S., Mohanraj, R., Rebekah, G., Rao, D., & Manhart, L. E. (2013). Assessing HIV/AIDS stigma in South India: Validation and Abridgement of the Berger HIV Stigma Scale. *AIDS Behav*, 17, 434-443. doi:10.1007/s10461-011-0128-3

Journal Abstract: HIV-related stigma has been associated with depression, poor adherence, and nondisclosure of HIV positive status, all of which can lead to increased transmission of HIV and poorer health outcomes for HIV-infected individuals. The Berger HIV Stigma scale has been used in multiple settings but never adapted and validated in India, home to the world's second largest HIV-infected population. We assessed the reliability and validity of a Tamil translation of the original 40-item scale, and conducted confirmatory and exploratory factor analyses to assess cultural appropriateness and abbreviate the scale. Reliability and validity were high ($\alpha = 0.91$; test-retest reliability

ICC = 0.89). Exploratory and confirmatory factor analysis resulted in an abridged 25-item version of the scale that possessed better psychometric properties than the 40-item version. This culturally validated, abridged HIV-Stigma scale can be used in busy clinical settings to identify individuals in need of psychosocial support and assess post-intervention changes in stigma in Southern India.

Annotation: This study was conducted among HIV-positive men and women from PLHIV support networks from one urban and one semi-rural setting. The authors tested an abridged 25-item Berger HIV stigma scale (original scale contained 40 items) to measure HIV-related stigma in South Indian context and to assess its psychometric properties (reliability and validity). The exploratory and confirmatory factor analyses found that the abridged 25-item scale had better psychometric properties than the original 40-item version. The authors recommend that this culturally-validated and abridged Berger HIV stigma scale could be used to identify the need for mental health services and to assess the effectiveness of stigma reduction interventions among PLHIV in Indian clinical settings. The authors acknowledged certain limitations that included: difficulty in comprehension of some of the questions that might have resulted in incorrect responses; and lower effectiveness of some questions that used first-person narrative. The usefulness of the abridged version to other populations that visit clinics (those from marginalized groups such as sex workers, IDUs and MSM) thus need to be explored in future studies.

20. Title: Nebhinani, N., Mattoo, S. K., & Wanchu, A. (2012). HIV Stigma and Specified Correlates in North India. *Indian J Psychol Med*, 34(4), 324-331. doi: 10.4103/0253-7176.108203

Journal Abstract:

Background: Worldwide, the stigma and discrimination impede HIV-AIDS programs across the continuum of prevention to care. We studied stigma and related issues in HIV-positive subjects.

Materials and Methods: At a tertiary care hospital in North India, we studied 100 HIV-positive outpatients not receiving antiretroviral therapy. The subjects self-administered Tanzania Stigma Indicator and Community Endline-Individual Questionnaire. Psychiatric morbidity was screened with General Health Questionnaire (GHQ-I2 Hindi) and diagnosed with Structured Clinical Interview for DSM-IV (SCID).

Results: A typical subject was middle aged (25-44 years, 77%), school non-completer (63%), village dweller (61%), and male (59%). Only 35 subjects could differentiate between HIV and AIDS, and only 24 were aware of antiretroviral therapy. Unprotected sex, sharing injections, and blood transfusions were reported spontaneously as possible sources of transmission by 56-79% subjects each. About 80% of subjects reported no fear in touching HIV-positive subjects or their objects. Avoiding injections, being faithful to uninfected partner, avoiding blood transfusions, using condoms, and avoiding sharing razors/blades were reported spontaneously as HIV preventive measures by 40 to 26 subjects each. Half of the subjects blamed self for contracting HIV. Only 38 subjects reported others behaving differently with HIV-positive subjects. HIV status disclosure was reported by 98 subjects (73 to family or relatives). Urban subjects reported higher primary stigma and shame or blame. Psychiatric disorders, present in 45 subjects, showed no association with stigma items.

Conclusions: The subjects had a limited knowledge, especially of treatment aspects. Stigma showed no association with psychiatric disorders. The study reflects a strong need for public health measures to enhance awareness and knowledge about HIV/AIDS.

Annotation: This cross-sectional hospital-based study was conducted among a convenience sample of PLHIV outpatients who are not on ART with the aim of examining the

presence of an association between stigma (self-stigma and discrimination experiences) and mental health issues among PLHIV. The study seems to have inadequate power to identify significant associations between stigma and mental health issues. Future studies need to be designed to have adequate sample size and power to identify associations between self-stigma, discrimination experiences and mental health problems among probability-based samples of PLHIV from both urban and rural settings.

II. General Public (Men, Women, Youth, Health care providers and others)

21. Title: Ekstrand, M. L., Bharat, S., Ramakrishna, J., & Heylen, E. (2011). Blame, Symbolic Stigma and HIV Misconceptions are Associated with Support for Coercive Measures in Urban India. *AIDS Behav.* DOI 10.1007/s10461-011-9888-z

Journal Abstract: This study was designed to examine the prevalence of stigma and its underlying factors in two large Indian cities. Cross-sectional interview data were collected from 1,076 non-HIV patients in multiple healthcare settings in Mumbai and Bengaluru, India. The vast majority of participants supported mandatory testing for marginalized groups and coercive family policies for PLHA, stating that they “deserved” their infections and “didn’t care” about infecting others. Most participants did not want to be treated at the same clinic or use the same utensils as PLHA and transmission misconceptions were common. Multiple linear regression showed that blame, transmission misconceptions, symbolic stigma and negative feelings toward PLHA were significantly associated with both stigma and discrimination. The results indicate an urgent need for continued stigma reduction efforts to reduce the suffering of PLHA and barriers to prevention and treatment. Given the high levels of blame and endorsement of coercive policies, it is crucial that such programs are shaped within a human rights framework.

Annotation: This is the first large scale study to quantify different dimensions of individual manifestations of AIDS-related stigma among non HIV-positive patients in urban India. The result from this study shows the prevalence of higher-level of stigmatizing and discriminatory attitudes (including endorsement of coercive policies such as mandatory HIV testing and prohibiting PLHIV from getting married and having children) against marginalized groups such as men who have sex with men and female sex workers and PLHIV in general. Analysis from this study show that AIDS stigma attitudes and intent to discriminate against PLHIV are driven primarily by HIV transmission misconceptions, blame and negative feelings towards PLHIV, highlighting the importance of addressing these factors in future programs.

22. Title: Kermodé, M., Holmes, W., Langkham, B., Thomas, M. S., & Gifford, S. (2005). HIV-related knowledge, attitudes & risk perception amongst nurses, doctors & other healthcare workers in rural India. *Indian J Med Res* 122, September 2005, pp 258-264

Journal Abstract: Background & objective: People with HIV in India frequently encounter discrimination while seeking and receiving healthcare services. The knowledge and attitudes of healthcare workers (HCWs) influences the willingness and ability of people with HIV to access care, and the quality of the care they receive. Previous studies of HIV-related knowledge and attitudes amongst Indian HCWs have been conducted primarily in large urban hospitals. The objective of this study was to assess HIV-related knowledge, attitudes and risk perception among a group of rural north Indian HCWs, and to identify predictors of willingness to provide care for patients with HIV infection. Methods: A cross-sectional survey of 266 HCWs (78% female) from seven rural north Indian health settings was undertaken in late 2002. A self-administered written questionnaire was made available in English and Hindi, and the response rate was 87 per cent. Information was gathered regarding demographic details (age, sex, duration of employment, job category); HIV-related

knowledge and attitudes; risk perception; and previous experience caring for HIV-positive patients. Logistic regression modelling was undertaken to identify factors associated with willingness to care for patients with HIV. Results: The HCWs in this study generally had a positive attitude to caring for people with HIV. However, this was tempered by substantial concerns about providing care, and the risk of occupational infection with HIV was perceived by most HCWs to be high. After controlling for confounding, HCWs willingness to provide care for patients with HIV was strongly associated with having previously cared for patients with HIV ($P = 0.001$). Knowledge of HIV transmission and perception of risk were not associated with willingness to provide care. Interpretation & conclusion: The findings of this study showed a general willingness of HCWs to provide care for patients with HIV, tempered by concerns regarding provision of such care. Strategies to address HCWs concerns are likely to ameliorate the discrimination experienced by people with HIV when accessing healthcare services. These include the development of programmes to promote occupational safety of HCWs and involving people with HIV in awareness training of HCWs.

Annotation: The study highlights that in spite of the willingness among health care workers to provide care for PLHIV, the perceived risk of occupational transmission of HIV acts as a barrier in providing quality care and might contribute to discriminatory practices. Thus, a key recommendation is to ensure occupational safety of health care workers (in terms of preventing occupational risk of HIV transmission).

23. Title: Mahendra, V., Gilborn, L., Bharat, S., Mudoi, R., Gupta, I., George, B., . . . Pulerwitz, J. (2007). Understanding and measuring AIDS-related stigma in health care settings: A developing country perspective. *Sahara J: Journal of Social Aspects of HIV/AIDS/Journal De Aspects Sociaux Du VIH/SIDA*, 4(2), 616-625.

Journal Abstract: AIDS-related stigma and discrimination remain pervasive problems in health care institutions worldwide. This paper reports on stigma-related baseline findings from a study in New Delhi, India to evaluate the impact of a stigma-reduction intervention in three large hospitals. Data were collected via in-depth interviews with hospital staff and HIV-infected patients, surveys with hospital workers (884 doctors, nurses and ward staff) and observations of hospital practices. Interview findings highlighted drivers and manifestations of stigma that are important to address, and that are likely to have wider relevance for other developing country health care settings. These clustered around attitudes towards hospital practices, such as informing family members of a patient's HIV status without his/her consent, burning the linen of HIV-infected patients, charging HIV-infected patients for the cost of infection control supplies, and the use of gloves only with HIV-infected patients. These findings informed the development and evaluation of a culturally appropriate index to measure stigma in this setting. Baseline findings indicate that the stigma index is sufficiently reliable ($\alpha = 0.74$). Higher scores on the stigma index – which focuses on attitudes towards HIV-infected persons – were associated with incorrect knowledge about HIV transmission and discriminatory practices. Stigma scores also varied by type of health care providers – physicians reported the least stigmatising attitudes as compared to nursing and ward staff in the hospitals. The study findings highlight issues particular to the health care sector in limited-resource settings. To be successful, stigma-reduction interventions, and the measures used to assess changes, need to take into account the socio-cultural and economic context within which stigma occurs.

Annotation: This article focuses on the results of development, testing and evaluation of a culturally-relevant stigma measurement index. Since this scale has been shown as reliable and valid for an Indian setting, future interventions among health care providers can use this scale to assess the effectiveness of interventions. Given the presence of diverse cultural settings within each Indian state, pilot-testing of the scale is needed before adapting it to other regions.

24. Title: Meundi, A. D., Amma, A., Rao, A., Shetty, S., & Shetty, A. K. (2008). Cross-Sectional Population-Based Study of Knowledge, Attitudes, and Practices Regarding HIV/AIDS in Dakshina Kannada District of Karnataka, India. *Journal of the International Association of Physicians in AIDS Care (JIAPAC 2008 7: 27 originally published online 6 June 2007 DOI: 10.1177/1545109707302088)*

Journal Abstract: Objective: To assess HIV/AIDS-related knowledge, attitudes, and practices among the general population in South India. Methods: The 1669 participants (834 males, 835 females) aged 19-49 years were surveyed using a stratified 2-stage random sampling design with probability proportional to size. Results: Although 54% of participants knew that AIDS is caused by “HIV” virus and 44% could correctly identify all modes of transmission, 52% believed in one or more myths, 41% did not know that condoms can prevent HIV, and 18% had not heard of a condom. Higher HIV knowledge scores were significantly associated with male gender, higher education, currently married, higher frequency of reading newspapers, listening to radio or watching television and willingness to get tested for HIV ($P < .01$). Thirty-four percent felt that HIV-infected individuals should be kept away from others, and 40% were not willing to accept a family member with HIV. There was a significant and positive correlation between knowledge and attitude scores ($P < .01$). Among respondents who ever had sexual intercourse, significantly more males declared having more than one sexual partner compared to females ($P < .01$). Only 16% of respondents reported that they consistently used condoms. Sixty-two percent of the respondents were willing to undergo an HIV test if provided free of cost. This willingness to opt for HIV testing increased significantly with better knowledge score, better attitude score, and higher education status ($P < .01$). Conclusions: HIV/AIDS prevention campaigns in India should focus on public education, stigma reduction, promotion of condom use, and risk-reduction behaviors in urban and rural communities targeted toward young adults.

Annotation: This article shows how the presence of negative perceptions and discriminatory attitudes among general public against PLHIV hinders HIV testing and providing care for PLHIV. Thus, this article suggests the need to address negative attitudes of general population toward PLHIV by designing and implementing culturally appropriate multi-dimensional interventions to reduce HIV-related stigma.

25. Title: Pisal, H., Sutar, S., Sastry, J., Kapadia-Kundu, N., Joshi, A., Joshi, M., . . . Shankar, A. V. (2007). Nurses' health education program in India increases HIV knowledge and reduces fear. *Journal of the Association of Nurses in AIDS Care, 18(6), 32-43*

Journal Abstract: Few health care facilities are adequately prepared to manage and care for HIV/AIDS patients in India. Nurses play a critical role in patient care but are often ill-equipped to deal with their own fears of occupational risk and handle the clinical aspects of HIV/AIDS care, leading to stigma and discrimination toward HIV-positive patients. The authors examine the impact of a 4-day HIV/AIDS health education program on knowledge and attitudes of nurses in a government hospital. This education program was developed using a training of trainers model and qualitative research. A total of 21 master trainers underwent 6 days of training and began training of 552 hospital nurses (in 2004-2005). Using a pretest-posttest design, the authors assessed changes in knowledge and attitudes of 371 trained nurses. Significant improvements were seen in nurses' HIV/AIDS knowledge in all areas including care, treatment, and issues of confidentiality and consent. Fear of interaction with people living with HIV/AIDS was reduced significantly. The short course was successful in increasing nurses' knowledge in all aspects. There is great potential to expand this stigma-reduction intervention to other public and private hospitals.

Annotation: The study presents the impact of a four-day HIV/AIDS health education training among nurses to improve their knowledge on HIV and attitude towards PLHIV, with a pre- and post-test evaluation. The study was conducted in three phases. The key findings suggest that there was an improvement in the knowledge levels of nurses regarding HIV and AIDS, informed consent, universal precautions, and care and treatment. Fear of infection, and stigmatizing and discriminatory behaviours among nurses decreased after training; and understanding the importance of confidentiality of the HIV status of patients was increased. Furthermore, study recommends that hospitals need to support nurses with adequate supplies of essential protective material (for adopting universal precautions). The study concludes that a short course to improve knowledge, attitude and behaviours may have a significant impact on reducing the stigma faced by PLHIV.

26. Title: Pramanik, S., Chartier, M., & Koopnam, C. (2006). HIV/AIDS Stigma and Knowledge among Predominantly Middle-Class High School Students in New Delhi, India. *J. Commun. Dis.* 38 (1) 2006: 57-69

Journal Abstract: This study examined stigmatizing attitudes toward HIV/AIDS among predominantly middle-class adolescents in New Delhi high schools. This study was specifically designed to: 1) assess stigmatizing attitudes toward HIV/AIDS and sexuality; HIV/AIDS knowledge, and awareness of HIV-related health resources; and 2) examine whether HIV-related stigma and knowledge are related to one another and to gender, parents' education, and exposure to HIV/AIDS education. In four high schools in New Delhi, 186 students completed a questionnaire assessing stigmatization of HIV/AIDS, stigmatization of sexuality, knowledge of HIV/AIDS, HIV/AIDS education and resources, and demographic characteristics. Adolescents varied in how much they stigmatized persons with HIV/AIDS. They generally lacked accurate knowledge about the disease and of related health resources. However, those with greater exposure to HIV/AIDS education demonstrated significantly greater HIV/AIDS knowledge. Female adolescents demonstrated significantly less knowledge about HIV/AIDS compared with male adolescents, while the males reported significantly greater exposure to HIV/AIDS education compared with the females. These results suggest a need for greater HIV/AIDS education and awareness of health resources, especially among female adolescents. Education must directly address stigmatizing attitudes about HIV/AIDS, gaps in HIV/AIDS knowledge and awareness of HIV-related health resources.

Annotation: The study findings have documented the presence of HIV and sexuality-related stigmatizing attitudes among male and female high school students in New Delhi. The author used three scales to assess the presence of stigmatizing attitudes among male and female high school students: 1) Endorsing stigmatization of HIV/AIDS (9 items); 2) Refuting stigmatization of HIV/AIDS (6 items); and 3) Endorsing stigmatization of sexuality (7 items). More than one-third of the participants endorsed the statement that HIV/AIDS is a punishment from God for people who have multiple partners, and nearly a third agreed that 'People who have AIDS deserve it'. Under refuting stigmatization of HIV, more than two-thirds said that they would be willing to talk or work with someone with HIV. More than two-thirds endorsed the statements that sex outside of marriage and homosexuality are wrong. The author argues that because adolescents who endorsed most stigmatizing views towards HIV and sexuality were not necessarily those with less knowledge on HIV, education about the biology of HIV alone may not be sufficient for tackling stigma. Thus, study suggests need to focus on attitudes of students on sexuality in general. The authors recommend the use of highly trained and motivated outreach workers to teach sex education in high school classrooms as school teachers often do not want to teach sexuality education and HIV.

27. Title: Pallikadavath, S., Garda, L., Apte, H., Freedman, J., & Stones, R. W. (2005). HIV/AIDS in rural India: Context and health care needs. *Journal of Biosocial Science*, 37(5), 641-655.

Journal Abstract: Primary research on HIV/AIDS in India has predominantly focused on known risk groups such as sex workers, STI clinic attendees and long-distance truck drivers, and has largely been undertaken in urban areas. There is evidence of HIV spreading to rural areas but very little is known about the context of the infection or about issues relating to health and social impact on people living with HIV/AIDS. In-depth interviews with nineteen men and women infected with HIV who live in rural areas were used to collect experiences of testing and treatment, the social impacts of living with HIV and differential impacts on women and men. Eight focus group discussions with groups drawn from the general population in the four villages were used to provide an analysis of community level views about HIV/AIDS. While men reported contracting HIV from sex workers in the cities, women considered their husbands to be the source of their infection. Correct knowledge about HIV transmission co-existed with misconceptions. Men and women tested for HIV reported inadequate counselling and sought treatment from traditional healers as well as professionals. Owing to the general pattern of husbands being the first to contract HIV women faced a substantial burden, with few resources remaining for their own or their children's care after meeting the needs of sick husbands. Stigma and social isolation following widowhood were common, with an enforced return to the natal home. Implications for potential educational and service interventions are discussed within the context of gender and social relations.

Annotation: The study is among the few studies to cover rural areas and reports social stigma, misconceptions, lack of knowledge, and the impact of HIV on women in rural Maharashtra. The study highlights the impact of HIV on married women. Often the women lack social and economic support for treatment and care, and lack support from husband if the woman is first found to be diagnosed as HIV-positive. Sometimes, HIV-positive women are sent back to parents' home. The study recommends creation of a cadre of specialized health workers to reach women in the rural areas¹¹, it recommends developing effective service delivery model that reaches destitute and marginalized rural people, and the need for medical expertise in the rural settings for initiating and monitoring the ART.

28. Title: Rogers, A., Meundi, A., Amma, A., Rao, A., Shetty, P., Antony, J., . . . Shetty, A. K. (2006). HIV-related knowledge, attitudes, perceived benefits, and risks of HIV testing among pregnant women in rural Southern India. *AIDS Patient Care & STDs*, 20(11), 803-811.

Journal Abstract: The rising prevalence of HIV among pregnant women in rural India is of great concern. Prenatal voluntary counseling and HIV testing (VCT) is critical to prevent mother-to-child transmission of HIV (PMTCT). We surveyed 202 pregnant women attending a rural antenatal clinic in Southern India to investigate HIV-related knowledge, attitudes toward infant feeding practices, and perceived benefits and risks of HIV testing. Of the total of 202 women surveyed, 189 women (94%) had heard of HIV/AIDS and 60% of them had relatively good knowledge regarding risk factors for HIV transmission. However, 48% did not know that there are "means to prevent mother-to-child HIV transmission." If women were not to breastfeed her baby, negative attitudes expected from the partner would include 84% thinking that that the mother is harming the baby, 78% thinking she is not a good mother, 74% thinking she has HIV, and 66% thinking she has been unfaithful. Ninety-seven percent of women did not perceive themselves at risk for HIV and only 57% had been tested for HIV. Although, 85% of women expressed their willingness to be tested, most were concerned about confidentiality and disclosing HIV serostatus because of fear of negative reactions from their husbands, parents, and community. Many social and cultural barriers confront pregnant women when they decide to opt for HIV testing. If VCT and PMTCT interventions are to be successful, urgent attention must be focused on education, development of innovative culturally appropriate interventions that empower women to make decisions about

¹¹ Even before this article's publication, however, the concept of 'accredited social health activist' (ASHA) was introduced around 2004.

HIV testing, involvement of men, and addressing stigma and discriminatory attitudes toward people living with HIV/AIDS.

Annotation: This is one among the few studies conducted in rural areas that focused on understanding the knowledge about HIV, perceived benefits and risks of HIV testing, and beliefs and attitudes to breast-feeding practices among pregnant women in rural Karnataka. Findings showed high knowledge levels about HIV transmission during pregnancy, delivery, and breast feeding, but less than half were aware about the intervention to prevent mother to child transmission of HIV. Issues related to disclosure and stigma were identified as well: women were worried about confidentiality and disclosure of HIV status to others due to fear of negative reactions from their husband and parents, and the community. While women agreed that HIV-positive mothers should not breastfeed, there were fear of negative consequences if their husbands think that they are HIV-positive or unfaithful. The study recommends involving husbands in counselling HIV-positive women on infant-feeding and informing communities about the programme on prevention of mother to child transmission of HIV (PMTCT).

29. Title: Sivaram, S., Zelaya, C., Srikrishnan, A. K., Latkin, C., Go, V. F., Solomon, S., & Celentano, D. (2009). Associations between social capital and HIV stigma in Chennai, India: Considerations for prevention intervention design. *AIDS Education and Prevention*, 21(3), 233-250.

Journal Abstract: Stigma against persons living with HIV/AIDS (PLHA) is a barrier to seeking prevention education, HIV testing, and care. Social capital has been reported as an important factor influencing HIV prevention and social support upon infection. In the study, we explored the associations between social capital and stigma among men and women who are patrons of wine shops or community-based alcohol outlets in Chennai. We found that reports of social capital indicators were associated with reduced fear of transmission of HIV/AIDS, lower levels of feelings of shame, blame and judgment, lower levels of personal support and perceived community support for discriminatory actions against PLHA. Specifically, when participants reported membership in formal groups, perception of high levels of collective action toward community goals, high norms of reciprocity between neighbors and residents in daily life, and presence of trusted sexually transmitted disease care providers, all levels of measures of stigma were lower. Although we defined social capital rather narrowly in this study, our findings suggest that seeking partnerships with existing organizations and involving health care providers in future interventions may be explored as a strategy in community-based prevention interventions.

Annotation: This study, which was conducted among men and women who are patrons of wine shops in Chennai, shows strong association between social capital indicators and measures of stigma. The higher the association of an individual in social capital indicators (such as membership in formal groups – youth groups, fan clubs – in community, collective action towards community goals and norms of reciprocity between friends and neighbour) the lower the level of stigma associated with HIV. Thus, the authors that future community-based interventions aimed to reduce HIV-related stigma can explore the possibility of involving other formal groups and health care providers.

30. Title: Vyas, K. J., Patel, G. R., Shukla, D., & Mathews, W. C. (2010). A comparison in HIV-associated stigma among healthcare workers in urban and rural Gujarat. *Sahara J: Journal of Social Aspects of HIV/AIDS/Journal De Aspects Sociaux Du VIH/SIDA*, 7(2), 71-75.

Journal Abstract: The present study measures levels of stigma within health care settings in urban and rural Gujarat, in an attempt to understand how this may have contributed to the state's increasing HIV incidence. Two sites were studied: a rural hospital in Bardoli and an

urban hospital in Surat. HIV-associated stigma among healthcare workers (N=170) was assessed using a Stigma Index. Overall, analyses suggest an increase in medical education was found to be associated with higher stigmatisation ($p < 0.001$). Furthermore, a statistically significant difference between stigma scores of HCWs in rural and urban Gujarat was not observed.

Annotation: This article measures and compares the levels of HIV-related stigma within health care settings in urban and rural Gujarat. In direct contrast to the findings from another article (Mahendra et al., 2007), this article reports that an increase in medical education was associated with higher stigmatization. That is, hospital ward staff reported least stigmatizing attitudes when compared with nurses and doctors. This article suggests that in addition to improving health care providers' knowledge about HIV, trainings should also focus on increasing the acceptance of people living with HIV and sexual minorities - by focusing on value clarification and sensitising the providers on the issues of these marginalised communities.

31. Title: Zelaya, C. E., Sivaram, S., Johnson, S. C., Srikrishnan, A. K., Solomon, S., & Celentano, D. D. (2008). HIV/AIDS stigma: Reliability and validity of a new measurement instrument in Chennai, India. *AIDS and Behavior*, 12(5), 781-788. doi:10.1007/s10461-007-9331-7

Journal Abstract: HIV/AIDS stigma is a frequently cited barrier to HIV prevention, including voluntary counseling and testing. A reliable and valid measurement instrument is critical to empirically assess the extent and effects of HIV/AIDS stigma. The paper reports the development and psychometric testing of an HIV/AIDS stigma scale among 200 men in India. The resulting 24-item scale and the four subscales had good internal consistency (Cronbach's alpha overall was 0.81; subscales were 0.86, 0.73, 0.72 and 0.76, respectively). The scale and distinct subscales suggest a valid and reliable measure for HIV/AIDS stigma in a setting with highly prevalent HIV risk behaviors.

Annotation: This article presents results of development and psychometric testing of a 24-item HIV/AIDS stigma scale among relatively high risk and low income men in Chennai, India. Since this scale has been shown as reliable and valid to measure HIV/AIDS stigma among a relatively high risk male population in Chennai, it can be adapted by researchers or public health practitioners who wish to study HIV/AIDS stigma, its distribution or predictors, or who wish to evaluate the impact of HIV/AIDS stigma interventions.

32. Title: Bharat, S., Ramakrishna, J., Heylen, E., & Ekstrand, M. L. (2014). Gender-based attitudes, HIV misconceptions and feelings towards marginalized groups are associated with stigmatization in Mumbai, India. *Journal of Biosocial Science*, pp 1-16. doi: 10.1017/S0021932014000054

Journal Abstract: This study examined the association of gender-based attitudes, HIV misconceptions and community feelings for marginalized groups with stigmatizing responses towards people with HIV/AIDS in Mumbai, India. Participants included 546 men and women sampled in hospital settings during 2007–2008. Structured measures were used to assess avoidance intentions and denial of rights of people with HIV/AIDS. Mean age of participants was 32 years; 42% had less than 10 years of education. Higher HIV transmission misconceptions ($b \frac{1}{4} 0.47$; $p < 0.001$), more traditional gender attitudes ($b \frac{1}{4} 0.11$; $p < 0.01$) and more negative feelings towards HIV-positive people ($b \frac{1}{4} 0.23$; $p < 0.001$) were related to higher avoidance intentions. Endorsement of denial of rights was also significantly associated with higher transmission misconceptions ($b \frac{1}{4} 0.20$; $p < 0.001$), more traditional gender attitudes ($b \frac{1}{4} 0.33$; $p < 0.001$) and greater negative feelings towards HIV-positive people ($b \frac{1}{4} 0.12$; $p < 0.05$), as well as with a lower education level ($b \frac{1}{4} -0.10$; $p < 0.05$). The feelings respondents had towards people with HIV/AIDS were more strongly correlated

with their feelings towards those with other diseases (tuberculosis, leprosy) than with feelings they had towards those associated with 'immoral' behaviour (e.g. sex workers). Eliminating HIV transmission misconceptions and addressing traditional gender attitudes are critical for reducing HIV stigma in Indian society.

Annotation: This cross-sectional study among non-HIV-infected patients recruited from urban hospitals revealed the presence of stigmatizing responses (avoidance intentions) towards PLHIV, with HIV misconceptions and traditional gender attitudes as significant predictors. Based on the findings, the authors suggest that stigma reduction interventions need to address avoidance intentions so that these intentions are not then translated into discrimination and denial of rights of PLHIV. These findings are consistent with other studies that demonstrated that HIV transmission misconceptions and avoidance intentions are present among general public, including those who are well educated, even after nearly three decades of HIV epidemic in India. Also, the authors suggest that making the general public to understand the rights of PLHIV might help in stigma reduction. The sample being non-HIV-infected patient populations visiting urban hospitals, the findings need to be extrapolated with caution to the general public.

33. Title: Ekstrand, M. L., Ramakrishna, J., Bharat, S., & Heylen, E. (2013). Prevalence and drivers of HIV stigma among health providers in urban India: implications for interventions. *Journal of the International AIDS Society, 16(Suppl 2)*. doi:10.7448/IAS.16.3.18717

Journal Abstract:

Introduction: HIV stigma inflicts hardship and suffering on people living with HIV (PLHIV) and interferes with both prevention and treatment efforts. Health professionals are often named by PLHIV as an important source of stigma. This study was designed to examine rates and drivers of stigma and discrimination among doctors, nurses and ward staff in different urban healthcare settings in high HIV prevalence states in India.

Methods: This cross-sectional study enrolled 305 doctors, 369 nurses and 346 ward staff in both governmental and nongovernmental healthcare settings in Mumbai and Bengaluru, India. The approximately one-hour long interviews focused on knowledge related to HIV transmission, personal and professional experiences with PLHIV, instrumental and symbolic stigma, endorsement of coercive policies, and intent to discriminate in professional and personal situations that involve high and low risk of fluid exposure.

Results: High levels of stigma were reported by all groups. This included a willingness to prohibit female PLHIV from having children (55 to 80%), endorsement of mandatory testing for female sex workers (94 to 97%) and surgery patients (90 to 99%), and stating that people who acquired HIV through sex or drugs "got what they deserved" (50 to 83%). In addition, 89% of doctors, 88% of nurses and 73% of ward staff stated that they would discriminate against PLHIV in professional situations that involved high likelihood of fluid exposure, and 57% doctors, 40% nurses and 71% ward staff stated that they would do so in lowrisk situations as well. Significant and modifiable drivers of stigma and discrimination included having less frequent contact with PLHIV, and a greater number of transmission misconceptions, blame, instrumental and symbolic stigma. Participants in all three groups reported high rates of endorsement of coercive measures and intent to discriminate against PLHIV. Stigma and discrimination were associated with multiple modifiable drivers, which are consistent with previous research, and which need to be targeted in future interventions.

Conclusions: Stigma reduction intervention programmes targeting healthcare providers in urban India need to address fear of transmission, improve universal precaution skills, and involve PLHIV at all stages of the intervention to reduce symbolic stigma and ensure that relevant patient interaction skills are taught.

Annotation: This cross-sectional study was conducted among health care professionals in urban health care settings in two high HIV prevalence states. This study focused on knowledge related to HIV transmission, experiences of personal and professional interactions with PLHIV, instrumental and symbolic stigma, endorsement of coercive policies and intent to discriminate in professional and personal situations that involve exposure to fluids with high and low HIV risk. The study findings revealed inadequate knowledge about HIV transmission even among professional healthcare providers (doctors and nurses). The results showed that more negative feelings towards PLHIV, higher work-related instrumental stigma and less professional contact with PLHIV were associated with higher odds of discriminatory intentions. The healthcare providers endorsed mandatory HIV testing for female sex workers and surgery patients, and also endorsed statements that denied PLHIV their rights to marriage and having children. The authors recommend stigma reduction interventions among healthcare providers: focusing on universal precautions; addressing misconceptions related to HIV transmissions; and safeguarding the rights of PLHIV in all aspects, including right to marriage and having children.

34. Title: Bharat, S. (2011). A systematic review of HIV/AIDS-related stigma and discrimination in India: Current understanding and future needs. *SAHARA-J: Journal of Social Aspects of HIV/AIDS*, 8:3, 138-149. doi:10.1080/17290376.2011.9724996

Journal 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.

Annotation: Thirty articles on HIV/AIDS stigma were reviewed with the objective of examining the status of research, summarizing key findings and identifying gaps. The articles reviewed included conceptual articles and articles on stigma assessment, stigma measures and stigma reduction interventions. The review found that majority of the studies have documented negative attitudes among general public towards PLHIV, PLHIV being blamed for their HIV status, fear of contagion due to casual contact with PLHIV and avoidance intentions towards PLHIV. It also identified that there is limited literature on designing and testing evidence-based stigma reduction interventions, especially in the family and community settings. The author suggested the need for context-specific stigma reduction interventions, including those that could address structural issues. A vital gap as identified by the author was the lack of interventions to address various forms of stigma - layered, courtesy and internalized stigma. Another gap identified by the author was the knowledge gap on stigma faced by IDUs, TG populations and children who are HIV-positive

or are born to PLHIV. The author recommends a strong and comprehensive national stigma research agenda, which also focuses on evidence-based stigma reduction interventions.

35. Title: Catalani, C., Castaneda, D. & Spielberg, F. (2013). Development and assessment of traditional and innovative media to reduce individual HIV/AIDS-related stigma attitudes and beliefs in India. *Frontiers in Public Health, Volume 1*, doi:10.3389/fpubh.2013.00021

Journal Abstract: Although stigma is considered a major barrier to effective response to the HIV/AIDS epidemic, there is a lack of evidence on effective interventions. This media intervention took place among key HIV-vulnerable communities in Southern India. Two HIV stigma videos were created using techniques from traditional film production and new media digital storytelling. A series of 16 focus group discussions were held in 4 rural and 4 urban sites in South India, with specific groups for sex workers, men who have sex with men, young married women, and others. Focus groups with viewers of the traditional film (8 focus groups, 80 participants) and viewers of the new media production (8 focus groups, 69 participants) revealed the mechanisms through which storyline, characters, and esthetics influence viewers' attitudes and beliefs about stigma. A comparative pre-/post-survey showed that audiences of both videos significantly improved their stigma scores. We found that a simple illustrated video, produced on a limited budget by amateurs, and a feature film, produced with an ample budget by professionals, elicited similar responses from audiences and similar positive short-term outcomes on stigma.

Annotation: This is a mixed methods study conducted in four rural and four urban settings and used focus groups and quantitative assessments of intervention. Two media interventions (feature film and illustrated video) to address HIV-related stigma were developed and tested among key populations (FSWs, MSM, young married women and married men). The interventions were designed taking into account cultural relevance and believability of storyline, perceived susceptibility, relevance and attitudes related to stigma, identification and empathy with main characters and video esthetics. One group of participants viewed the feature film and the other the illustrated video. The findings indicated that both interventions had almost equal but significant impact on audiences by decreasing HIV-related stigma attitudes and beliefs among viewers. Thus, the authors concluded that the message effectiveness is more crucial than the professional production standards or celebrity engagement. This led the authors to also speculate that production of effective videos to address HIV stigma through innovative media production techniques is possible, even with minimally trained staff and limited funding.

36. Title: Vlassoff, C., Weiss, M. G., & Rao. S. (2013). A question module for assessing community stigma towards HIV in rural India. *Journal of Biosocial Science, 45*, 359-374. doi:10.1017/S0021932012000697

Journal Abstract: This paper describes a simple question module to assess community stigma in rural India. Fear of stigma is known to prevent people from seeking HIV testing and to contribute to further disease transmission, yet relatively little attention has been paid to community stigma and ways of measuring it. The module, based on a vignette of a fictional HIV-positive woman, was administered to 494 married women and 186 unmarried male and female adolescents in a village in rural Maharashtra, India. To consider the usefulness of the question module, a series of hypotheses were developed based on the correlations found in other studies between HIV-related stigma and sociodemographic characteristics (age, education, discussion of HIV with others, knowing someone living with HIV, knowledge about its transmission and whether respondents acknowledged stigmatizing attitudes as their own or attributed them to others). Many of the study's hypotheses were confirmed. Among married women, correlates of stigma included older age, lack of discussion of HIV and lack of knowledge about transmission; among adolescents, lower education and lack of discussion of HIV were the most significant correlates. The paper concludes that the

question module is a useful tool for investigating the impact of interventions to reduce stigma and augment social support for people living with HIV in rural India.

Annotation: This study was conducted among married women and adolescent boys and girls from rural setting. Both the groups - adolescents and married women - were considered to be at high risk for HIV infection, and findings from these two groups were compared with older married women who were presumed to be at lower risk of HIV. The study assessed a vignette-based module that used simple questions to assess the presence of community stigma towards HIV-positive persons. The authors claim that many of their *a priori* hypotheses were confirmed. For example, among the married women, the older women expressed more stigma than the younger women; and adolescents with lower education expressed higher stigma than those relatively higher education. The authors recommend that this module to assess community stigma could be useful in evaluating the impact of stigma reduction interventions. However, to compare sex differences in people's responses, this instrument can also be tested with vignette of a fictional HIV-positive man in the rural setting, and also be tested among married men of different age groups.

37. Title: Shivalli, S. (2014). Occupational Exposure to HIV: Perceptions and Preventive Practices of Indian Nursing Students. *Advances in Preventive Medicine*, 2014, 1-5. doi: 10.1155/2014/296148

Abstract:

Introduction: Nurses have a frontier caring role that brings them in close contact with patients' blood and body fluids. An understanding of their professional behavior is essential to assess and minimize the occupational exposure to HIV among them.

Objectives: (1) To appraise the knowledge, attitudes, and preventive practices of nursing students pertaining to occupational exposure to HIV. (2) To quantify the risk and correlates of exposure to HIV among them.

Methodology: Cross-sectional study was conducted in a nursing college of Varanasi, India. A semistructured and pretested pro forma consisting of questions pertaining to modes of HIV transmission, universal precaution practices, and various aspects of nursing HIV patients was utilized. Independent sample *t*- and *z*-tests were applied to judge the association of study variables with the knowledge and risk of HIV.

Results: The study sample consisted of 87 female and 16 male nurses. Participants' knowledge of HIV transmission was satisfactory. More than 80% of them had an exposure to blood/body fluid in the last year. Exposure rates for blood/body fluid did not show a significant association ($P > 0.05$) with study variables.

Conclusion: There were serious lacunae in implementation of the universal precautions despite satisfactory knowledge. Reinforcement of universal precautions is required.

Annotation: This cross-sectional study was conducted among female and male nursing students in an urban setting. The study assessed the knowledge of HIV transmission and past occupational exposure to potentially HIV-containing fluids and examined the association between HIV transmission knowledge and occupational risk of HIV. The findings revealed satisfactory knowledge of HIV transmission. However, almost all the participants preferred HIV testing for all inpatients so that then they can take safety precautions based on patients' HIV status, clearly a behaviour or intention that was not seen as discriminatory by these students. The author suggests capacity building among nursing students to strengthen their practice of universal precautions.

III. Female Sex Workers

38. Title: Argento, E., Reza-Paul, S., Lorway, R., Jain, J., Bhagya, M., Fathima, M., . . . O'Neil, J. (2011). Confronting structural violence in sex work: Lessons from a community-led HIV prevention project in Mysore, India. *AIDS Care*, 23(1), 69-74.

Journal Abstract: Evidence from community-led HIV prevention projects suggests that structural interventions may result in reduced rates of HIV and STIs. The complex relationship between empowerment and confronting stigma, discrimination and physical abuse necessitates further investigation into the impact that such interventions have on the personal risks for sex workers. This article aims to describe lived experiences of members from a sex worker's collective in Mysore, India and how they have confronted structural violence. The narratives highlight experiences of violence and the development and implementation of strategies that have altered the social, physical, and emotional environment for sex workers. Building an enabling environment was key to reducing personal risks inherent to sex work, emphasizing the importance of community-led structural interventions for sex workers in India.

Annotation: This study narrates the experiences of community-led structural intervention (CLSI) of sex workers in confronting structural violence; advocating with police, building support from boyfriends and brokers, and negotiating protective strategies with lodge owners and male clients. Collective strength of sex workers is claimed to have resulted in challenging unequal power balances and reduced violence and human rights violations they faced from police, boyfriends, brokers, lodge-owners and clients. Thus, the study presents CLSI as an effective approach to empower women in sex work.

39. Title: Blankenship, K. M., Biradavolu, M. R., Jena, A., & George, A. (2010). Challenging the stigmatization of female sex workers through a community-led structural intervention: Learning from a case study of a female sex worker intervention in Andhra Pradesh, India. *AIDS Care*, 22(Suppl 2), 1629-1636. doi:<http://dx.doi.org/10.1080/09540121.2010.516342>

Journal Abstract: Structural interventions represent a potentially powerful approach to HIV prevention among female sex workers (FSW) that focus on changing the social context of risk rather than individual behavior. Community-led structural interventions (CLSI) represent a particular form of structural interventions whereby the collective energy of FSW is directed toward action to address the contextual factors that promote their risk. Among these different contextual factors that may be the target of CLSI, are social norms that stigmatize FSW and their work. Drawing from ethnographic data collected as part of an ongoing analysis of the implementation and impact of a CLSI in coastal Andhra Pradesh, India, we present a case study of the challenges and opportunities faced by a CLSI seeking to confront stigmatization of FSW through its interactions with a government-sponsored AIDS education program targeted to the general public. The government program promoted slogans that stigmatized FSW by attributing HIV/AIDS to them. Through participation in the program, the CLSI was complicit in promoting this same stigmatization. Yet it also used participation in the program as an opportunity to raise awareness among FSW of the CLSI and to mobilize FSW. In addition, the CLSI organized an alternative public rally, outside of but parallel to the government program, where they reframed FSW not as the carriers of HIV but as public health workers combating it. With this case study, we suggest that CLSI for HIV prevention among FSW are implemented in a context of inequality that constrains their actions, but they can still employ strategies that have the potential to transform that context.

Annotation: The study presents the case study of a community-led structural intervention (CLSI) that used collective identity and collective action to confront health education messages on HIV prevention that contained stigmatizing messages about sex workers.

Raising collective consciousness, the CLSI decided to counter those negative messages by being part of spreading health education messages on HIV prevention, and by organizing a parallel rally that presented positive images of sex workers. Sex workers interacted with police and other government officials to change their negative perceptions about sex workers. Thus, this study shows that sex workers have agency and act for themselves, and appropriate support needs to be available for the same.

40. Title: Biradavolu, M.R., Burris, S., George, A., Jena, A., Blankenship, K.M. (2009). Can sex workers regulate police? Learning from an HIV prevention project for sex workers in Southern India. *Social Science & Medicine* 68 , 1541–1547

Journal Abstract: There is an argument that policing practices exacerbate HIV risk, particularly for female sex workers. Interventions that mobilize sex workers to seek changes in laws and law enforcement practices have been prominent in India and have received considerable scholarly attention. Yet, there are few studies on the strategies sex worker advocates use to modify police behavior or the struggles they face in challenging state institutions. This paper draws upon contemporary theories of governance and non-state regulation to analyze the evolving strategies of an HIV prevention non-governmental organisation (NGO) and female sex worker community-based organizations (CBOs) to reform police practices in southern India. Using detailed ethnographic observations of NGO and CBO activities over a two year period, and key informant interviews with various actors in the sex trade, this paper shows how a powerless group of marginalized and stigmatized women were able to leverage the combined forces of community empowerment, collective action and network-based governance to regulate a powerful state actor, and considers the impact of the advocacy strategies on sex worker well-being.

Annotation: The study presents the strategies adopted by female sex workers to counter the police who treated sex workers as persons engaging in immoral behaviour, and as a threat to social order. An NGO identified social change Agents (SCA) from the sex workers community and trained them as peer educators and community mobilizers, and helped establishing community-based organisations of sex workers. The NGO organized interactive sessions for police to create an enabling environment, and developed a Crisis Intervention Team involving government officials, politicians, lawyers, human rights activists, and media to counter the discriminatory practices of police and regulate their behaviours.

41. Title: Cornish, F. (2006). Challenging the stigma of sex work in India: material context and symbolic change. *Journal of Community and Applied Social Psychology*, 16(6).

Journal Abstract: Stigmatization and discrimination against social groups raise obstacles to the participation of their members in community interventions. Internalized stigma and a lack of empowering experiences promote fatalistic expectations that little can be achieved. This paper discusses how the Sonagachi Project in Kolkata, India, challenges stigma as part of its community development and health promotion efforts with sex workers, drawing on interviews with 19 sex workers involved in the Project and one group discussion among the Project's leaders. The internalized stigma of prostitution is challenged (1) by asserting that sex workers have rights which should be respected, (2) by claiming equivalence to other oppressed but politically successful groups and (3) by providing evidence of sex workers' positive achievements. These arguments are made plausible to sex workers by a material context that provides evidence and experience of the possibility of change. I conclude that interventions designed to problematize stigma and discrimination should back up the conceptual alternatives that they present by producing concrete changes to a community's living conditions.

Annotation: The findings show that presence of stigma against sex work results in widespread discrimination against them, and presence of self-stigma acts a barrier in

mobilizing sex workers. The study shows how sex workers have succeeded in overcoming stigma and realised their rights. Thus, this article argues that HIV interventions among sex workers should also address stigma and discrimination through rights-based approach.

42. Title: Chakrapani, V., Newman, P. A., Shunmugam, M., Kurian, A. K., & Dubrow, R. (2009). Barriers to free antiretroviral treatment access for female sex workers in Chennai, India. *AIDS Patient Care & STDs*, 23(11), 973-980.

Journal Abstract: India's National AIDS Control Organization (NACO) provides free first-line antiretroviral treatment (ART) at government centres for people living with HIV. To assist in developing policies and programs to ensure equity in ART access, we explored barriers to ART access among female sex workers (FSWs) living with HIV in Chennai. Between August and November 2007, we conducted three focus group discussions and two key informant interviews. Data were explored using framework analysis to identify categories and derive themes. We found interrelated barriers at the family/social, health care system/programmatic, and individual levels. Major barriers included fear of adverse consequences of disclosure of HIV status due to stigma and discrimination associated with HIV and sex work, lack of family support, negative experiences with health care providers, lack of adequate counselling services at government centres and by outreach workers employed by nongovernmental organizations (NGOs), perceived biased treatment of FSWs who are not referred by NGOs, lack of adequate knowledge about ART, and fatalism. Barriers can be addressed by: creating effective measures to reduce stigma associated with HIV/AIDS and sex work at the familial, societal, and health care system levels; incorporating information about ART into targeted interventions among FSWs; training counsellors at government hospitals and NGO outreach workers on treatment issues; improving infrastructure and staffing levels at government centers to allow adequate time and privacy for counselling; and implementing government mass media campaigns on ART availability. Finally, it is crucial that NACO begin monitoring ART coverage of FSWs and other marginalized populations to ensure equitable ART access.

Annotation: This is the first published study to explore barriers to ART among positive Female Sex Workers (FSWs) in Chennai. HIV-positive FSWs face dual stigmas of being a sex worker and being HIV-positive. Disclosure of HIV status to the family often amounts to disclosure of their sex work and result in discrimination; rejection by family, domestic violence, and isolation. HIV-positive FSWs do not want to disclose their HIV status with other FSWs for fear of losing potential clients and thus loss of income. Lack of adequate information about ART, fatalism, and discrimination faced from the health care providers - all pose barriers to access. The study recommends that accurate information on ART needs to be provided in targeted interventions, and measures need to be taken to reduce stigma at family, society and health care settings.

43. Title: Liu, S., Srikrishnan, A. K., Zelaya, C. E., Solomon, S., Celentano, D. D., & Sherman, S. G. (2011). Measuring perceived stigma in female sex workers in Chennai, India. *AIDS Care*, 23(5), 619-627. doi:<http://dx.doi.org/10.1080/09540121.2010.525606>

Journal Abstract: Although sex work is highly stigmatized throughout the world, a limited body of research has examined stigma among female sex workers (FSWs). We developed a Sex Worker Stigma (SWS) Index to measure perceived stigma among 150 FSWs in Chennai, India. These women were at a median age of 35 years and reported, on average, having engaged in sex work for nine out of the previous 12 months. The two-factor structure of the index was verified in both exploratory and confirmatory factor analyses with acceptable goodness of fit. The final 10-item index comprises of two domains of perceived stigma from the community and perceived stigma from one's family. Cronbach's α coefficients were 0.87 and 0.88 for each domain, respectively. In regression analysis, we

found that income from jobs other than sex work was correlated with decreased levels of perceived stigma from both the community ($b = 0.16$; 95% CI: (0.30 and 0.02) and the family ($b = 0.24$; 95% CI: (0.40 and 0.07); prior experience of accessing health care system increased perceived stigma from the community while heavier financial responsibility for the family was associated with lower perceived stigma from women's family. With the proposed SWS Index, we have a valid and reliable metric to document and track levels of perceived stigma among FSWs to assess the impact of stigma reduction interventions.

Annotation: The study tested and validated a psychometric tool, a 10-item index to quantify female sex worker (FSW) perception of Sex Work Stigma (SWS) in two domains: felt stigma from community and family. The findings indicate that financial independence/dependence mediates the way sex workers interpret perceived stigma. For example, higher monthly income was associated with lower level of perceived stigma. The tool measured perceived stigma related to sex work, and did not cover other forms of stigma like enacted stigma, and stigma associated with HIV. This SWS index can be adapted and tested among other subgroups of FSWs such as brother-based sex workers and 'mobile' or 'floating' sex workers.

44. Title: Misra, G., Mahal, A., & Shah, R. (2000). Protecting the rights of sex workers: The Indian experience. *Health & Human Rights*, 5(1), 88-115.

Journal Abstract: Although India is a signatory to numerous international agreements on the rights of women and has a constitution that prohibits discrimination and exploitation by gender, as well as a plethora of related legislation, it has failed to satisfactorily protect the human rights of women, particularly those of sex workers. This is manifested in high levels of violence in the sex industry, child sex workers, lack of access to health care, and high levels of HIV infection. Policies that revolve around rescue and rehabilitation, or are based on the premise that sex work is immoral, are unlikely to effectively promote the well-being of sex workers. An alternative paradigm, which revolves around an explicit recognition of the human rights of sex workers together with an activist approach to achieve them, involving collaboration between NGOs and collectives of sex workers, has worked well to protect the human rights and health of sex workers in India.

Annotation: The study presents case studies of two sex work collectives that operate in different locations in India. The study has documented the approaches used by sex worker collectives to challenge ambiguous legislation, and stigmatizing and negative societal constructs. The study recommends that interventions should consider two key aspects: the context in which sex workers operate and the challenges they face; and restructuring the stigmatized image of sex workers.

45. Title: Shahmanesh, M., Wayal, S., Andrew, G., Patel, V., Cowan, F. M., & Hart, G. (2009). HIV prevention while the bulldozers roll: Exploring the effect of the demolition of goa's red-light area. *Social Science & Medicine*, 69(4), 604-612.

Journal Abstract: Interventions targeting sex-workers are pivotal to HIV prevention in India. Community mobilisation is considered by the National AIDS Control Programme to be an integral component of this strategy. Nevertheless societal factors, and specifically policy and legislation around sex-work, are potential barriers to widespread collectivisation and empowerment of sex-workers. Between November 2003 and December 2005 we conducted participatory observation and rapid ethnographic mapping with several hundred brief informant interviews, in addition to 34 semi-structured interviews with key-informants, 16 in-depth interviews with female sex-workers, and 3 focus-group-discussions with clients and mediators. This provides a detailed examination of the demolition of Baina, one of India's large red-light areas, in 2004, and one of the first accounts of the effect of dismantling the

red-light area on the organisation of sex-work and sex-workers' sexual risk. The results suggest that the concentrated and homogeneous brothel-based sex-work environment rapidly evolved into heterogeneous, clandestine and dispersed modes of operation. The social context of sex-work that emerged from the dust of the demolition was higher risk and less conducive to HIV prevention. The demolition acted as a negative structural intervention; a catastrophic event that fragmented sex-workers' collective identity and agency and rendered them voiceless and marginalised. The findings suggest that an abolitionist approach to sex work and legislation or policy that either criminalises this large group of women, or renders them as invisible victims, will increase the stigma and exclusion they experience. For the targeted HIV prevention approaches advocated by the National AIDS Control Programme to be effective, there is a need for legislation and policy that supports sex-workers' agency and self-organisation and enables them to create a safer working environment for themselves.

Annotation: This study is a detailed account of government's decision and actions in dismantling a 'red-light area' in an apparently good intent of 'rehabilitation' of sex workers and to counter trafficking of women. However, the government actions were shown to have actually resulted in loss of collective identity of sex workers, loss of income, increased violence, increased competition among sex workers and consequent increase risk of HIV. The study concludes that supportive legislation and policies are needed in relation to sex work and to protect their rights.

46. Title: Swain, S.N., Saggurti, N., Battala, M., Verma, R.K., Jain, A.K. (2011). Experience of violence and adverse reproductive health outcomes, HIV risks among mobile female sex workers in India. *BMC Public Health* 2011, 11:357. Retrieved from <http://www.biomedcentral.com/content/pdf/1471-2458-11-357.pdf>

Abstract: Female sex workers (FSWs) are a population sub-group most affected by the HIV epidemic in India and elsewhere. Despite research and programmatic attention to FSWs, little is known regarding sex workers' reproductive health and HIV risk in relation to their experiences of violence. This paper therefore aims to understand the linkages between violence and the reproductive health and HIV risks among a group of mobile FSWs in India. **Methods:** Data are drawn from a cross-sectional behavioural survey conducted in 22 districts from four high HIV prevalence states (Andhra Pradesh, Karnataka, Maharashtra, Tamil Nadu) in India between September 2007 and July 2008. The survey sample included 5,498 FSWs who had moved to at least two different places for sex work in the past two years, and are classified as mobile FSWs in the current study. Analyses calculated the prevalence of past year experiences of violence; and adjusted logistic regression models examined the association between violence and reproductive health and HIV risks after controlling for background characteristics and program exposure. **Results:** Approximately one-third of the total mobile FSWs (30.5%, n = 1,676) reported experiencing violence at least once in the past year; 11% reported experiencing physical violence, and 19.5% reported experiencing sexual violence. Results indicate that FSWs who had experienced any violence (physical or sexual) were significantly more likely to be vulnerable to both reproductive health and HIV risks. For example, FSWs who experienced violence were more likely than those who did not experience violence to have experienced a higher number of pregnancies (adjusted odds ratio [OR] = 1.2, 95% confidence interval [CI] = 1.0-1.6), ever experienced pregnancy loss (adjusted OR = 1.4, 95% CI = 1.2-1.6), ever experienced forced termination of pregnancy (adjusted OR = 2.4, 95% CI = 2.0-2.7), experienced multiple forced termination of pregnancies (adjusted OR = 2.2, 95% CI = 1.7-2.8), and practice inconsistent condom use currently (adjusted OR = 1.97, 95% CI: 1.4-2.0). Among FSWs who experienced violence, those who experienced sexual violence were more likely than those who had experienced physical violence to report inconsistent condom use (adjusted OR = 1.8, 95% CI: 1.4-2.3), and experience STI symptoms (adjusted OR = 1.3, 95% CI: 1.1-1.7). **Conclusion:** The pervasiveness of violence and its association with reproductive health and HIV risk highlights

that the abuse in general is an important determinant for reproductive health risks; and sexual violence is significantly associated with HIV risks among those who experienced violence. Existing community mobilization programs that have primarily focused on empowering FSWs should broaden their efforts to promote reproductive health in addition to the prevention of HIV among all FSWs, with particular emphasis on FSWs who experienced violence.

Annotation: This study is amongst the first to examine the relationship between the experience of violence and reproductive health and HIV risks among 'mobile' FSWs in India. The study recommends that structural factors at the individual, community and society need to be changed to facilitate an enabling environment to improve the reproductive and sexual health of female sex workers.

IV. Men who have Sex with Men and Transgender People

47. Title: Chakrapani, V., Newman, P. A., Shunmugam, M., McLuckie, A., & Melwin, F. (2007). Structural violence against kothi-identified men who have sex with men in Chennai, India: A qualitative investigation. *AIDS Education and Prevention*, 19(4), 346-364. doi:<http://dx.doi.org/10.1521/aeap.2007.19.4.346>

Journal Abstract: This qualitative investigation explored the experiences and contexts of stigma and discrimination among HIV-positive and high-risk kothi-identified men who have sex with men (MSM) in Chennai, India, and ramifications for HIV prevention. MSM were recruited through community agencies (n = 10) and public sex environments (n = 8), along with three key informants. In-depth, semi-structured interviews were conducted, audiotaped, and transcribed. Narrative thematic analysis and a constant comparative method were used to identify themes. Findings revealed multiple intersecting social and institutional contexts and experiences of stigmatization, discrimination, and violence across police, community, family, and health care systems, as well as illuminating consequences for MSM. Multi-systemic structural violence places kothis at extreme vulnerability for HIV infection and AIDS. Public mass media antidiscrimination campaigns, education and training of health care providers and police, funding of indigenous MSM community organizations, and decriminalization of consensual sex between same-sex adults may help to combat stigma, discrimination, and violence against MSM, which is fundamental to effective HIV prevention.

Annotation: This article highlights that stigma and discrimination against kothi-identified MSM may need to be explored as a product of structural and social factors, as opposed to traditional models that focus on stigma as an individual-level phenomenon. Thus the findings from this article suggest the need to: 1) decriminalize same-sex relations among consenting adults; 2) educate police on the rights of sexual minorities; and 3) design and implement programs for health care providers, both to counteract ignorance and end outright prejudice and discrimination. Structural violence is the organising concept for this article and internalised stigma has not been dealt within this article. This qualitative study focuses only on kothi-identified MSM and thus studies are needed among other subgroups of MSM to test and adapt this model.

48. Title: Chakrapani, V., Newman, P. A., & Shunmugam, M. (2008). Secondary HIV prevention among kothi-identified MSM in Chennai, India. *Culture, Health & Sexuality*, 10(4), 313-327. doi:<http://dx.doi.org/10.1080/13691050701816714>

Journal Abstract: This study explored experiences and contexts of HIV risk and prevention among HIV-positive kothi-identified men in Chennai, India. In-depth, semi-structured interviews were conducted with 10 HIV-positive men and three service providers, recruited using purposive sampling. Interviews were audio-taped, transcribed in Tamil and translated

into English. Data were analysed using a narrative thematic approach and constant comparative method. Misconceptions about HIV transmission; cultural taboos around discussing sexual behaviour and HIV; stigma related to same-sex behaviour; harassment; and the criminalization of consensual sex between men present formidable challenges to HIV prevention. Frank and open discussion about male-to-male sexual behaviour and living with HIV, which may support health and HIV prevention, may be dangerous in the context of pervasive risks due to stigmatization, violence and criminalization. Instead, culturally appropriate, multi-level interventions developed in collaboration with community stakeholders are needed to support HIV prevention among kothi-identified men in South India.

Annotation: This study provides insight on how stigma related to same-sex sexual behaviour, harassment and criminalization of consensual sex between men act as strong deterrent in adapting and sustaining safer sex practices among HIV-positive kothi-identified MSM in Chennai, India.

This study has highlighted the various challenges for secondary HIV prevention among HIV-positive kothi-identified MSM in Chennai, including barriers to condom use, difficulties with sexual negotiation and self-disclosure of HIV status, fear of partner and societal rejection, HIV-related stigma and sexual prejudice. Findings from this study also show that there is a lack of discussion about sexual behaviour and safer sex with HIV-positive MSM by the health care providers. The authors note that sometimes it is not clear whether stigma and discrimination faced by HIV-positive MSM are due to their HIV-positive status or because of their same-sex sexual behaviour. This article stressed the need to develop culturally relevant prevention interventions for HIV-positive kothi-identified MSM and the need for health care providers to address same-sex/bisexual behaviours in their counselling or clinical sessions that might help MSM living with HIV to openly discuss about both their sexuality issues and sexual practices.

49. Title: Chakrapani, V., Newman, P. A., & Shunmugam, M., & Dubrow, R. (2011). Barriers to free antiretroviral treatment access among kothi-identified men who have sex with men and aravanis (transgender women) in Chennai, India. *AIDS Care*. First published on: 14 June 2011 (iFirst). **DOI:** 10.1080/09540121.2011.582076

Journal Abstract: The Indian government provides free antiretroviral treatment (ART) for people living with HIV. To assist in developing policies and programs to advance equity in ART access, we explored barriers to ART access among kothis (men who have sex with men [MSM] whose gender expression is feminine) and aravanis (transgender women, also known as hijras) living with HIV in Chennai. In the last quarter of 2007, we conducted six focus groups and four key-informant interviews. Data were explored using framework analysis to identify categories and derive themes. We identified barriers to ART access at the family/social-level, health care system-level, and individual-level; however, we found these barriers to be highly interrelated. The primary individual-level barrier was integrally linked to the family/social and health care levels: many kothis and aravanis feared serious adverse consequences if their HIV-positive status were revealed to others. Strong motivations to keep one's HIV-positive status and same-sex attraction secret were interconnected with sexual prejudice against MSM and transgenders, and HIV stigma prevalent in families, the health care system, and the larger society. HIV stigma was present within kothi and aravani communities as well. Consequences of disclosure, including rejection by family, eviction from home, social isolation, loss of subsistence income, and maltreatment (although improving) within the health care system, presented powerful disincentives to accessing ART. Given the multi-level barriers to ART access related to stigma and discrimination, interventions to facilitate ART uptake should address multiple constituencies: the general public, health care providers, and the kothi and aravani communities. India needs a national policy and action plan to address barriers to ART

access at family/social, health care system, and individual levels for aravanis, kothis, other subgroups of MSM and other marginalized groups.

Annotation: This article has highlighted that even though antiretroviral treatment is available for free in the government hospitals, barriers at several levels (family/social-level, health care system-level, and individual-level) deter HIV-positive kothi-identified MSM and aravanis from accessing HIV treatment-related services. The article provides evidence that within their own communities, MSM and aravanis living with HIV are discriminated. In addition, discrimination faced in the health care settings also discourages some kothis and aravanis from accessing the services. The findings point out the need to address multiple constituencies (the general public, health care providers and kothi/aravani communities) to decrease stigma faced by HIV-positive MSM and TG people.

50. Title: Misra, G. (2009). Decriminalising homosexuality in India. *Reproductive Health Matters*, 17(34), 20-28.

Journal Abstract: This paper examines the successful fight against the provision in Section 377 of the Penal Code of India that criminalised private consensual sex between adults of the same sex. This law had led to serious discrimination against people engaging in homosexual acts, who were subjected to frequent beatings and blackmail attempts by police, who used the threat of prosecution against them. NGOs working with sexual minorities have also been harassed and sometimes charged under Section 377. By stigmatising homosexuality and threatening gay men with prison, the law is also likely to have impeded the battle against HIV. The provision was read down in July 2009 after an innovative, sustained, mass media campaign by activists. The Voices Against 377 coalition brought together sexuality and lesbian, gay, bisexual and transgender (LGBT) organisations, who were previously marginalised, with groups working in areas such as children's rights and feminist groups, showing that support for non-discrimination towards sexual minorities was broad-based. Further legal and social changes are needed for LGBT individuals to gain full acceptance and equality within Indian society. However, the judgement transcended the LGBT issue with the implication of protection for all minorities and introduced for the first time in South Asia the idea of sexual citizenship.

Annotation: This review article narrates the history of Section 377, its enforcement in India, its impact on the lives of sexual minorities and how communities successfully advocated reading down of Section 377 and what further changes are needed to achieve the desired legal and social changes for sexual minorities to gain full acceptance and equality within the society. The article provides evidence (citing Gupta et al., 2006¹²) for how Section-377 was used to exploit same-sex attracted people and how criminalisation of consensual adult same-sex relationships interferes with providing HIV prevention services to vulnerable MSM coming to cruising sites. The author notes that legal reform alone may not be sufficient as there is a need for changes in the societal attitudes towards same-sex sexualities.

51. Title: Solomon, S. S., Mehta, S. H., Latimore, A., Srikrishnan, A. K., & Celentano, D. D. (2010). The impact of HIV and high-risk behaviours on the wives of married men who have sex with men and injection drug users: Implications for HIV prevention. *Journal of the International AIDS Society*, 13 Suppl 2(Suppl 2), S7.

Journal Abstract: Background: HIV/AIDS in India disproportionately affects women, not by their own risks, but by those of their partners, generally their spouses. We address two marginalized populations at elevated risk of acquiring HIV: women who are married to men

¹² Gupta, A. (2006). Section 377 and the dignity of Indian homosexuals. *Economic and Political Weekly*. 18 November 2006.

who also have sex with men (MSM) and wives of injection drug users (IDUs). Methods: We used a combination of focus groups (qualitative) and structured surveys (quantitative) to identify the risks that high-risk men pose to their low-risk wives and/or sexual partners. Married MSM were identified using respondent-driven recruitment in Tamil Nadu, India, and were interviewed by trainer assessors. A sample of wives of injection drug users in Chennai were recruited from men enrolled in a cohort study of the epidemiology of drug use among IDUs in Chennai, and completed a face-to-face survey. Focus groups were held with all groups of study participants, and the outcomes transcribed and analyzed for major themes on family, HIV and issues related to stigma, discrimination and disclosure. Results: Using mixed-methods research, married MSM are shown to not disclose their sexual practices to their wives, whether due to internalized homophobia, fear of stigma and discrimination, personal embarrassment or changing sexual mores. Married MSM in India largely follow the prevailing norm of marriage to the opposite sex and having a child to satisfy social pressures. Male IDUs cannot hide their drug use as easily as married MSM, but they also avoid disclosure. The majority of their wives learn of their drug-using behaviour only after they are married, making them generally helpless to protect themselves. Fear of poverty and negative influences on children were the major impacts associated with continuing drug use. Conclusions: We propose a research and prevention agenda to address the HIV risks encountered by families of high risk men in the Indian and other low- and middle-income country contexts.

Annotation: This article has shown that stigma related to HIV and fear of negative consequences due to disclosure of one's sexual practices and HIV status pose risk of HIV transmission to the women partners of MSM and IDUs. Thus, in the context of prevention of HIV transmission self-stigma related to both HIV status and sexual practices need to be addressed.

52. Title: Thompson, L. H., Khan, S., du Plessis, E., Lazarus, L., Reza-Paul, S., Hafeez Ur Rahman, S., . . . Lorway, R. (2013). Beyond internalised stigma: daily moralities and subjectivity among self-identified kothis in Karnataka, South India. *Cult Health Sex*, 15(10), 1237-1251. doi: 10.1080/13691058.2013.818714

Journal Abstract: The Bill and Melinda Gates Foundation has poured a tremendous amount of resources into epidemic prevention in India's high HIV prevalence zones, through their Avahan initiative. These community-centred programmes operate under the assumption that fostering community-based organisational development and empowering the community to take charge of HIV prevention and education will help to transform the wider social inequalities that inhibit access to health services. Focusing on the South Indian state of Karnataka, this paper explores a troubling set of local narratives that, we contend, hold broader implications for future programme planning and implementation. Although confronting stigma and discrimination has become a hallmark in community mobilisation discourse, communities of self-identified kothis (feminine men) who were involved in Avahan programme activities continued to articulate highly negative attitudes about their own sexualities in relation to various spheres of social life. Rather than framing an understanding of these narratives in psychological terms of 'internalized stigma', we draw upon medical anthropological approaches to the study of stigma that emphasise how social, cultural and moral processes create stigmatising conditions in the everyday lives of people. The way stigma continues to manifest itself in the self-perceptions of participants points to an area that warrants critical public health attention.

Annotation: This qualitative article aimed to frame the negative attitudes of kothis (apparently the study had included both kothi-identified feminine MSM and kothi-identified male-to-female transgender people) towards their own sexualities from a medical anthropological perspective emphasising how social, cultural and moral processes lead to such negative attitudes towards self. Consistent with the findings from other qualitative

studies among kothis in other cities, the paper reported family as a key place where heteronormativity is enforced, gender expression transgressions are not tolerated, and marriage is seen as a norm once men reach a certain age. Negative attitudes towards self among kothis were described in terms of seeing oneself as 'abnormal' and seeing one's sexuality as a 'habit' or 'addiction'. The paper also highlighted that non-disclosure of one's sexuality could not only be seen as a way to prevent discrimination but also to avoid bringing shame and dishonour to one's family. Moreover, getting married to a woman was seen as a way to prove one's masculinity, and offering a cover to protect one's same-sex attraction/behavior, as revealed in other studies. Framed in these ways, the paper seems to have attained its stated goal of framing kothis' negative attitude towards self in terms of social, cultural and moral processes. The apparent lack of any individual in the sample who had a positive image or healthy acceptance of one's sexuality ('deviant case') is striking. Also, even though the authors had stated that they had deliberately evenly split the sample of kothis into those who were part of ongoing HIV intervention services and those who were not, differences, if any, in the attitudes towards self among these two groups were not discussed. Based on the findings, the authors stress that future interventions among kothis "should more explicitly incorporate 'sex-positive' ideologies ... and actively engage in deconstructing stigmatising and pathologising discourse on sexuality", although this recommendation is applicable for both the general public and those with any kind of non-heterosexual sexualities.

53. Title: Logie, C. H., Newman, P. A., Chakrapani, V., & Shunmugam, M. (2012). Adapting the minority stress model: Associations between gender non-conformity stigma, HIV-related stigma and depression among men who have sex with men in South India. *Soc Sci Med*, 74(8), 1261-1268. doi: DOI 10.1016/j.socscimed.2012.01.008

Journal abstract: Marginalization and stigmatization heighten the vulnerability of sexual minorities to inequitable mental health outcomes. There is a dearth of information regarding stigma and mental health among men who have sex with men (MSM) in India. We adapted Meyer's minority stress model to explore associations between stigma and depression among MSM in South India. The study objective was to examine the influence of sexual stigma, gender non-conformity stigma (GNS) and HIV-related stigma (HIV-S) on depression among MSM in South India. A cross-sectional survey was administered to MSM in urban (Chennai) (n = 100) and semi-urban (Kumbakonam) (n = 100) locations in Tamil Nadu. The majority of participants reported moderate/severe depression scores. Participants in Chennai reported significantly higher levels of GNS, social support and resilient coping, and lower levels of HIV-S and depression, than participants in Kumbakonam. Hierarchical block regression analyses were conducted to measure associations between independent (GNS, HIV-S), moderator (social support, resilient coping) and dependent (depression) variables. Sexual stigma was not included in regression analyses due to multicollinearity with GNS. The first regression analyses assessed associations between depression and stigma subtypes. In Chennai, perceived GNS was associated with depression: in Kumbakonam enacted/perceived GNS and vicarious HIV-S were associated with depression. In the moderation analyses, overall GNS and HIV-S scores (subtypes combined) accounted for a significant amount of variability in depression in both locations, although HIV-S was only a significant predictor in Kumbakonam. Social support and resilient coping were associated with lower depression but did not moderate the influence of HIV-S or GNS on depression. Differences in stigma, coping, social support and depression between locations highlight the salience of considering geographical context in stigma analyses. Associations between HIV-S and depression among HIV-negative MSM emphasize the significance of symbolic stigma. Findings may inform multi-level stigma reduction and health promotion interventions with MSM in South India. (C) 2012 Elsevier Ltd. All rights reserved.

Annotation: This is one of the first studies to test Meyer's minority stress model among Indian MSM. It is also the first study to test a gender non-conformity stigma scale among feminine MSM in India. The findings provided support for the minority stress model as gender non-conformity stigma and HIV-related stigma were found to be significantly (positively) associated with depression among both urban and rural MSM. Social support and resilient coping were, however, not found to moderate depression. The study findings offer evidence for the need to incorporate multi-level stigma reduction measures among health interventions with MSM in India.

V. Injecting Drug Users

54. Title: Latkin, C., Srikrishnan, A. K., Yang, C., Johnson, S., Solomon, S. S., Kumar, S., . . . Solomon, S. (2010). The relationship between drug use stigma and HIV injection risk behaviors among injection drug users in Chennai, India. *Drug & Alcohol Dependence*, 110(3), 221-227.

Journal Abstract: The purpose of this study was to examine the relationship between perceived drug use stigma, acquiescence response bias, and HIV injection risk behaviours among current injection drug users in Chennai, India. Methods: The sample consists of 851 males in Chennai, India who reported having injected drugs in the last month and were recruited through street outreach. Results: Results indicate a strong and consistent positive association between drug use stigma and HIV injection drug use risk behaviours. This association held across the injection behaviours of frequency of sharing needles, cookers, cotton filters, rinse water, per-filled syringes and common drug solutions, even after controlling for acquiescence response bias, frequency of injection, and HIV/HCV serostatus. Conclusions: These findings suggest that future HIV prevention and harm reduction programs for injection drug users and service providers should address drug use stigma.

Annotation: The study found strong positive association between drug use stigma and HIV-related risk behaviours. One notable feature of the study is that it examined acquiescence response biases and their influence on participants' responses (acquiescence response biases refer to the tendency of some respondents to agree with questions, regardless of question's content or meaning). The authors conclude that drug use stigma needs to be addressed in HIV prevention interventions for injecting drug users.

GREY LITERATURE

I. People Living With HIV

55. Title: Bharat, S., Aggleton, P., & Tyrer, P. (2001). India: HIV and AIDS-related Discrimination, Stigmatization and Denial. Retrieved from http://data.unaids.org/publications/irc-pub02/jc587-India_en.pdf

Executive Summary as provided in the report: The study is a detailed and elaborate presentation of HIV/AIDS related discrimination, stigma and denial that exists at various levels; by health care providers/professionals, followed by discrimination experienced at various levels of life of PLHA ranging from schooling, family and societal, employment, insurance and cremation. The study also presents the double stigma and discrimination faced by marginalized groups like sex workers and MSM. The study is detailed with narratives and case studies that present the scenario of both the Mumbai and Bangalore. The study is unique and probably the first in the Indian context to present how Discrimination, Stigma and denial operate and often the causes for its operation. The study also makes in-depth and elaborate recommendation in all the areas, covered in the study, PLHA, marginalized groups, health care sector and legislation (anti-discrimination and

others). The study is an essential contribution to the literature on understands stigma, discrimination and denial existence, operation and causes in various walks of life of the PLHA.

56. Title: Darak, S., Kulkarni, S. (2005). People with HIV: Stigma, Coping and Support Systems: An Insider's Perspective. Retrieved from Prayas Pune Website http://www.prayas pune.org/health/download/Stigma_Report.pdf

Summary: The study discusses aspects of disclosure, stigma, coping mechanisms adapted by PLHIV and support systems available to them. Various forms of discrimination faced by PLHIV in different settings have been documented. One particular contribution of this study is the information available on coping mechanism. The authors describe two types of coping mechanisms used by PLHIV - disengagement and engagement coping mechanisms. Disengagement mechanisms included denial, avoidance, hiding, seeking magical cures and wishful thinking. Engagement coping strategies included seeking information and treatment, selective disclosure, taking precautions to maintain health, dealing with problems, and adapting preventive sexual behaviours planning for the future of their family. The study recommends that: health care providers need to be trained to reduce fear of occupational risk of HIV infection, and to increase their knowledge and awareness; and PLHIV need to be counselled to cope with the situation, and educated about their rights.

57. Title: Pulerwitz, J., Michaelis, A.P., Weiss, E., Brown, L., Mahendra, V.S., Looking Back, Moving Forward, Reducing HIV-related Stigma Retrieved from Population council India website; http://www.popcouncil.org/pdfs/2010HIV_HorizonsStigmaBackground.pdf

Summary: The paper summarizes the work of Horizon program on stigma and discrimination. It highlights the activities implemented and developed in collaboration with international and local partners, and discusses the interventions, strategies and approaches adapted towards reducing stigma. The paper recommends further research in the areas of understanding the influence of interventions from the perspectives of PLHIV, and whether effectiveness of interventions will be affected by factors such as gender and age.

58. Title: Chakrapani, V. (2007). Stigma, Discrimination and Violence faced by People living with HIV and AIDS (PLHA) & marginalized populations (FSW, MSM and Hijras): A qualitative and quantitative baseline study. South India AIDS Action Programme, Chennai India.

Summary: This report is based on a situational assessment to document the extent and nature of stigma/discrimination faced by people living with HIV and marginalized populations to plan evidence-based advocacy activities of a civil society consortium. This study used mixed methods methodology with survey among 401 people and qualitative methods – 32 focus groups and 15 key informant interviews. The study populations were PLHIV FSW, MSM and hijras, and men/women from the 'general population' (referred to as 'people living in the immediate environment' or PIE). The findings reported various forms of stigma and discrimination faced by PLHIV, MSM, hijras and female sex workers.

The report recommends the need for both long-term and short-term measures that include: sensitization of general population and staff of health-care institutions and law enforcement agencies; decriminalizing adult consensual same-sex relationships and voluntary sex work by adults; and enacting anti-discrimination laws.

II. Men who have Sex with Men and Transgender people

59. Title: Asia Pacific Network of People Living with HIV/AIDS (2009). Report on Access to HIV-related Health Services in Positive Women, Men who have Sex with Men (MSM), Transgender (TG) and Injection Drug Users (IDU).

Annotation: In 2009, the Asia Pacific Network of People Living with HIV/AIDS (APN+) conducted a network-based research project aimed to explore the experiences of women, men who have sex with men/transgender people (MSM/TG) and injecting drug users (IDUs) living with HIV in accessing ART and other HIV-related healthcare services. Specifically, the study examined the experiences of PLHIV with linkages to PLHIV support organizations and services in areas of HIV counselling and testing, ART adherence, treatment for opportunistic infections (OIs) and healthcare providers' (HCPs) attitude toward the targeted marginalized groups. Quantitative and qualitative measures were used to help assess the target groups' experiences. Over 3,000 PLHIV from 10 countries across Asia participated in the research. Participants were recruited through the APN+ national PLHIV networks, PLHIV support groups, local ART clinical centres, MSM and IDU drop-in centres, and drug treatment facilities. Data were collected during the second half of 2008. The findings from the report highlight how perceived or actual discrimination by HCPs based on sexual identity and gender expression of HIV-positive MSM, and gender-identity of HIV-positive TG deter them from accessing health care settings. In addition, this report demonstrates how stigma associated with HIV status (within the MSM/TG community and rejection by sexual partners) prevents HIV-positive MSM/TG from accessing HIV treatment services. Thus, this report provides evidence for the need to sensitize and train health care providers as well as sensitize the MSM/TG communities on the issues of people living with HIV.

60. Title: Chakrapani, V., Babu, P., Ebenezer, T. (2004). Hijras in sex work face discrimination in the Indian health-care system. *Research for Sex Work*. p12-14.

Annotation: This article, based on both primary data and evidence from other studies of the first author, documents various kinds of stigma and discrimination faced by aravanis (male-to-female transgender people) in sex work in the health care settings and what can be done. The suggestions include training and sensitizing health care providers on the issues of transgender people; need for providing proper care for post-operative (i.e., after removal of male external genitalia) complications faced by aravanis; and creating transgender-sensitive outpatient registration and in-patient admission procedures.

61. Title: Chakrapani, V., Shanmugam, M., Michael, S., Velayudham, J., Newman, P. A. (2008). HIV Testing Barriers and Facilitators among Populations at-risk in Chennai, India. Indian Network for People living with HIV (INP+), Chennai, India.

Executive summary as provided in the report:

Study purpose: This qualitative study explored barriers and facilitators to knowing one's HIV status among marginalized populations - men who have sex with men (MSM), Hijras/Aravanis (Trans women), female sex workers (FSW), and injecting drug users (IDUs) in Chennai, India.

Methodology: Participants were recruited through voluntary organizations in Chennai. Twelve focus groups (n=84 participants) and 12 key informant interviews were conducted, audiotaped and transcribed. Narrative thematic analysis and a constant comparative method were used to identify themes.

Key findings: Findings revealed barriers at multiple intersecting levels and contexts. At the individual level, the primary barriers were: fear of adverse consequences if diagnosed as HIV-positive; fear of inability to cope with a positive HIV test result; precedence given to drug

use (among IDUs); not being convinced of the benefits of knowing one's HIV status; and low HIV risk perception. At the health care system level, discrimination from providers, unfriendly administrative procedures, long waiting time, and the need to come back to collect test results acted as deterrents. The program, policy and legal barriers include presence of criminal laws against the marginalized groups, inability to follow up with clients because of lack of effective coordination among voluntary organizations, inconsistent funding support for HIV prevention programs, and lack of media campaigns that reach out and appeal to marginalized groups.

Key Recommendations

- Launch social marketing campaigns to promote HIV testing among marginalized groups.
- Address psychological barriers to HIV testing in outreach education & counselling.
- Educate about various benefits of knowing one's HIV status.
- Ensure that available HIV counseling/testing services are of high quality.
- Provide a range of HIV tests (including urine-/saliva-based) with same-day test results.
- Reduce stigma/discrimination through public educational programs.
- Support establishment of 'community-based HIV counselling and testing centres' run by voluntary agencies.

62. Title: Chakrapani, V., Boyce, P., Dhanikachalam, D. (2011). *Sexual Violence against Men who have Sex with Men (MSM) in India: Intersections with HIV*. NACO / DFID Technical Assistance Support Team (TAST) and National AIDS Control Organisation (NACO). New Delhi.

Summary: Violence against men who have sex with men (MSM) and transgender people in India is a largely hidden epidemic, and along with HIV, forms a 'syndemic' that needs to be effectively addressed. Many MSM especially those who are feminine and/or who engage in sex work, face violence on the streets, in the sex work places, or in their personal lives, which increases their vulnerability to HIV and other health concerns. This report demonstrates the interconnections between HIV and sexual violence, discusses the existing sexual violence prevention strategies and support services for victims of sexual violence, and put forwards action points to mitigate the impact of the syndemic.

The summative recommendations from this report focus on two areas – 1) prevention of sexual violence; and 2) providing services for victims of sexual violence.

To prevent sexual violence against MSM, the steps that can be taken through current and future targeted HIV interventions include: violence prevention and mitigation education for MSM; meetings with police in the local police stations; and crime mapping by NGOs/CBOs to help MSM avoid risky areas. In addition, an enabling environment needs to be created to prevent and report violence. The activities include: a) awareness-raising among MSM communities through targeted interventions and online sites about sexual violence and its consequences to gain support for victims; and b) training police, lawyers, and healthcare providers to promote understanding and acceptance of the human rights and right to health of sexual minorities, to adapt and implement sensitive procedures in handling male victims of sexual violence, and to provide appropriate and sensitive medical and psychological care. Services for victims of sexual violence that can be provided through the targeted interventions include: attending to the immediate physical and mental health needs of the victim, providing free sexual post-exposure antiretroviral prophylaxis at government hospitals; screening for HIV/sexually transmitted infections (STIs) and providing empirical treatment for STIs; linking victims with legal support and providing free legal services; and providing long-term mental health counselling support.

63. Title: Prabhugate, P.A. (2011). Understanding stigma and self-esteem of Men who have Sex with Men in Mumbai, India. Dissertation Abstracts International Section A: Humanities and Social Sciences. Vol.71 (12-A),2011, pp. 4569.

Abstract from the Thesis: The present study examined the psychosocial correlates of stigma and self-esteem of Men who have Sex with Men (MSM) in Mumbai, India. Specifically the study examined how the factors of sexual identity, disclosure of sexual orientation and marital status were related to stigma and self-esteem of MSM. Secondly the present study also examined the relationship between life events and social support with stigma and self-esteem of MSM, and if stigma is independently related to self-esteem of MSM. A secondary analysis of data from the Mental Health Baseline study of MSM in Mumbai was conducted for the purpose of this study. Face-to-face interviews were conducted to gather data from 210 MSM. A sample of 150 MSM participants was analyzed included the present study. Findings revealed that participants who reported their sexual identity being "Kothi" or "gay" were more likely to report higher scores on perception of stigma, those who disclosed their sexual orientation to family were associated with greater perceived stigma. In addition participants who reported higher negative impact of life events were also associated with greater stigma perception. With regards to self-esteem of the study participants, participants who reported higher satisfaction with social support had higher scores on self-esteem, however participants who disclosed their sexual orientation to family had lower scores on self-esteem.

64. Title: Stangl, A., Carr, D., Brady, L., Eckhaus, T., Claeson, M., Nyblade, L. (2010). Tackling HIV-Related Stigma and Discrimination in South Asia Lessons Learned from the 2008 Development Marketplace. Retrieved from International Center for Research on Women website: http://www.icrw.org/files/publications/Tackling-HIV-Stigma-and-Discrimination-in-South-Asia-Lessons-Learned-from-the-Development-Marketplace_0.pdf

Annotation: In 2008, the South Asia Region Development Marketplace (SARDM), "Tackling HIV and AIDS Stigma and Discrimination" provided support to 26 NGOs/CBOs in six countries to pilot innovative HIV-related stigma and discrimination reduction interventions over a 12- to 18-month period. In India, 12 interventions had been implemented by various NGOs/CBOs. This includes, interventions that aimed at reducing stigma and discrimination faced by people living with HIV, Female Sex Workers, Men who have Sex with Men and Drug Users. Target audience included; 1) General public and society at large; 2) Health care providers; 3) Police; 4) Truckers and 5) Village panchayat leaders and 6) PLHIV and marginalized communities. A variety of approaches - street theatres, game shows, developing/screening of short-films, providing employment opportunities through entrepreneurship - have been used by these organizations to reach diverse audiences.

65. Title: Chakrapani, V., Samuel, M., Shunmugam, M., & Sivasubramanian, M. (2013). Modelling the Impact of Stigma on Depression and Sexual Risk Behaviours of Men who have Sex with Men and Hijras/Transgender women in India: Implications for HIV and Sexual Health Programmes. Jointly published by Madras Christian College, the Humsafar Trust and C-SHaRP, with support from ICMR. Retrieved from: http://www.c-sharp.in/research_policy/Research_Reports.html

Annotation:

Objectives: This study adapted Meyer's minority stress model to examine the influence of sexual minority stigma and HIV-related stigma on depression and sexual risk among men who have sex with men (MSM) and male-to-female transgender (TG) people in India. It was hypothesised that resilient coping and social support would act as moderators and/or mediators.

Methods: A sequential explanatory mixed methods design was used. In the first phase, a cross-sectional survey was administered to 300 MSM and 300 TG recruited from 3 urban and 3 rural sites. Hierarchical block regression analyses were conducted and structural equation models were fitted and examined. In the second phase, qualitative in-depth interviews were conducted among 39 MSM and TG participants.

Key findings: The study offered empirical support for the adapted minority stress model as it was found that sexual minority stigma and HIV-related stigma were associated with depression among both MSM and TG people, and HIV-related stigma was associated with sexual risk among MSM. Evidence from the qualitative component indicated that sexual minority stigma influences sexual risk. Also, depression and alcohol use were found to be significant predictors of sexual risk among both MSM and TG people.

Conclusion: The study findings offer support for the inclusion of multi-level (individual, family, societal and structural levels) stigma reduction measures within existing HIV prevention and care interventions for MSM and TG people in India.

III. Injecting Drug Users

66. Title: Chakrapani, V., Velayudham, J., Michael, S., Shanmugam, M. (2008). Barriers to free antiretroviral treatment access for injecting drug users in Chennai, India. Indian Network for People living with HIV and AIDS (INP+), Chennai, India.

Summary based on the 'executive summary' of the report:

Background: National AIDS Control Organization (NACO), India, provides free first-line antiretroviral treatment (ART) for eligible people living with HIV (PLHIV) since 2004. To assist in developing policies and programs to ensure equity in ART access to IDUs, we explored the various factors that hinder free ART access for IDUs living with HIV in Chennai, India.

Methods: Three focus groups (n=19 IDUs) and 4 key-informant interviews were conducted, audiotaped, transcribed and translated. Data were explored using framework analysis to identify categories and derive themes.

Results: Barriers at several levels were identified. Individual-level barriers: lack of concern about health while on drugs; lack of correct knowledge of ART; misconceptions such as 'ART does not suit IDUs'; fear of need to stop taking drugs/alcohol if started on ART; fear of rejection by drug using peers since taking ART would reveal their HIV-positive status; and belief that they would not adhere to ART regimen. Health system barriers: lack of local residence proof (for homeless IDUs) to get enrolled in government ART program; perceived and actual discrimination from health care providers; lack of screening for Hepatitis-B/C viruses (HBV/HCV) before starting ART; lack of free treatment for HIV and HCV/HBV co-infected people; and dilemma among doctors whether to start ARVs for current users and for those on sublingual buprenorphine substitution treatment. Social, Policy and Programmatic barriers: Stigma and discrimination against IDUs living with HIV; and lack of effective linkages between needle syringe programs and drug dependence treatment programs (including opioid substitution programs) as well as government ART centers.

Conclusions: Barriers to ART access for IDUs need to be addressed by: assisting current users living with HIV to take rational decisions about their health by linking them with harm reduction and drug dependence treatment programs including opioid substitution; providing correct information on interactions between ART and street drugs; offering screening and treatment for HBV/HCV co-infections; educating/sensitizing health care providers; and having a national policy and action plan on equity in ART access to marginalized groups.

67. Title: Chakrapani, V., Kumar J Kh. (2009). Drug Control Policies and HIV Prevention and Care Among Injection Drug Users in Imphal, India. In Wolfe D & Saucier R (Eds.) *At What Cost? HIV and Human Rights Consequences of the Global War on Drugs*. New York: Open Society Institute - International Harm Reduction Development. Retrieved from: http://www.soros.org/initiatives/health/focus/ihrd/articles_publications/publications/atwhatcost_20090302

Summary based on the introduction of this book chapter: The study finds that people who use drugs have a high likelihood of being stopped and searched, ostensibly due to security concerns related to the insurgency. In reality, they may be an easy target from which police and military forces can extort bribes. Respondents reported that searches are more common near drug hotspots, or for people with visible injection scars. Police activities had a direct impact on drug users' ability to practice harm reduction and access health services: people who use drugs were afraid to carry clean syringes, and reported injecting in a hurried manner or in less safe areas on the body to avoid detection by police. Respondents said that police often staked out drop-in centers and needle exchange programs to arrest drug users as they exited. Furthermore, police harass and hamper the work of peer educators and outreach staff. People who use drugs had to pay regular "taxes" to police in order to avoid arrest; they also reported the ability to bribe their way out of arrests or to obtain lighter sentences. Drug users who are not able to pay their way out of prison find themselves in a situation where drugs continue to be available, but clean injecting equipment is not, resulting in up to 30 inmates sharing one syringe. Sex workers who use drugs face particular harassment and abuse.

The negative health implications of these police tactics are clear: people who use drugs are afraid to engage with harm reduction services, they are more likely to share used syringes, sex workers who use drugs have to take more clients in order to make up the money lost to police bribes, and heavy reliance on incarceration means that increasing numbers of people are at risk of HIV infection and other blood-borne viruses.

68. Title: Chakrapani, V., Shunmugam, M., Logie, C., Newman, P. A. (April 2010). *Access and Adherence to Tuberculosis Treatment for Injecting Drug Users (IDUs) in Imphal, India: Barriers & Facilitators*. A mixed methods study. Indian Network for People living with HIV/AIDS, India.

Executive Summary as provided in the report:

Background: People living with HIV (PLHIV) and injecting drug users (IDUs) are at increased risk of getting TB. In 2009, a mixed methods study was conducted in Imphal districts in Manipur, India, to identify barriers and facilitators to access and adherence to TB treatment for IDUs, including PLHIV.

Methods: Survey (n=97 male IDUs), 6 focus groups (n=30) and 8 key-informant interviews were conducted. Participants were primarily recruited from government/non-governmental TB DOTS (Directly Observed Treatment-Short Course) centres, and PLHIV networks. For quantitative data analysis, SPSS was used. Qualitative data were explored using framework analysis to derive themes.

Results: Most were HIV-positive (n=93/97;95.8%). In the past one month, injecting drug use and alcohol use were 16.5% and 11.3% respectively. Participants accessed TB treatment at private clinics (n=56;57.7%), non-governmental organisation (NGO) DOTS centres (n=30;30.9%), and government DOTS centres (n=11;11.3%). Among PLHIV, two-thirds (n=57/93;61.2%) were on antiretroviral treatment (ART). Patient-related access delay, 2 or more weeks between onset of TB symptoms and first visit to formal healthcare provider, was experienced by 84.5% (n=82/97). About one-tenth (n=11/97;11.3%) missed TB doses (consecutively) from one week to more than two months. Higher levels of patient delay was

associated with the belief that taking TB and ART medication together was difficult (OR=4.6;p< 0.05). Social support and utilization of NGO TB services were significant predictors of TB treatment adherence. Being on buprenorphine opioid substitution treatment (OST) facilitated access and adherence. Access and adherence barriers included perceived/actual discrimination from healthcare providers, fear of side-effects, mistrust about the quality of government TB medications, and lack of family support.

Conclusions: TB treatment access/adherence for IDUs living with HIV can be promoted by: providing adequate TB education/counselling; building the capacity of service providers to address individual/healthcare system barriers; initiating programs to increase support from family/society; and connecting IDUs with opioid substitution treatment services.

IV. General Public (Men, Women, Youth, Health care providers and others)

69. Title: ICRW & STRIVE (2013). A global HIV stigma reduction framework adapted and implemented in five settings in India – Summary Report. Retrieved from: http://www.in.undp.org/content/dam/India/docs/HIV_and_development/a-global-hiv-stigma-reduction-framework--summary-report.PDF

Summary: This report summarizes the results from the pilot-testing of five stigma reduction and measurement projects that used a global HIV stigma and reduction framework. Pilot-testing was conducted among five different populations/settings: 1) students, faculty and management from the educational settings; 2) female sex workers and family members; 3) panchayat leaders and local community people; 4) workplace management team and workers; 5) healthcare professionals and men who have sex with men. Pilot-testing reveals concrete results like stigma reduction curriculum development for college students, integration of targeted interventions, engagement of Gram Panchayat and work place associations, and reduction of internalized stigma through multi-level intervention. Thus the framework was found to be relevant and feasible which could be adapted in Indian context for stigma reduction interventions and measurement. ICRW reports that it has found the global framework to be relevant to the Indian context and helpful in stigma-reduction programme development and implementation.

Box 3. Community-initiated stigma reduction activities: Practice informing evidence or Evidence informing practice?

Stigma reduction activities are often initiated by those directly affected, for example by networks of people living with HIV or by members of marginalised communities and sometimes by community agencies working for them. Often these initiatives are based on the community agencies/leaders' experiences in working with their communities and on their subjective notion of what might work in reducing stigma. Limited information is available on whether available research evidence ever informs such community-initiated stigma reduction activities. Information is also lacking on the impact of these activities in reducing stigma and on health outcomes. To address these issues, besides the desk review of academic and gray literature, we also interviewed select front-line agencies and community activists who have initiated certain HIV-related stigma reduction activities in two high HIV prevalence states: Maharashtra and Tamil Nadu.

We interviewed individuals from four agencies that work with various marginalised communities – men who have sex with men, transgender women, sex workers, and one that works with health care providers. The areas explored in our interviews were:

- Reasons for initiating the stigma reduction activity
- Basis for designing the programme (experiences, scientific evidence, if any)
- Details of the programme (goal/objectives, components/elements, activities)
- How is success / effectiveness assessed?
- Any documentation of the programme/activity to reflect on the impact made
- Plans for sharing the experiences, success and lessons learnt with others (and/or what have been done so far in relation to these)
- What learnings can be extracted for research purposes
- Access to evidence base to design stigma reduction interventions

Case study – 1: Lotus Sangam - Reducing stigma faced by feminine men who have sex with men (MSM) through street theatre

Lotus Sangam, is a community-based organisation working with MSM in Tanjavur district, Tamil Nadu. Since its inception (2000), Lotus has reached more than 1500 MSM in and around Kumbakonam with HIV prevention services and counselling, and engaged in advocacy to reduce stigma and discrimination faced by MSM. Outreach and field experiences of Lotus revealed that MSM in and around Kumbakonam (especially from villages) faced discrimination from local communities and family due to lack of understanding about same-sex sexualities. To avoid discrimination many feminine same-sex attracted men (especially youth) moved out of their villages.

To address the wide-spread discrimination against visibly feminine same-sex attracted men in villages, Lotus Sangam with support from the World Bank South Asia Region Development Marketplace (SARDM) grant developed and implemented an 18-month innovative pilot intervention (street theatre) in and around the villages of Kumbakoman. This project aimed at changing the negative attitudes and practices that prevented MSM and transgender people from accessing legal redressals through their municipal governments known as *panchayats*.

Prior to project implementation, a baseline qualitative study was conducted among MSM and panchayat leaders to inform script development and provide baseline data for evaluation. In total, Lotus organized 75 performances of the play in three districts (Thanjavur, Thiruvavur, and Nagapattinam) with the support of panchayat leaders. Over the course of one year, Lotus reached approximately 270 panchayat leaders and 11,250 villagers.

Endline study showed that the project resulted in bringing in a positive change in the attitude and

behaviour of panchayat leaders and villagers and thereby decreased the incidents of discrimination and promotion of self-respect and health seeking behaviour of MSM in those villages. The endline study findings were disseminated in the form of reports, booklet, and conference abstracts - nationally and internationally.

Case study – 2: Bharathi Kannamma Trust - ‘Sensitizing college students about the issues of transgender people’

Bharathi Kannamma, a transgender woman, is a college graduate and now working on HIV prevention and care among transgender people in Madurai, Tamil Nadu. When she was studying in college, Bharathi had faced discrimination from co-students because of her feminine mannerisms; at that time she used to wear men’s attire and legally had a male identity only. In spite of the non-supportive environment at college, she completed her college education. Now she is a well-known transgender activist in Tamil Nadu because of her advocacy activities with government and general public.

One key focus of Bharathi Kannamma Trust, a not-for-profit agency established by Bharathi, is to eliminate discrimination faced by transgender people in colleges and to promote a supportive environment in the colleges by sensitising college students and management. She started organising half-day to one-day educational programmes on the issues faced by transgender people, sometimes in conjunction with providing education on HIV-related issues. So, far she has conducted educational programmes about transgender people in about 70 colleges in and around Madurai with an average of 200 college students per programme. Although she did not administer a pre- and post-training assessment of knowledge and attitude of the college students, usually she asks the students to note down their questions and impressions about transgender people before the start of the programme and asks them to review their responses at the end of the session, and also gets their feedback on the programme.

She believes that the success of the programme can be measured in terms of correct knowledge about transgender people and their attitude towards transgender people in public spaces and transgender students in college campuses. She recalled incidents of students recognising her in public places and coming forward to meet and greet her with no inhibitions that apparently implied that her educational programme has been successful with at least some students. Bharathi admits that even though she did not use any research evidence for designing her college education programmes, her own experiences and experiences from other transgender community members helped in choosing the content and format of the education programmes. So far she has not documented the process, success, and challenges faced by her programme formally because of time and resource constraints, but she is eager to do so if technical and financial support is available.

Case study 3 – SANGRAM, Sangli, Maharashtra: Rights and community based approaches to reducing stigma towards sex workers and other marginalized communities

Sampada Grameen Mahila Sanstha (SANGRAM) began its work in India in 1992 from Sangli in the State of Maharashtra. SANGRAM advocates for the sexual and reproductive health and rights of people marginalized due to gender, sexuality, sex work, HIV status, caste and religious minority, or those who challenge the dominant norms. It builds coalitions and capacity to address stigma and marginalisation, connecting SANGRAM’s grassroots work to policy change at both the national and international level. It focuses on building solidarity amongst diverse and marginalized communities by using a rights-centred approach to self-determination and organises the voiceless to collectivise as a key strategy. SANGRAM’s approach envisions the sex worker as a woman who can be empowered to change her circumstances and become an agent of change for herself and her community.

SANGRAM recognizes that stigmatization impacts the lives of sex workers in more ways than

one. The most basic of all is the denial of the right to practice the 'business of making money from sex'. "We protest against a society that deems us immoral and illegal mainly because we do not accept its mores, rules and governance. We protest against the various forces of mainstream society that deny us the right to liberty, security, fair administration of justice, respect for our lives, discrimination, freedom of expression and association," declares the VAMP statement succinctly. Activities at SANGRAM range from the grassroots to policy level interventions and public education. These are carried out through the collectives of female sex workers, Veshya Anyay Mukti Parishad [VAMP], MUSKAN [MSM and Male sex workers], SANGRAM + [Widows living with HIV/AIDS], MITRA [Sex worker's kids]. The activities include: Advocacy with police, judiciary, health system at the local, national and international levels; district advocacy campaign to combat stigma & discrimination and spread of HIV/AIDS among rural women and youth through village-level community programs in Sangli district; SANGRAM+ , a support group for HIV-positive widowed women; networking and work with orphans and vulnerable children. The district campaign holds village Panchayat discussions to reconsider situations where HIV-positive students, especially girls have been denied admission or expelled from school. CASAM, the Centre for Advocacy on Stigma and Marginalisation, undertakes advocacy for the reduction of stigma, violence and harassment of marginalised communities including sex workers. Activities of SANGRAM are informed by the international feminist and rights movement and driven by strong ideological underpinnings.

SANGRAM does not believe in monitoring the campaign teams' work. Monitoring is not evaluative, but a continuous reflective process for the entire team. SANGRAM's impact has been gauged by outcomes that are sustainable such as building leadership capacities in marginalized groups, building capacity to demand and procure human rights and humane treatment, strengthening the public health system in the district, creating an enabling environment and space in the government hospital for HIV testing and treatment. In addition, the systems level transformation of the HIV-related services in the government health system has benefited, not just the sex workers' collective, but anyone who wishes to avail of HIV-related services.

SANGRAM's initiatives suggest that community mobilisation and collectivisation approaches are key to addressing the structural factors shaping stigma due to HIV/AIDS. One strong lesson SANGRAM sends out is that it is imperative that stigma interventions are influenced by an approach that places human rights, dignity and the status of vulnerable groups at its core.

Case study 4 – PRAYAS: Addressing stigma and discrimination within the health care sector

PRAYAS was founded in 1994 by a committed physician and his two doctor colleagues in Pune city, Maharashtra. Dr. Vinay Kulkarni, the co-founder, and the coordinator for the health group program, has been working with HIV-positive patients since 1986. PRAYAS has been instrumental in behaviour and attitude change of health care providers largely in Pune. The work began with creating awareness about HIV/AIDS and sexuality but soon expanded to interventions, clinical care and counselling centre, information centre, and research. The approach of PRAYAS involves training on HIV/AIDS knowledge and activities such as "*Catch them young*", specifically developed for young doctors, to enhance their understanding of HIV/AIDS and universal precautions, changing their attitudes towards HIV positive patients and sensitising them to adopt non-stigmatizing behaviour towards HIV-positive patients. In addition to training programs, short films have been developed. For example, "*Am I at Risk?*" is a short film targeted at health care providers to address fear associated with treating HIV-positive patients. At least five training programs with supportive supervision and guidance are held for each health provider in Pune. A formal evaluation of the effectiveness of these trainings, however, was not conducted.

Over a period of 15 to 20 years PRAYAS has been instrumental in changing the attitudes of several health care providers in Pune. Continuous interactions, and training and hand-holding of health care providers have resulted in creating a non-stigmatizing health seeking environment for

HIV-positive patients at the PRAYAS clinic. PRAYAS currently works with over 50 health care providers in 10 districts who provide care and treatment services to HIV positive patients without stigma and discrimination. Over 26 paediatric doctors have been trained, and there is an attitude change towards working with HIV-positive children. PRAYAS clinic has over 3500 registered HIV-positive patients and 450 HIV-positive children linked with the free ART programs. Nearly 500 new registrations occur every year.

PRAYAS conducted a research study on stigma and discrimination, coping and support systems of HIV-positive patients. A component of the research study presents facets of stigma and discrimination encountered from health care providers. PRAYAS has been open to sharing experiences, learning with NGOs, Government, NACO, UNICEF, WHO and local organizations. PRAYAS strongly recommends intervention at the health system level to reduce HIV-related stigma and discrimination.

Inferences

Key patterns observed in these case studies are:

1. Stigma reduction initiatives by the community agencies and leaders are based on the felt need of the communities and are designed based on their experiences as those community activists/leaders had experienced stigma in that particular setting (college, village) or from a particular set of people (college students, village leaders, families). Some community-led activities (like that of SANGRAM) seem to be influenced by international feminist and human rights movements and have an ideological base to their approach.
2. Research evidence has rarely been used in designing these community-initiated stigma reduction activities although there is openness among the agencies to use available research evidence. Additionally, community-based organisations are undertaking studies on stigma to generate evidence from within.
3. Community activists have their own 'program theory' – that is, how a community-initiated stigma reduction program will work, which may or may not have a theoretical basis from the researcher's or program evaluator's point of view.
4. Rigorous documentation of the interventions or concrete monitoring and evaluation plans for measuring the success or effectiveness of interventions are limited, although some efforts are evident to measure program effectiveness or success.

Recommendations

1. Community-based stigma approaches such as the one by SANGRAM has the potential to address structural factors underlying stigma. However, well-designed research will help examine the impact of addressing structural factors on stigma reduction and identify the dynamics of stigma reduction process. There is a need to document community-initiated stigma reduction programmes on what type of programmes work and how. Such lessons from the practitioners and experiences from the field level will be helpful when designing evidence-based stigma reduction initiatives.
2. Support should be made available for community agencies in designing stigma reduction programmes both on the basis of their experiences as well as assisting them in using the available evidence-base on stigma reduction interventions. Fostering and strengthening collaborations between academic/research institutions and community agencies will be helpful for both researchers and practitioners to design and evaluate stigma reduction initiatives that are informed both by theory and experience/practice.
3. Support should also be available for community agencies to properly document and share the lessons learnt (in terms of identifying both the facilitating factors and challenges) with various stakeholders, so that effectiveness of the interventions can be measured robustly.
4. There is a need to consider community perspectives and experiences of the community representatives when designing and testing stigma reduction interventions that are primarily based on theories of empirical research evidence.

APPENDIX 1. SUMMARY OF PEER-REVIEWED ARTICLES ON HIV-RELATED STIGMA

No.	Author(s)	Year of publication	Study design	Methods	Study population(s)	Study objectives
1	Chandra et al.	2003	Cross-sectional	Qualitative research in-depth interview	HIV-positive men and HIV-positive women	The aim of this study was to examine aspects related to self-disclosure of their seropositive status among 68 persons (35 men and 33 women) infected with HIV.
2	Elamon et al.	2005	Cross-sectional	Qualitative research focused group discussion and in-depth interview	Health care workers and HIV-positive people	The aim of this study was to examine the occurrence of arbitrary discrimination (i.e., unjustified discrimination) in the lives of PLHIV.
3	Finn et al.	2009	Cross-sectional	Qualitative research in-depth interview	Voluntary or paid workers from HIV-related NGOs in India	This article critically explores the constitutive effects and inherent power relations of HIV 'Positive Speakers' Bureaus (PSBs) as a platform for such a display.
4	Green et al.	2007	Cross-sectional	Quantitative research survey	HIV-positive people	To test whether simple observation of the presence and relationship of attendants and visitors to married HIV-positive people in an HIV care centre may provide a simple, inexpensive and indirect indicator of care giving AIDS-related stigma and discrimination by assessing whether the measure is sensitive to gender, location, age and source of infection.
5	Krishna et al.	2005	Cross-sectional	Qualitative research in-depth interview	PLHIV and Family members involved in care and support of PLHIV	This study was aimed at understanding the impact of HIV on the family system in the Indian context.
6	Mulye et al.	2005	Cross-sectional	Mixed method Survey & In-depth interviews	People living with HIV/AIDS	The present study attempted to analyse the prevalence and experiences of stigma, discrimination and confidentiality issues, as well as voluntary disclosure and partner notification in HIV-infected patients.
7	Paxton et al.	2005	Cross-sectional	Quantitative research survey	HIV-positive people	To develop an understanding of the nature, pattern and extent of AIDS-related discrimination in several Asian countries.
8	Rahangdale et al.	2010	Cross-sectional	Qualitative research focused group discussion and in-depth interview	HIV-infected women; Male and female family members of HIV-infected women; Health care providers and NGO staff	The purpose of this study is to explore how feared and experienced stigma acts as a barrier to access PPTCT-related services.

9	Souza et al.	2010	Narrative analysis	Qualitative research in-depth interview	HIV-positive women	The study used narrative methodologies to explore the illness journeys of two women who were married young and have been living with HIV/AIDS for over a decade.
10	Subramanian et al.	2009	Cross-sectional	Quantitative research survey	HIV-infected persons	To examine psycho-social impact of HIV and quality of life of HIV-infected persons from a major government sexually transmitted disease (STD) clinic in Chennai, Tamil Nadu, South India.
11	Steward et al.	2008	Cross-sectional	Mixed method in-depth interview and survey	People living with HIV	To examine whether a multi-component framework, initially consisting of enacted, felt normative, and internalized forms of individual stigma experiences, could be used to understand HIV-related stigma in Southern India.
12	Suhadev et al.	2011	Cross-sectional	Quantitative research survey	Spouses of HIV-Infected Men	This study aimed to examine the process of HIV-related disclosure and its patterns, reasons for nondisclosure, and reactions of HIV disclosure among the spouses of HIV-infected men in South India.
13	Thomas et al.	2009	Cross-sectional	Qualitative research, Focused group discussion	HIV-infected mothers	The purpose of this study is to examine and understand the various factors that impact Mothers Living with HIV to understand their various health care needs, barriers to receiving health care, and their perceptions with regard to stigma and disclosure issues.
14	Thomas et al.	2005	Cross-sectional	Quantitative research survey	HIV positive individuals	This clinic-based study aims at understanding stigma among 203 HIV positive individuals from Chennai, South India.
15	Tarakeshwar et al.	2007	Cross-sectional	Qualitative research in-depth interview	HIV-positive adults	The primary aim of this study was to develop a broad understanding of how HIV-infected men and women in India who had access to care provided by an NGO in Chennai, Tamil Nadu, manage their HIV-related health needs.
16	Hollen et al.	2010	Ethnographic research	Ethnographic interviews	HIV-positive women	The focus of this paper is on heterosexual HIV-positive women's own perspectives on the gendering of stigma.
17	Malave et al.	2014	Cross-sectional	Quantitative research survey	HIV-positive men and women	The purpose of this paper was to describe gender differences in the experience of living with HIV in Bengaluru, India.

18	Charles et al.	2012	Cross-sectional	Quantitative research survey	HIV-positive men and women	The objective of the study was to determine the prevalence of severe stigma and to study the association between this, depression and the quality of life (QOL) of people living with HIV/AIDS (PLHA) in Tamil Nadu
19	Jeyaseelan et al.	2013	Cross-sectional	Quantitative research survey	HIV-positive men and women	The study assessed the reliability and validity of a Tamil translation of the original 40-item scale, and conducted confirmatory and exploratory factor analyses to assess cultural appropriateness and abbreviate the scale.
20	Nebhinani et al.	2012	Cross-sectional	Quantitative research survey	HIV-positive outpatients	To study stigma and related issues in HIV-positive subjects.
21	Ekstrand et al.	2011	Cross-sectional	Cross-sectional interview	Non-HIV patients in multiple healthcare settings in Mumbai and Bengaluru	The present paper describes types and levels of HIV stigma and intentions to discriminate against PLHA among individuals in outpatient clinics in Mumbai and Bengaluru, two large Indian cities located in Maharashtra and Karnataka states, respectively.
22	Kermode et al.	2005	Cross-sectional	Quantitative research survey	Health care workers	The objective of this study was to assess HIV-related knowledge, attitudes and risk perception among a group of rural north Indian HCWs, and to identify predictors of willingness to provide care for patients with HIV infection.
23	Mahendra et al.	2007	Intervention study	Mixed method in-depth interview and survey	PLHIV, Care givers & Hospital Staff (Doctors, Nurses & Ward Boys)	This paper reports on stigma-related baseline findings from a study in New Delhi, India to evaluate the impact of a stigma-reduction intervention in three large hospitals.
24	Meundi et al.	2008	Cross-sectional	Quantitative research survey	Men & Women	To assess HIV/AIDS-related knowledge, attitudes, and practices among the general population in South India.

25	Pisal et al.	2007	Multi-phase study	Initial formative qualitative research followed by intervention assessment	Nurses	The study examined the impact of a 4-day HIV/AIDS health education program on knowledge and attitudes of nurses in a government hospital.
26	Pramanik et al.	2006	Cross-sectional	Quantitative research survey	Male and female high school students	This study examined stigmatizing attitudes toward HIV/AIDS among predominantly middle-class adolescents in New Delhi high schools.
27	Pallikadavath et al.	2005	Cross-sectional	Qualitative research focused group discussion and in-depth interview	Men & women infected with HIV and general population	The objective of the study was to obtain primary data about HIV in a rural context, gathering information about the circumstances of HIV transmission, how HIV status was communicated, treatment decisions, the social and family response, and social, health and economic needs.
28	Rogers et al.	2006	Cross-sectional	Quantitative research survey	Pregnant women	The objective of this study was to assess HIV/AIDS-related knowledge, attitudes, and perceived benefits and risks of HIV testing among pregnant women in rural India.
29	Sivaram et al.	2009	Randomized trial	Community-based cluster randomized trial; Ethnographic in-depth interview; Survey of behavioural and biological risk; Baseline cohort; Follow-up assessment & Intervention-related training	Men & women	This study explored the associations between social capital and stigma among men and women who are patrons of wine shops or community-based alcohol outlets in Chennai.

30	Vyas et al.	2010	Cross-sectional	Quantitative research survey	Health care workers	The objectives of the present study were to identify the general manifestations of stigma against PLHA in healthcare settings, and to measure specific HIV-related attitudes and risk perceptions among doctors, nurses, and ward staff working in both urban and rural settings in Gujarat.
31	Zelaya et al.	2008	Cross-sectional	Quantitative research survey	Men	The paper reports the development and psychometric testing of an HIV/AIDS stigma scale among 200 men in India.
32	Bharat et al.	2014	Cross-sectional	Quantitative research survey	Non-HIV-infected patients	This study examined the association of gender-based attitudes, HIV misconceptions and community feelings for marginalized groups with stigmatizing responses towards people with HIV/AIDS in Mumbai, India.
33	Ekstrand et al.	2013	Cross-sectional	Quantitative research survey	Health care providers	This study examined the prevalence and drivers of stigma and discrimination among doctors, nurses and ward staff in different urban healthcare settings in high HIV prevalence states in India.
34	Bharat et al.	2011	Review article	Systematic review	All relevant populations (general public, key populations and health care providers)	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..
35	Catalani et al.	2013	Intervention study	Mixed methods	Key populations	Development and testing of media interventions among key populations on HIV-related stigma
36	Vlassoff	2013	Intervention study	Quantitative	Married women and unmarried male/female adolescents	This paper tested a vignette-based module to assess community stigma in rural India.
37	Shivalli	2014	Cross-sectional	Quantitative research survey	Nursing students	To appraise the knowledge, attitudes, and preventive practices of nursing students pertaining to occupational exposure to HIV and to quantify the risk and correlates of exposure to HIV among them.
38	Argento et al.	2011	Cross-sectional	Qualitative research focused group discussion and in-depth interview	Male and female sex workers, TGSWs, police officers, brokers, boyfriends, and lodge owners	This article aims to describe lived experiences of members from a sex worker's collective in Mysore, India and how they have confronted structural violence.

39	Blankenship et al.	2010	Ethnographic research	Observations, formal and informal in-depth interviews	Female sex workers, brokers, clients and public officials	This article presents the case study of the challenges and opportunities faced by a community-led seeking to confront stigmatization of FSW through its interactions with a government-sponsored AIDS education program targeted to the general public.
40	Biradavolu et al.	2009	Ethnographic observations	Observations & key informant interviews	Sex workers, their intimate partners, police, madams, lawyers and clients	This paper draws upon contemporary theories of governance and non-state regulation to analyze the evolving strategies of an HIV prevention non-governmental organisation (NGO) and female sex worker community-based organizations (CBOs) to reform police practices in southern India.
41	Cornish et al.	2006	Cross-sectional	Qualitative research group discussion and in-depth interview	Female sex workers and Project leaders	This paper examines the efforts of a sex workers' organisation in India to challenge the internalized stigma of sex work.
42	Chakrapani et al.	2009	Cross-sectional	Qualitative research focused group discussion and in-depth interview	Female sex workers	To assist in developing policies and programs to ensure equity in ART access, we explored barriers to ART access among female sex workers (FSWs) living with HIV in Chennai.
43	Liu et al.	2011	Cross-sectional	Quantitative research survey	Street-based FSWs	To examine the psychometric properties of a new stigma index for street-based FSWs in Chennai, India.
44	Misra et al.	2000	Review/Opinion article	Case studies of two sex work collectives that operate in different locations in India.	FSWs	The study has documented the approaches used by sex worker collectives to challenge ambiguous legislation, and stigmatizing and negative societal constructs.
45	Shahmanesh et al.	2009	Participatory observation, rapid ethnographic mapping and in-depth qualitative method	Participatory observation, Ethnographic mapping, In-depth interviews, key informant interviews and focused group discussion	Sex-workers, health-professionals, bar and lodge-owners, Female brothel-owners), pimps, motorcycle-taxis, rickshaw and taxi-drivers, security-guards, NGO workers, shopkeepers, Betel nut sellers, street-vendors, security-guards, and local leaders	The study described the effect of the eviction of sex workers from a geographical area on their vulnerability to HIV.

46	Swain et al.	2011	Cross-sectional	Quantitative research survey	Female sex workers	To understand the linkages between violence and the reproductive health and HIV risks among a group of mobile FSWs in India.
47	Chakrapani et al.	2007	Cross-sectional	Qualitative research in-depth interview	Kothi-identified MSM including those living with HIV	This qualitative investigation explored the experiences and contexts of stigma and discrimination among HIV-positive and high-risk kothi-identified men who have sex with men (MSM) in Chennai, India, and ramifications for HIV prevention.
48	Chakrapani et al.	2008	Cross-sectional	Qualitative research in-depth interview	HIV-positive kothi-identified MSM	This study explored experiences and contexts of HIV risk and prevention among HIV-positive kothi-identified men in Chennai, India.
49	Chakrapani et al.	2011	Cross-sectional	Qualitative research focused group discussion	Kothi-identified MSM & Aravanis	The goal of this study was to inform effective interventions to increase ART access for kothis and aravanis living with HIV in Chennai; to that end, we aimed to identify and understand barriers faced by these marginalized groups in accessing free ART at government treatment centres.
50	Misra et al.	2009	Review article	Secondary data analysis, desk review, argumentation	MSM and TG people	This paper examines the successful fight against the provision in Section 377 of the Penal Code of India that criminalised private consensual sex between adults of the same sex.
51	Solomon et al.	2010	Cross-sectional	Mixed method focused group discussion and survey	Married MSM and Wives of Injection Drug Users	To highlight the impact of high-risk behaviour on the wives of married MSM and injection drugs users, offer recommendations for future prevention initiatives, and identify gaps in our current knowledge of the influence of male sexual and drug use behaviours on families' risks.
52	Thompson et al.	2013	Cross-sectional	Qualitative research	Self-identified kothis	This qualitative article aimed to frame the negative attitudes of kothis (apparently included both feminine kothi-identified MSM as well as male-to-female transgender people) towards their own sexualities from a medical anthropological perspective emphasising how social, cultural and moral processes lead to such

						negative attitudes towards self.
53	Logie et al.	2012	Cross-sectional	Quantitative research survey	MSM	This study examined the influence of sexual stigma, gender non-conformity stigma (GNS) and HIV-related stigma (HIV-S) on depression among MSM in South India.
54	Latkin et al.	2010	Longitudinal study	Quantitative research survey	Injection drug users	To examine the relationship between perceived drug use stigma, acquiescence response bias, and HIV injection risk behaviours among current injection drug users in Chennai, India.

APPENDIX 2. SUMMARY OF GREY LITERATURE ON HIV-RELATED STIGMA IN INDIA

No.	Author(s)	Published by	Year of publication	Study design	Methods	Study population(s)	Study objectives
55	Bharat et al.	UNAIDS Geneva	2001	Cross-sectional	Qualitative research focused group discussion, in-depth interview and key informant interview	HIV-positive people (men & women), commercial sex workers, gay men, hijras, hospital staff, doctors, NGO staff, nurses, industry personnel, social welfare officers, lawyers/activists, insurance expert, gay activists	This study aimed to examine forms, determinants, and outcomes of HIV/AIDS-related discrimination, stigmatization, and denial in India, and to explore their possible social, demographic, and cultural correlates.
56	Darak et al.	Prayas	2005	Qualitative and Exploratory	Mixed method in-depth interview and survey	HIV-positive people	To understand: <ul style="list-style-type: none"> - Dimensions, context, levels and forms of stigmatisation from the perspective of people living with HIV/AIDS - Diffusion of information of a person's HIV status and the apparent reasons for that - Different support systems for PLHIV - Various strategies adopted by PLHIV for coping with the disease - Stigmatisation in the health care system; its forms, context and consequences.
57	Pulerwitz et al.	Population Council	2010	Review/Synthesis paper	Critical analysis/review and synthesis	PLHIV, key populations	This series of synthesis papers presents lessons learned and best practices on six key topics that Horizons investigated: HIV-related stigma, access to antiretroviral therapy, men who have sex with men, orphans and vulnerable children, HIV and gender, and prevention of mother-to-child transmission of HIV.
58	Chakrapani et al.	South India AIDS Action Programme	2007	Cross-sectional	Mixed method survey, focused group discussion and key informant interview	PLHIV, FSW, MSM and Hijras, and men/women from the 'general population'	<ul style="list-style-type: none"> - To document the extent and nature of various forms of stigma, discrimination and violence faced by PLHA and marginalized groups like FSWs, MSM, and Hijras. - To understand the possible reasons behind the stigma, discrimination and violence faced by PLHA and marginalized populations.

59	APN+	APN+	2009	Cross-sectional	Mixed method survey, focused group discussion and key informant interview	HIV-positive women, MSM/TG and injection drug users	To explore the experience of women, men who have sex with men/transgender people (MSM/TG) and injecting drug users (IDUs) living with HIV in accessing ART and other HIV-related healthcare services.
60	Chakrapani et al.	Research for Sex work online journal	2004	Review article	Primary data and evidence from other studies of the first author	Hijras/TG people	This article, based has documented various kinds of stigma and discrimination faced by aravanis (male-to-female transgender people) in sex work in the health care settings
61	Chakrapani et al.	INP+	2008	Cross-sectional	Qualitative research focused group discussion and key informant interview	MSM, Hijras/Aravanis, Female sex workers & Injection drug users	This qualitative study explored barriers and facilitators to knowing one's HIV status among marginalized populations - men who have sex with men (MSM), Hijras/Aravanis (Transwomen), female sex workers (FSW), and injecting drug users (IDUs) in Chennai, India.
62	Chakrapani et al.	Futures Group International Pvt. Ltd.	2011	Case study design	Qualitative field research and literature review	Full-time staff of NGOs/CBOs working with MSM; peer educators and beneficiaries	This report demonstrates the interconnections between HIV and sexual violence, discusses the existing sexual violence prevention strategies and support services for victims of sexual violence, and put forwards action points to mitigate the impact of the syndemic.
63	Prabhugate, P.A.	(Author's PhD Thesis)	2011	Cross-sectional survey	Interviews and secondary data analysis	MSM	The present study examined the psychosocial correlates of stigma and self-esteem of Men who have Sex with Men (MSM) in Mumbai, India.
64	Stangl et al.	The International Bank for Reconstruction and Development / The World Bank	2010	Results from pilot-innovative interventions	Case study methodology, In-depth interviews	MSM	To document the lessons learnt and success stories from the pilot-innovative interventions to tackle HIV and AIDS stigma and discrimination.
65	Chakrapani et al.	MCC, HST & ICMR	2013	Cross-sectional	Mixed methods	MSM & Hijras/TG	To examine the influence of sexual stigma (SxS)/gender non-conformity stigma (GNS), transgender identity stigma (TGS) and HIV-related stigma (HIVS: vicarious, felt normative, enacted and internalised) on mental health (depression) and

sexual risk (unprotected anal sex) among men who have sex with men (MSM) and hijras/transgender people in India.

66	Chakrapani et al.	INP+	2008	Cross-sectional	Qualitative research focused group discussion and key informant interview	IDUs living with HIV	To assist in developing policies and programs to ensure equity in ART access to IDUs, we explored the various factors that hinder free ART access for IDUs living with HIV in Chennai, India.
67	Chakrapani et al.	OSI	2009	Cross-sectional	Qualitative research focused group discussion and key informant interview	Male and female IDUs, Police official, NGO director and program manager	To explore the effects of the actions of law enforcement agencies (most notably, police activities) on access to and utilization of HIV prevention and treatment services for IDUs in Imphal in order to devise appropriate structural level interventions to improve their quality of life.
68	Chakrapani et al.	INP+	2010	Cross-sectional	Mixed method survey, focused group discussion and key informant interview	IDUs including PLHIV	To identify barriers and facilitators to access and adherence to TB treatment for IDUs, including PLHIV.
69	ICRW & Strive	ICRW	2013	Intervention	Pilot-testing of global HIV stigma reduction framework	Faculty, students, programme staff, FSWs, panchayat members, PLHIV, health workers, MSM, members of HR and CSR divisions, leadership team from industrial houses, community members	Pilot-testing and adoption of global HIV stigma reduction framework

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