

Summer Training Report

By

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Part 1:

**Human Immunodeficiency Virus Stigma Reduction among Patients and Healthcare
Provider in India.**

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Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ARD	AIDS-related deaths
ART	Antiretroviral therapy
FSW	Female Sex Worker
HTG	Hijra/Transgender people
HIV	Human Immunodeficiency Virus
HRG	High Risk Group
ICMR	Indian Council of Medical Research
IDU	Injecting Drug Users
NACO	National AIDS Control Organization
NACP	National AIDS Control Program
MSM	Men having Sex with Men
PLHIV	People Living With HIV
PMTCT	Prevention of Mother to Child Transmission of HIV
TRG	Technical Resource Group
UNAIDS	Joint United Nations Program on HIV/AIDS
WHO	World Health Organization
SDG	Sustainable Development Goals
SAD	Stigma and Discrimination
NHP	National Health Program
STI	Sexually transmitted infection

Abstract

HIV/AIDS related stigma is a prime hurdle to eradication and its pay hardship and suffering on PLHIV, which leads them to avoid the acceptance to this disease. For this it effects the community and individual. This review paper is based on existing research literature on HIV/AIDS stigma reduction in India. To understand is HIV stigma affects the achievement of end the AIDS epidemic by 2030? 20 publication were selected carefully, specially focused on HIV stigma among healthcare provider and patients and some are Stigma reduction intervention. Research analyzing the interdependence between stigma and HIV services, because stigma effects the treatment, program and leads to virologic failure. Interference is required to direct different forms of stigma -enacted, perceived, internalized and vicarious how leads depression. Overall, this review suggests developing the action or program against HIV stigma and achieve the govt's goal of stigma reduction by which achieve the goal end the AIDS epidemic by 2030.

Keywords: HIV/AIDS, Stigma, Discrimination, PLHIV, Attitudes, Interventions, India.

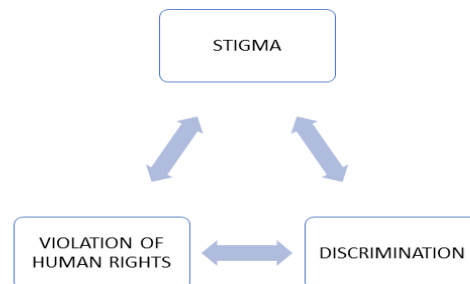
Introduction

Stigma is a hurdle in worldwide fight against HIV/AIDS prevention [1]. National AIDS Control Program in India also find stigma is the major block of HIV prevention. The key guideline of 3rd phase of NACO address the “stigma and discrimination” [2]. Stigma indicates the negative feelings and behavior against individual, groups and communities. Stigma is a negative belief which leads to discrimination, the action comes from the believe. Contradictory and lack of knowledge about transmission perceive stigma [3]. Hatred hurts more than the virus. Stigma also delay the seeking care or treatment and motivate the PLHIV to disclose avoidance of their disease status to their family ,community .stigma also disrupt medical treatment which leads to virologic failure, also work as a barrier to prevention of mother -to-child transmission [4].Research shows that worldwide PLHIV face lack of care ,violence, school drop, labeling hospital files and beds by which they lost the confidentiality ,leaving home which effects their quality of life [5] [6].Though with the advance treatment HIV transform from a near death sentence to manageable chronic diseases, stigmatization and discrimination act prevent PLHIV to reach to the effective HIV treatment [7]. And

unfortunately, health personal also involve in this hatred game. For the stigma they act weird with the PLHIV they use double gloves, mask and sometimes also deny giving treatment to them [8].

According to Goffman's theory of social stigma is "an attitude, behavior, or reputation which is socially discrediting in a particular way, it causes an individual to be mentally classified by others in an undesirable, rejected stereotype rather than in an accepted, normal one" [9] [10]. Sociologist Scambler also said about felt and enacted stigma, this enactment is a small part of an overall stigma [11]. According to Deacon concept of stigma is- discrimination, a act or behavior arise from stigma, that drawback people in various ways [12]. In India classified by four specific forms of stigma. Two is interpersonal form of stigma, those are: enacted(discrimination), an individual personally felt and Vicarious that is not personal experienced by the individual it is basically the story of other persons experience. Other two are Felt Normative which is the perception of stigma prevalence and internalized stigma, the personal support of stigma beliefs. All the four category has a correlation with each other. The disclosure avoidance is a primary outcome of stigma and the psychological distress is the primary outcome of the disclosure avoidance [13].

The stigma is a belief and discrimination are an action which comes after belief. [14]



[compiled by author](#)

Methodology:

Search data in PubMed /Google Scholar based on six keywords HIV/AIDS, Stigma, Discrimination, PLHIV, Attitudes, Interventions, India, with restrict the time period of last ten years. These keywords give a wide number of results without restricting the particular state in India. But initially I choose a list of 25 articles. Specially with the HIV /AIDS stigma in India as a key objective,

published in English language periodicals up to April 2020, were included Review articles, case studies. A cross search also made on website of Indian National AIDS Control Organization (NACO) and UNAIDS and WHO. From these 25 articles I include carefully for resulting only 15 and 10 were excluded because of the irrelevance.

Research Question:

Is HIV related stigma being a potential barrier to achieve the target of eradicating AIDS as a public health threat by 2030?

Objectives:

- To understand the intricacies pertaining to HIV-related stigma in India and its effect on accessing HIV healthcare.
- To outline possible solutions for mitigating HIV-related Stigma in India.

Result & Discussion:

India has 3rd largest HIV epidemic in the world [15]. HIV estimation 2017 stated that India HIV prevalence among adults (aged 15-49) was estimated 0.2 per cent. This figure is small compared to most other middle-income countries but because of India huge populations (1.3 billion) this equates to 2.1 million people living with HIV [16, 15]. India stands committed to achieve the sustainable development goal (SDGs) to achieve end of AIDS as a public health threat by 2030 through its National AIDS Control Program, National Health Policy (NHP 2017) and National Strategic Plan for HIV /AIDS and STI 2017-2024 with a well define road map and has articulate medium term for 2020. The 2020 targets are – (a) cutting down new HIV infections by 75% from the baseline value of 2010. (b) reach to the 90-90-90 target. (c) To estimate mother-to-child transmission of HIV and syphilis by 2020 and (d) To remove HIV /AIDS associated stigma & discrimination by 2020. These targets are enduring with Global fact track target progressing action to end the AIDS epidemic by 2030. National Health Policy 2017, promises to achieve the global target of 90-90-90 for HIV /AIDS by 2020, that is:- “90% of all people living with HIV will know their HIV status. 90% of all people with diagnosed HIV infection will receive sustained Antiretroviral therapy. 90% of all people receiving Antiretroviral therapy will have viral suppressions” [2].

And here as per 2017 latest HIV estimation 21.4lakhs (2140000) know their status. 14 lakhs are diagnosed with HIV and 11.8 lakhs people living with HIV were on life saving ART, means still have not reached out 47% in the PLHIV category, and <50% are on ART. Which indicates still India only at about 75% of the first 90 and the figures are far below for the 2nd and 3rd 90s. Stigmatization and discrimination (SAD) play a major role of hardship and lagging behind the access and attachment to HIV treatment and support programs among people living with HIV (PLHIV), so they are being left out to leads a productive life and it also being a barrier of preventing farther infection [17]. So, it is very necessary to achieve the goal of ending the pandemic diseases HIV by 2030 which is set by the UNAIDS, focus on the 4th aim of the 2020 targets [2].

Diseases stigma is a process by which one can experience discrimination, diminution, it holds a negative and unfair beliefs about the diseases which make disadvantage both the individual and the community [10]. It works as a barrier of accessing health and social care in a right time. The finding from these studies depending with regards the behavior towards PLHIV. The cross-sectional studies show enrolled doctors, nurses, ward staff in both governmental and non-governmental in Mumbai and Bengaluru India. Here approximately 70% of doctors and nurses indicated that they had received some form of HIV training, compared to 44% of ward staff. Despite their higher levels of HIV education, doctors and nurses did not score sufficiently higher on transmission knowledge than ward staff. At least half of the participants healthcare provider said that they would stop attending or prefer extra gloves or protection with the patient who are living with HIV/AIDS. In this proportion was higher among nurses and doctors than ward staff. But rather than doctors more nurse and ward staff stated that PLHIV need a separate clinic or chamber for seeking treatment [4]. Also analyses the other studies showed that 49.0% of PLWHA experienced medical discrimination, and 55.3% received discriminatory treatment, 48.4% experienced refusal of treatment, 36.4% had private information leaked and 12.9% received mandatory test. However, 52.2% patients chose to endure discrimination in silence. Compared with the Asymptomatic HIV-infected patients, AIDS patients perceived more medical discrimination.

And most of the health providers are blame the infected people and also hold a thought about the high risk group get what they deserve. All over the culture HIV stigma can increase the

possibilities of sexual risk taking by bringing out the hardship and suffering on PLHIV as well as it prevents them to disclose their infection to their partner and child which make delay on their testing, counseling which makes a barrier to prevent of mother-to-child transmission (PMTCT) [18]. So, it also becomes a barrier to vaccine research and to deter infected individuals from seeking timely medical treatment [17]. PLHIV have reported avoiding or delaying treatment seeking for STI/HIV infections, out of fear of public humiliation and fear of discrimination by healthcare workers. So, most of the time stigma fears accelerate the virologic failure by living medical regimen or delaying in testing and treatment services, when it needed which also helps to develop and transmission a drug-resistant virus. So, at the end of the day it is not the virus or the diseases that kills people, but it is the hatred and discrimination against them for that they do not test and for that the virus being transmitted. In India the High-Risk Groups are Female Sex Workers (FSWs), Men who have Sex with Men (MSM), Injecting Drug Users (IDU), Hijra and Transgenders (HTG), Prisoners and Bridge Populations such as Migrants and Long-Distance Truckers [16]. So when seek treatment these group face enacted ,discrimination or a rude abandoned behavior from healthcare because of stigma. So it is finding that the PLHIV avoid to disclose their status not always for facing the discrimination ,they also face the vicarious and for that reason they get a shape for felt normative stigma beliefs, the perception of prevalence stigma which they experience from the community against the other person. It holds them back from disclose. Study shows that sometimes persons also felt that the behavior that they receive from society they deserve it; this type of thought comes their mind for the internalized stigma about the diseases. It is also analyzed that Stigma; avoidance disclosure and depression all are corelated. PLHIV felt normative stigma beliefs for the enacted and vicarious stigma which is co-related with disclosure avoidance. And the enacted stigma, internalized stigma and disclosure avoidance associated with depression symptom. Basically, stigma also effected the educated people in a same range as the uneducated people because it is not only about the education it is all about lack of knowledge of the modes of transmission of HIV ,because as the PLHIV rejected by the family, community and from the workplace also they rejected from medical treatment [17] [19]. In many reports shows that more than 60%of men PLHIV and more than $\frac{3}{4}$ of female PLHIV have face discrimination of both health facility government and the private [17]. Many healthcare provider and facilities found deny providing care and also many doctors deny to delivery of

the HIV positive women [8] .So if we want to decrease or eliminate the stigma then we have to focus on spreading knowledge about the mode of transmission of HIV, also have to focus mainly on IEC activities and media and government also have to play a vital role against HIV stigma. Otherwise with so many program or strategy stigma will prevent the implementation.

Actually, though science has an exponential progress but when it comes to the mindset it has not been changed. We have our believe system somewhere that stops us to treating the PLHIV equally. Despite of receiving HIV training, the healthcare provider has misconception about the HIV virus transmission knowledge, which creates a highly stigma among them and those stigmata reflects on their behavior as discrimination and then they started offensive behavior like: Delaying in providing treatment, Use extra precautions like extra gloves, mask etc. Sometime denying for treatment. Use different OPD /place for PLHIV. Maintain distance Create peculiar facial expression. Which creates very offensive, very hard situation and also the PLHIV started to feel left out which mainly kills them more rather than the virus. If the doctor or the other healthcare provider have that type of thinking after receiving so many trainings then, think about the people who live in a rural area or those who are neither involve in healthcare nor receiving any training program about it.

Overview of HIV/AIDS in India, HIV Estimations 2017:

According to NACO in 2017, adult (15-49 years) prevalence estimation was 0.22% in India. Approximately 21.40 lakh PLHIV in the country. 87.58 thousand people were newly infected with HIV in 2017, while 69.11 thousand PLHIV died from AIDS-related causes in the same year [2]. With 3.30 lakh PLHIV, Maharashtra had the highest number of PLHIV contributing 15% to the total PLHIV size in the country. Andhra Pradesh 2.70 lakh, Karnataka 2.47 lakh, and Telangana 2.04 lakh are other States with PLHIV number in the range of 2 to 3 lakh. West Bengal had 1.44 lakh Tamil Nadu 1.42 lakh, Uttar Pradesh 1.34 lakh and Bihar 1.15 lakh PLHIV in 2017. Together these 8 States contribute almost three fourths of total PLHIV in the country [16] .But we would not see an end to the epidemic as long as PLHIV feels unsafe and are forced to the fringes of their communities.

Mode of HIV Transmission:

Though India's epidemic is slowing down between 2010 and 2017, new infections declined by 27% and AIDS related deaths more than halved falling by 56%. But if we still have some myths about HIV that holds back to reach our target like: Sharing glass of water that get transmit the HIV virus .If you care HIV positive person then you can contact with HIV virus .If you hugging or shaking hands haring living space, sharing public amenities such as toilet, swimming pools. By animals or insects bite getting contact with HIV virus and so on,

Those myths need to be devasted to achieve the 2020 target. And must be known the right mode of transmission, because than only it can be possible to reduce the stigma about HIV, and then only the effected person can come freely to receiving the treatment of HIV(ART).But now despite of free antiretroviral treatment being available, uptake remain low as many people face difficulties in accessing clinic, and except their HIV status in public. For the stigma and discrimination PLHIV face social isolation, restriction from their rights, negative feeling.

Interventions to reduce HIV/AIDS related stigma:

Many stigma related interventions are going to grow but very few are effectively target transmission misconception and to increase interaction with PLHIV. Various program need to be design with the collaboration of PLHIV to increase the involvement of effected people, then it reduce the fear of transmission [4]. For increasing the knowledge of rights of PLHIV must be arrange the education program [20].Use professional role modes for inspired people and arrange training program hospital, clinics, nursing and medical school.

Details of Studies included for review:

Sr No	Authors/year	Study Site	Type of Study	Sample	Methods
1	Wayne T. Steward ,2012	South India	Qualitative	198	interview

2	Maria L Ekstrand,2020	Indian Institute	participation	3182	Interactive interventions
3	Maria L Ekstrand, Jayashree Ramakrishna,2013	Mumbai, Bangalore	qualitative	1020	Long interview focused on knowledge
4	Bimal Charles,2014	Tamilnadu	Quantitative	400	stigma, depression and quality of life Scale, Berger scale, Major Depression Inventory (MDI) scale, WHO BREF scale.
5	Shalini Bharat,2012	India	Qualitative &Quantitative	70	Article review
6	Kate Winskell,2011	sub-Saharan Africa	qualitative	75000	Discussion in interview
7	Adeline Nyamathi,2016	Rural Andhra Pradesh	qualitative	68	Interview and observation
8	Naresh Nebhinani,2013	(PGIMER), Chandigarh, North India	quantitative	100	stigma, depression

					and quality of life Scale
9	Kristi L. Stringer,2012	Alabama, Mississippi	qualitative	651	questionnaires'
10	Wayne T. Steward,2017	Mumbai, Bengaluru	qualitative	961	Key information Interview,
11	Elsa Heylen,2012	Mumbai, Bengaluru	qualitative	346	Key information Interview
12	Sudha Sivaram,2013	Chennai	qualitative	61	questionnaires
13	Shilpa M. Shah,2009	Bengaluru	qualitative	250000	intervention
14	Laura_Nyblade,2015	Karnataka	practical	36000	intervention
15	Nithin Kumar,2018	Dakshina Kannada District	Qualitative	104	Based on interview

CONCLUSION

Transmission-related fears and misconceptions, is mainly present limited experience working with PLHIV, blame and negative feelings towards PLHIV seem to be driving both endorsement of coercive measures and intent to discriminate against PLHIV in personal and professional contexts. The findings are the stigma reduction interventions need to target common misconceptions, even among highly educated and already trained healthcare providers and as well as general people. The fact that more experience with PLHIV was associated with lower rates of stigma and discrimination in all groups of people which suggests that:

- Interventions may be more effective if PLHIV are involved at all stages of intervention development and implementation to ensure sufficient and meaningful interactions.
- It might also be helpful to involve experienced healthcare providers, who have extensive experience treating PLHIV as role models for their junior colleagues to provide opportunities for observational learning, help change norms in the workplace.
- Doctors treating PLHIV respectfully are also likely to make an impression and set a standard for the other healthcare provider in their institutions, given the hierarchical nature of relationships in these settings.

Government should also take some major steps to reduce the stigma and discrimination about HIV. Government should increase investments in health education to improve people's knowledge of HIV and its modes of transmission [21]. Enforce HIV antidiscrimination laws to deter offenders from discriminating against people living with HIV. One of the objectives of the law is to help more people to seek testing, treatment and care services without fear of facing stigma and discrimination. The law does not permit HIV screening as a prerequisite for employment and school admissions. End the discrimination against key populations like men who have sex with men, sex workers and transgender people as this discourages them from accessing care, pushes them underground and increases their risk of transmitting HIV. Only education can help deconstruct stigma. It can destroy harmful stereotypes and make people understand the reality of the situation. The leaders and the celebrities can also take part to increase the awareness and help to achieve the 2020 target successfully [22].

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PART 2:

eHealth: More than just an electronic record

The University of Sydney

E-learning platform: Coursera

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Objective:

objectives of this course are:

- Try to recognize the challenges and limitations of implementing eHealth as apart into a clinical practice and in people's daily life health and wellbeing.
- Getting a fundamental idea about how new technologies can helpful for access eHealth to break all the barrier of accessing healthcare.

Course Content:

- Introduction to eHealth
- Experts view about eHealth
- Health in your hands
- Collecting your own data
- Apps social media and health online
- Designing and evaluating eHealth solution
- Data and the “quantified self”
- Electronic health records
- Predictive and precision medicine
- Patient reported data in practice
- Privacy and security
- Using data to improve performance
- Improving access to healthcare
- Innovation in healthcare
- Supporting health professionals
- eHealth case study examples

Methodology: -

Type of study: e-learning

Methods: video, reading article, case study, quiz, assignment

Duration of study: 3 weeks

Study Subject: eHealth: more than just an electronic record

Key Learning: -**Introduction:**

eHealth is not only an electronic health record; it is also the way of using technology to support the communication between the healthcare provider and the consumer in short time. It is a beginning of revolution of the way of traditional healthcare delivery system. It helps us in so many different contexts, but the fastest increasing and transformation area of eHealth is “health in the hands of consumer”, which breaks the traditional believe of economics. In the time of eHealth consumers can record their lifestyle by using various types of apps which are available and can monitor health status or can reduce emergency with the help of getting a seamless quick treatment. eHealth helps both the consumers and the providers for the both context as the time saving and also in receiving treatment without hurdle of accessing. By gathering both biological and lifestyle data the future health model of patients can build with the help of eHealth. Basically, eHealth enhances our health by bringing new technologies to support human health.

eHealth has three main domains:

1st, eHealth bring health in the consumers’ hand:- nowadays consumers can monitor their life style ,diet plan and they are very interest in it by many health related apps ,wearable devices and also can gather information from social media.it helps them to understand the health status and also helps to avoid any kind of emergency.

2nd, Impact of modern technologies, how recent technologies integrated to existing models and how to communicate between professionals and consumers by using it.

3rd, data records, like how we store data in the helps of devices and apps.

Advantages & Use:

We find so many remarkable advantages of eHealth in healthcare, at present time we can virtually visit internationally by using telemedicine, telehealth, videoconference through skype or any other video apps, from their home without any interruption. It reduces the issue of access, transportation issue, pain and so many other reasons not wanting to leave their house. eHealth a make both physician and consumers understand easily what type of care actually needed which help to get treatment more direct. As day by day hardware gets cheaper it gets favors to build more tool for create remarkable technologies, inexpensive devices for communication which provide seamless treatment. A broader patient's group can access treatment which is totally opposite from the traditional face to face clinic. Nowadays to get day by day health status so many remarkable health apps are available. To motivate for level up people's health those apps sets so many goals and target as a game form, which helps to response their diet, stress physical activity, medication.

Now as the information available in internet people get ideas easily and it helps to understand the severity of existing conditions which help them to contact with physician without wasting time. eHealth shows a tremendous way of treatment to the stigma related mental health patients, who can't deal with it comfortably. As well as work as a good alternative for those patients who needed long time treatment like TBI patients, cancer patients who need a rehab facility or physiotherapy or may be weekly follow up they can get it from home with eHealth very easily. Every week get a video conference with physician where their family member can update their recovery status and help for the session.

Same for after surgery or cancer recovery or TBI recovery patients who wants to recover their depression and back to their community or to involve in day-to-day life. For eHealth possible to avoid duplicate test, and getting accurate data.

Basically, eHealth becomes a life changing way of treatment in our modern busy life. And it also helps very much to achieve the SDG goal "health for all" very soon, because treatment getting inexpensive and direct for eHealth.

Challenges:

Despite of all benefits of eHealth, it faces a vast challenge comes to its implementation.

- One of the main challenges associated with maintenance of its enormous DATA, and its detail ness.
- Cost is also a big challenge which makes the implementation time delay.
- At the implementation time Organization face so many problems which associated with legal, social and ethical barriers.
- A fastest internet speed and accessibility is also very important.
- Lack of awareness about eHealth make effect on implementation.
- Also, security concern is very much noticeable area where need to be work more for its growth.
- Most of the time consumers unable to read the data .so being able to understand they willing to connected with their practitioners and they must be answer them at that time to create a seamless connected and co-ordinate care.
- Physician must be expertise about data.
- Students need to be highly educated and skilled on handling patients on online.
- And in the market, there are so many apps are available but its needed to aware about their accuracy rate.

So, to overcome the challenges we need to FOCUS on various area like:

First of all, focus on tools, how these will be more effective. How the apps design more effectively. Easier to use and more acceptable.

Evaluate the app and devices in an appropriate manner and notice their impact on healthcare, because nowadays health professionals also prefer to advice their patients for the wearables device to monitoring patients activity, sleeping pattern, diet after the initial treatment and after continuing trac their activity and progress of health conditions they suggest them through skype or other device .

So, it's so much needed to evaluate a health app in a very accurate manner, check the accuracy level, how much its result clear or acceptable. Or that we need to develop to the app rating scale.

As confidentiality matters a lot in healthcare so, Govt should involve in the security matter to make some good rule, program or technology about data collection or data use management then it can be solved easily. And which helps to people use eHealth fearlessly.

It is needed to invest resources for supporting all the user's groups for developing required to communicate in eHealth.

Future:

eHealth is very useful for an epidemic outbreak tracking. like during our present corona virus diseases 2019 epidemic situation in the early stage of this diseases all the hospitals and the IT companies use internet technology to provide online health service, suggestions and coping strategies for the next stage and the post epidemic time .so, it's clear that in coming days it's going to be very eagerly acceptable.

Where everyone prefers to have their health in their fingertip.