Man In India, 93 (2-3) : 259-270

HIV/AIDS: KNOWLEDGE AND STIGMA AMONG WOMEN, WITH SPECIAL REFERENCE TO SCHEDULE CASTE COMMUNITY – IN KILMONAVOOR VILLAGE, TAMIL NADU

J. John Britto, A. Dunston Rajkumar and Thilakavathi. S.

Purpose: There is a growing concern on HIV/AIDS epidemic throughout the world in general and developing countries in particular. HIV weakens the immune system, making people vulnerable to infections and illness. Many opportunistic infections and malignancies are the major irrefutable manifestations of HIV illness. The mode of HIV/AIDS transmission is through blood and blood products, seminal and vaginal fluids, unprotected sex, infected blood transfusion, contaminated needles and artificial insemination. If the person is affected by HIV/AIDS, and manifestation and symptoms can be rapid weight loss, chronic diarrhoea, prolonged fever and persistence cough. Women who believe that they are in monogamous relationships are becoming infected because their husbands have had multiple sexual partners, if they are not faithful to their loved one. Although, media and other health related programme are enormously advocating the impact and prevention of HIV/AIDS, yet, the victims are trapped to this deadly disease are more. However, according to NACO, and National Family Survey reports are indicating that, the incidents are drastically reducing in India.

Design / Methodology / Approach: This study mainly focuses on objectives such as to study the knowledge, awareness and stigma of the HIV/AIDS among the scheduled caste community and their health, social and economical status, the utilization of the health facilities offered by the hospitals as well as the stigma attached in this regard. Primary data using convenient sampling through questionnaire and interview method and secondary data from wide range of literature and various journal publications have been utilized.

Research Limitation: The researcher had taken entire village population for this study. Only women are included and based on systematic random sample selection, only 234 samples are selected and included. Although, in the main village, there are other dominant caste people are living, only this study is limited particular to SC community.

Practical Implication: This study would help in improving their knowledge about HIV/AIDS illness and the available medical facilities as well as the stigma attached to the illness where by eliminating the wrong ideas and belief about the illness. The saying goes like that "Prevention is better than Cure, but, awareness, knowledge, and impact of the illness is more vital than the cure. Many people still do not know their HIV status, because of neglecting and negotiating the make use of condom for safety and precaution. Also, stigmatizing a victim is malicious act and is against the Human Right violation. To eradicate this disease, the people must be aware and has adequate knowledge about the disease, prevention and control method, rather than, to stigmatize and victimize the PLWA. Stigma and discrimination are abhorrent everywhere, resulting in human rights denied and life diminished. Stigma is a means of social control of a dominant group over those perceived to be socially inferior.

Stigma devalues individuals and groups based on characteristics such as sex, sexual orientation and gender identity, skin colour, caste level, religion, disease, or disability.

Address for communication: **J. John Britto, A. Dunston Rajkumar**, School of Social Sciences – VIT-University, Vellore and **Thilakavathi S.**, Deputy Director, Scientist E, National Institute of Epidemiology - ICMR – Chennai

Findings: The findings of this study has focused on Knowledge, Attitude and Stigma about HIV/AIDS among the SC women and brought out with genuine finding and suggestions to the policy makers.

Originality/Value: A study on HIV/AIDS Knowledge and Stigma among Women, in relation with special reference to SC Community is the original work of the author.

Keywords : HIV/AIDS, Knowledge, Stigma, SC women.

Introduction

India has the world's third largest population suffering from HIV/AIDS. However, the estimated number of HIV infections in India has declined drastically in recent years – from 5.5 million in 2005 to below 2.5 million in 2007. HIV/AIDS affect all sects of population, from children to adults, businessmen to homeless people, female sex workers to housewives, and gay men to heterosexuals. There is no single "group" affected by HIV. The causes and the consequences of HIV epidemic are closely associated with wide challenges to development, such as poverty, food, livelihood insecurity and gender inequality. Awareness means the consciousness, mindfulness, alterness and attractiveness.

Although the current data show that the global HIV/AIDS epidemic is stabilizing, statistics still report an unacceptably high level of infection and progress is uneven in many countries[1]. In 2007, approximately 33 million people worldwide were infected with the human immunodeficiency virus (HIV) **[1].** A person affected and living with HIV/AIDS (PLWHA) is undergoing medical troubles and also social problems related with the disease. One of the barriers in reaching those who are at risk or infected with HIV/AIDS is stigma[2]. Right from the beginning, the HIV/AIDS epidemic has been accompanied by an epidemic of fear, ignorance, and denial, leading to stigmatization of and discrimination against people with HIV/AIDS and their family members[3].

HIV/ AIDS related stigma and the resulting discriminatory acts create circumstances that fuel the spread of HIV[4] Stigma enhances secrecy and denial, which are also catalysts for HIV transmission[5]. Although the reaction to PLWHA varies, with some PLWHA receiving support which positively affects them, HIV/ AIDS stigma negatively affects seeking HIV testing, seeking care after diagnosis, quality of care given to HIV patients, and finally the negative perception and treatment of PLWHA by their communities and families, including partners[6,7,]. It isolates people from the community and affects the overall quality of life of HIV patients[2, 3, 6, and 8].

Definitions of Terms

Terms and Concept used

- ***Knowledge*:** According to Collins English Dictionary (1991: 860) defines that "Knowledge as the facts, feeling or experiences known by a person or groups

of people; state of knowledge; awareness, consciousness, or familiarity gained by experiences or learning; specific information about the subjects.

According to wikipedia.org Knowledge is a familiarity with someone or something, which can include information, facts, descriptions, or skills acquired through experience or education. It can refer to the theoretical or practical understanding of a subject. It can be implicit (as with practical skill or expertise) or explicit (as with the theoretical understanding of a subject); and it can be more or less formal or systematic.

- ***Attitude:*** According to Collins English Dictionary 1991:98; Attitude is "the way a person views something or tends to behave towards it, often in an evaluate way"

  According to wikipedia.org, an attitude is a favorable or unfavorable evaluation of something. Attitudes are generally positive or negative views of a person, place, thing, or event— this is often referred to as the attitude object. People can also be conflicted or ambivalent toward an object, meaning that they simultaneously possess both positive and negative attitudes toward the item in question.

- ***Stigma:*** According to Rethink's website comments that "stigma has been variously described as "a mark or sign of disgrace or discredit" (Oxford English Dictionary) to "an attribute that is deeply discrediting and that reduces the bearer from a whole and usual person to a tainted, discounted one" Stigma can be seen as an attitude, located at the individual level, based on ignorance, prejudice and fear of a particular group.

  Etymologically, the concept of "stigma" derives from a Greek word referring to a tattoo mark. It generally has two meanings. One is derived from Christianity and denotes bodily marks which resemble those of the crucifixion of Jesus Christ—they are attributed to divine favour. The second meaning is secular, namely marks of disgrace, discredit, or infamy [9].

Although the term knowledge, Attitude and Stigma are explained through literal meaning from the reputed English dictionary, the researcher used these terms to find out the basic knowledge, attitude and stigmatization among the SC women towards HIV/AIDS and the define given objectives.

Review of Literature

Today, the term "stigma" is applied more to social disgrace than to any bodily signs[10]. Stigma is generally recognized as an "attribute that is deeply discrediting" that reduces the bearer "from a whole and usual person to a tainted, discounted one"[11]. Stigma is also used to set the affected persons or groups apart from the normalized social order ("us" against "them") and this separation implies devaluation[2, 9, 12, 13].

HIV stigma is shaped not only by individual perceptions and interpretations of micro level interactions but also by larger social and economic forces [6]. It is a social construct, which has significant impact on the life experiences of individuals both infected and affected by HIV [14]. Stigma includes prejudice and can lead to active discrimination directed toward persons either perceived to be or actually infected with HIV and the social groups and persons with whom they are associated [15]. Since not all stigmatizing attitudes result in overtly discriminatory behaviors, Campbell *et al.* [6] described discrimination as negative behavior and stigmatization as any negative thoughts, feelings, or actions toward PLWHA irrespective of whether people are discriminated because they know that they are devalued.

In other words, discrimination has to be acted out externally while stigmatization can be overt or constitute libel, slander, or defamation of persons who are stigmatized [9]. Stigma is generally accepted to be an "attribute that is deeply discrediting" that reduces the bearer "from a whole and usual person to a tainted, discounted one" [16]. Valid knowledge about HIV/AIDS, particular HIV transmission routes and a higher level of self-protection awareness were crucial to the positive change of attitudes and behaviours. [17] "HIV-related stigma and discrimination have been acknowledged as an impediment to mitigating the HIV epidemic since its early days, yet programming and activities to reduce stigma and discrimination have been given much less attention than other aspects of the epidemic. Fortunately, in recent years there has been an increase in the literature on HIV stigma as the issue has gained visibility and greater conceptual clarity and as means to measure stigma have been refined" [18,19,20,21]

Scope of the Study

The study was conducted in between December 2011 and January 2012 in a Scheduled Caste community village named Kilmonavoor in Vellore Panchayat, Tamil Nadu. This village is situated nearly 10 km away from Vellore city and the total population of this village is 762 houses. Only women are included and based on systematic random sample selection.

This study aimed to assess HIV/AIDS-related knowledge, sources and perceived need, its stigma among the Scheduled Caste women in Kilmonavoor Village, are expressing their personal feeling and attitude towards the HIV/AIDS infected patients in terms of Stigma.

Material & Methods

Descriptive Design study was employed in single stage without any interventions and since the researcher used systematic random sample technique, initially, total household are counted and select the household mothers on the basis of houses starting from house number 1, 3, 5, 7, 9, 11 and so for the entire village. The total size of this study is 254 women from each houses starting from the house 1, 3, 5, 7,

and so on and the total populations of the entire household are 762. Survey method was used, and the arrangement for collection, analysis of data in a manner that aims to combine relevant to research purpose.

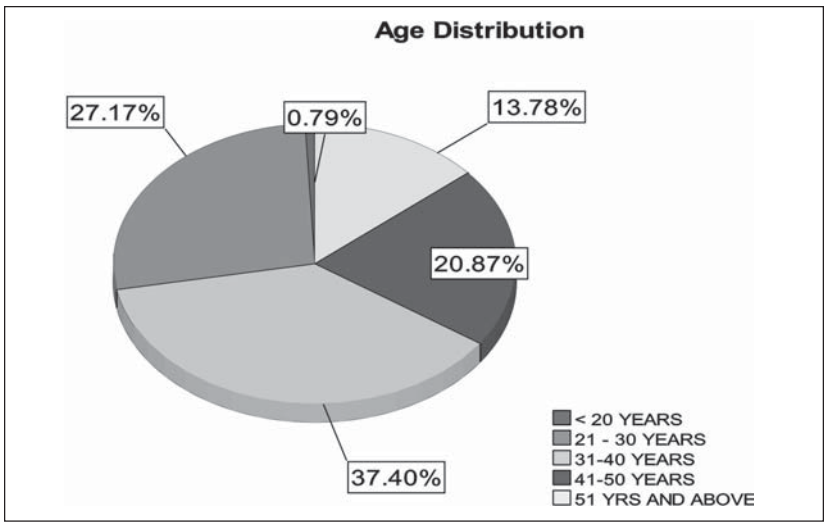
Pre-tested, semi structured questionnaire were used and trained Medical social workers were engaged in data collection in this village by explaining the questionnaire to the respondents to those who are not able to read and write. The collected data were cleaned for completeness and their consistency. Responses in each question were coded for simplicity of data entry.

Ethical consideration: A village level meeting was conducted prior to the study and the aim and objective of the study was explained very clearly and the entire villager were attended and we brief about the confidentially about their answers and the importance of providing the right information. Informal verbal consent was secured from the study subjects to participate in the study. The interventions provided were friendly and culturally acceptable.

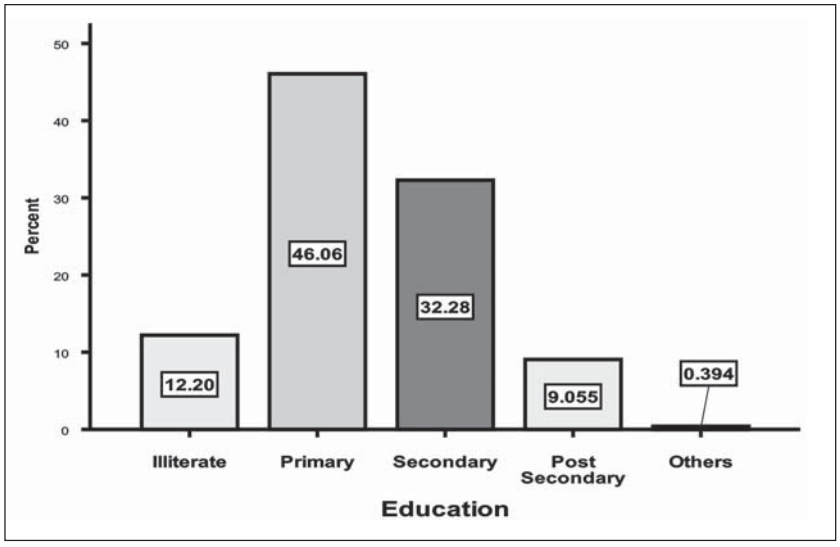
Results & Discussions

Demographic Variables

SOCIO - DEMOGRAPHICS		*n*	*%*
Age	< 20 Years	02	0.8
	21 – 30 Years	69	27.2
	31-40 Years	95	37.4
	41-50 Years	53	20.9
	51 Years and above	35	13.8
	Total	254	100.0
Education	Illiterate	31	12.2
	Primary	117	46.1
	Secondary	82	32.3
	Post Secondary	23	9.1
	Others	01	0.4
	Total	254	100.0
Economic Status of the respondent	10,000 and above	18	7.1
	5,000 to 10,000	65	25.6
	1 to 5000	104	40.9
	House Wife	67	26.4
Marital Status	Un married	05	2.0
	Married	240	94.5
	Divorced	05	2.0
	Widowed	04	1.6
	Total	254	100.0



The above pie diagram-01 shows the age of sample respondents. The average age of the sample respondents is 45, the maximum respondents fall under the category of 31 and 40 years of age, hence the data contributed by the respondents are young adult, reliable, relevant and accurate to fulfill the objectives under study.



The Bar Diagram – 02 shows that most of the sample respondents are literate and they are found with the qualifications right from primary school to post graduate and less number of 31 respondents bearing 12 per cent are illiterate. Hence, the

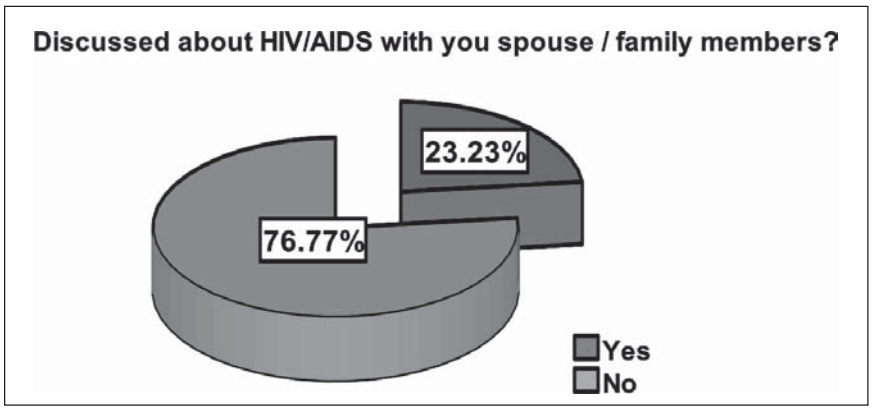
information given them will be highly useful and capable of effective inference in achieving the objectives

- As the average income of sample respondents is Rs.5040/= per month, most of them are just above poverty line and this would may affect their socio-economic status and hence, it would play vital role in the current study.
- The researcher has met utmost all streams of people with reference to their marital status. Maximum numbers of 240 respondents bearing utmost 95 per cent are married and they are the target audience for the current study

Knowledge Variable

Awareness & Knowledge			*n*	*%*
Awareness / Heard of the disease (HIV/AIDS)		Yes	138	54.3
		No	116	45.7
		Total	254	100.0
Awareness of the death of the HIV/AIDS Patients		Yes	18	7.1
		No	153	60.2
		Do not know	83	32.7
		Total	254	100.0
Knowledge (HIV/AIDS transmitted from mother to Child)		Yes	105	41.3
		No	66	26.0
		Do not know	83	32.7
		Total	254	100.0
Knowledge of STI can increase the chances of HIV/AIDS		Yes	73	28.7
		No	181	71.3
		Total	254	100.0
Prevention of HIV/AIDS	Abstain from sex		21	8.3
	Use condoms		09	3.5
	Use condoms with high risk persons		03	1.2
	Stay faithful & restrict sex with one partner only.		133	52.4
	Limit number of sex partners		01	0.4
	Avoid sex with prostitute		16	6.3
	Avoid Sex with Homosexual		03	1.2
	Avoid Blood Transfusion		20	7.9
	Avoid Injections		11	4.3
	Avoid Kissing		02	0.8
	Avoid mosquito bites		04	1.6
	Seek protection from traditional healer		01	0.4
	Other		03	1.2
	Do not know		27	10.6
	Total		254	100.0

- It is observed that 54 per cent know the disease of AIDS and 46 per cent are not aware of the disease, hence the study is inevitable under these circumstances.
- When the researcher asked about their awareness about the AIDS victim in and around the village, it's found that 60 per cent of the people say No, and 33 percent under don't know category and only 7 per cent know the causes of AIDS Virus. This would improve the scope of the study.
- Again, to explore their knowledge about the transmission of the disease, the data given by the sample respondents regarding whether AIDS can be transmitted from mother to a child. 105 respondents out of 254 representing 41 percent have agreed on this. 26 per cent do not agree with this and 33 per cent come under indifferent category.



- The above pie diagram shows that there are numerous media and propaganda about the disease, the researcher found that nearly 77% of the respondents are ashamed, feel shy to discuss about the disease in their family.
- Data regarding the relationship of STI and AIDS opined by the sample respondents. 29 per cent have agreed that there is possibility of getting AIDS when the people have the disease of STD, 72 per cent have disagreed with this.
- When the question about the prevention and avoiding of HIV/AIDS, 53 per cent of the sample respondents are of the opinion that if the people have only one life mate, they can avoid AIDS. Other factors have insignificant response, such as abstain from sex (8.3%), Avoid Blood Transfuse (7.9) and Avoid Sex with prostitute (6.3 per cent) and other variables show negligible per cent of less than 5 per cent.

Stigma Variables

ATTITUDE		*n*	*%*
Acceptance of the family members / spouse affected by HIV/AIDS.	Accept	143	56.3
	Segregate	67	26.4
	Do not know	44	17.3
	Total	**254**	**100.0**
Willingness to arrange marriage to your son / daughter to a family, where a family member is infected by HIV	Yes	19	7.5
	Certainly not	210	82.7
	Do not know	25	9.8
	Total	**254**	**100.0**
Opinion to allow HIV/AIDS patients / family to stay in you street or locality.	Yes	91	35.8
	Certainly not	129	50.8
	Do not know	34	13.4
	Total	**254**	**100.0**
Willingness to buy food / coffee /tea / snacks prepared by a vendor, who is HIV positive	Yes	81	31.9
	Certainly not	139	54.7
	Do not know	34	13.4
	Total	**254**	**100.0**
Awareness & Seen condom	Yes	73	28.7
	No	89	35.0
	Do not know	92	36.2
	Total	**254**	**100.0**

- Data regarding the opinion of sample respondents regarding whether the AIDS patients are isolated from the family or accepted inside the family. It is encouraging to see that around 57 per cent of the sample respondents are willing to accept inside the family and give them mental and physical support, 27 per cent of the sample respondents would like to separate from the family and other 17 per cent come under indifferent category.
- Regarding the marriage, the sensitive response of the sample respondents whether they arrange marriage of their sons/daughters with the family where any one of them is infected by the HIV. It is very shocking to note that 83 per cent of the sample respondents have opined that they will not get their children to married with the family where even if one is infected with HIV.
- Data regarding whether sample respondents are willing to stay in the street of HIV infected people; 51 per cent have declined, 36 per cent have agreed that they don't have any objections to stay along with HIV infected people.
- The researcher asked about the fact whether the respondents are willing to buy eatables prepared by vendors who are infected HIV. Around 55 per cent of the people gave negative opinion whereas, 32 per cent of the respondents are not afraid of taking eatables from these shops.
- It's an interesting fact about opinions of respondents who are willing to receive medical treatment from HIV infected health care workers. Around 39 per cent

of the people have given negative opinion and 27 per cent of the people do accept their willingness to receive treatment though they are infected with HIV and the remaining 34 per cent come under indifferent category.

- In response to awareness of condom, it has been found that 28 per cent are aware of condom, 35 per cent are not aware of condom and it is surprising to see that 36 per cent are under indifferent category (Do not know).

Summary of the Findings

This study attempted to explore the awareness, knowledge misconceptions and stigma with regards to HIV/AIDS of the scheduled caste women in the village. The awareness of the participants on the major modes of HIV/AIDS transmission (41% says through mother to child). Although their knowledge and awareness of the disease (54%), nearly 77% of the respondents are reluctant to talk and have a casual discussion about the disease, due to stigmatization.

NACO, TANSACS and various non governmental organisations are involved in various awareness camps, yet the stigmatization about the disease has not reduced. 43% of the respondents are not accepting their family members, who are affected by HIV/AIDS. Same as, 83% of the respondents are not willing to arrange their children's marriage with the HIV infected family members.

This study also indicated the level of stigmatizing and discriminating attitude among the study participants in the different intervention groups with variation from one item to another. The least stigmatizing and discrimination attitude observed was on HIV/AIDS positive patients are not allowed and encouraging to stay in their street. Also, the respondents are not willing to buy and drink from the HIV infected vendor's shop and even, if the medical personal are not exempted from the stigmatization and discrimination, more than three fourth of respondents are not willing to take the treatment from the HIV infected MPHW and other health care workers.

Suggestions & Conclusion

More and more awareness camps should be conduct periodically to enrich their knowledge about the disease. The local village committee should take initiative to bring the health personnel to deliver talks on this burning and deadly killer disease. Misconceptions were found to be predictors of HIV related stigma and discriminations, but it could be eliminating through street theatre play by the NGO. Remarkable reduction in HIV related misconceptions, stigmatizing, and discriminatory attitude were observed using the combined interventions. So, combined IEC interventions need to be transmission and prevention of HIV/AIDS and the associated stigma and discrimination and in depth study can be conducted in many area, different groups and communities to explore on knowledge, attitude, stigmatizing and discriminations.

Notes & References

1. Joint United Nations Programme on HIV/AIDS (UNAIDS) AIDS epidemic update, 2008, *http://data.unaids.org/pub/EPIslides/2007/2007_epiupdate_en.pdf.*
2. Greeff M, Phetlhu R, Makoae LN, *et al.* Disclosure of HIV status: experiences and perceptions of persons living with HIV/AIDS and nurses involved in their care in Africa. Qualitative Health Research. 2008; 18(3): 311–324. [PubMed]
3. International Center for Research on Women (2002) Addressing HIV-Related Stigma and Resulting Discrimination in Africa: A Three-Country Study in Ethiopia, Tanzania, and Zambia. Information Bulletin, March.
4. Busza, J. (1999). Literature Review: Challenging HIV-Related Stigma and Discrimination in Southeast Asia: Past Successes and Future Priorities. Population Council Horizon
5. Rankin W. W., Brennan S., Schell E., Laviwa J., Rankin S. H. The stigma of being HIV-positive in Africa. PLoS Medicine. 2005; 2(8): p. e247.
6. Gerbert B., Sumser J, Maguire BT. The impact of who you know and where you live on opinions about AIDS and health care. *Social Science and Medicine.* 1991; 32 (6): 677–681. [PubMed]
7. Herek G. M., Glunt E. K. An epidemic of stigma: public reactions to AIDS. American Psychologist. 1988; 43(11): 886–891. [PubMed]
8. Campbell C., Nair Y., Maimane S., Nicholson J. 'Dying twice': a multi-level model of the roots of AIDS stigma in two South African communities. *Journal of Health Psychology*. 2007; 12(3): 403–416. [PubMed]
9. Gilmore N, Somerville MA. Stigmatization, scapegoating and discrimination in sexually transmitted diseases: overcoming 'them' and 'us' Social Science and *Medicine*. 1994; 39(9): 1339–1358. [PubMed]
10. Hardon A., Boonmongkon P., Streefland P., *et al.* Applied Health Research Manual Anthropology of Health and Health Care. The Netherlands: The Hague: CIP-Data, Koninklijke Bibliotheek; 1995.
11. Goffman E. Stigma: Notes on the Management of Spoiled Identity. New York, NY, USA: Simon and Schuster; 1963.
12. Mawar N, Saha S, Pandit A, Muhajan U. The third phase of HIV pandemic: social consequences of HIV/AIDS stigma & discrimination & future needs. *Indian Journal of Medical Research*. 2005; 122(6): 471–484. [PubMed]
13. Strebel A., Crawford M., Shefer T., *et al.* Social constructions of gender roles, gender-based violence and HIV/AIDS in two communities of the Western Cape, South Africa. SAHARA. 2006; 3(3): 516–528.
14. Taylor B. HIV, stigma and health: integration of theoretical concepts and the lived experiences of individuals. *Journal of Advanced Nursing*. 2001; 35(5): 792–798. [PubMed]
15. *Http://www.cdc.gov/mmwr/preview/mmwrhtml/mm4947a2.htm.*
16. USAID. Signs of hope, steps for change, The Next steps for positive change in Attitudes that cause HIV/AIDS-related stigma and discrimination; 2005.
17. World Health Organization (WHO). Child and adolescent health and development (CAH). Young people-a window of hope in the HIV/AIDS pandemic. Available from: *http:// www.who.int/child-adolescent-health/ HIV/HIV_adolescents.htm*

18. Nyblade, L. and K. MacQuarrie (2006). Can We Measure HIV/AIDS-related Stigma and Discrimination? Current knowledge about quantifying stigma in developing countries. Washington, D.C., USAID.

19. Genberg, B. L., S. Kawichai, A. Chingono, M. Sendah, S. Chariyalertsak, K. A. Konda and D.D. Celentano (2008). "Assessing HIV/AIDS Stigma and Discrimination in Developing Countries." *AIDS and Behavior* 12(5): 772-780.

20. Stein, J. A. and L. Li (2008). "Measuring HIV-related Stigma Among Chinese Service Providers: Confirmatory Factor Analysis of a Multidimensional Scale." *AIDS and Behavior* 12(5): 789-795.

21. Visser, M. J., T. Kershaw, J. D. Makin and B. W. C. Forsyth (2008). "Development of Parallel Scales to Measure HIV-Related Stigma." *AIDS and Behavior* 12(5): 759-771.