



STIGMATA OF STIGMA AND CULPRITS OF NON-ADHERENCE THAT INFLUENCE THE HIV PATIENTS RECEIVING ART TREATMENT

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ABSTRACT

Background: HIV-related stigma and discrimination refers to prejudice, negative attitudes and abuse directed at people with AIDS. Self – stigma or internalised stigma has an equally damaging effect on mental wellbeing of people. These all limit access to HIV testing, treatment and other HIV services.

Aims and Objectives: To identify the influence of stigma on HIV patients and barriers to non-adherence of Anti Retroviral therapy.

Methodology: Cross-sectional observational study was conducted to identify the influence of stigma on HIV patients and barriers to non-adherence of Anti Retroviral therapy. HIV patients who met inclusion criteria were informed consented and included in the study and relevant data was collected in a pre tested standardized questionnaire.

Results: 250 patients who met the inclusion criteria were included in the study. On reviewing the data it was found that most of the patients experienced the stigma and were worried about people talking badly about them and avoidance from family, friends and colleagues in the work place. Our study also found that most of the patients were adherent to Anti Retroviral therapy and were regularly attending for check-up. The reasons for attending regularly were because of fear of progression of HIV and treatment will reduce the disease. Few patients didnot attend regularly for checkup because of work followed by difficulty in transport.

Conclusion: Based on the results obtained our study strongly concluded that most of the patients experienced the stigma and also they were adherent to ART therapy.

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INTRODUCTION

HIV/AIDS related stigma (H/A stigma) is invoked as a persistent and pernicious problem in any discussion about effective responses to the epidemic. In addition to devastating the familial, social, and economic lives of individuals, H/A stigma is cited as a major barrier to accessing prevention, care, and treatment services [1-3]. Despite widespread recognition of the differential treatment of persons living with HIV/AIDS (PLHA) by society and its institutions, over the first 25 years of the epidemic, community, national, and global actors have only had limited success in alleviating the deleterious effects of H/A stigma. In describing a sustained response to the HIV/AIDS epidemic, Peter Piot, Executive Director of UNAIDS, identifies tackling stigma and discrimination as one of five key imperatives for success [4]. At the same time, Piot notes that stigma reduction efforts are relegated to the bottom of AIDS program priorities, often without funding to support such activities[4].

HIV - related stigma and discrimination refers to prejudice, negative attitudes and abuse directed at people living with HIV

and AIDS. In 35% of countries with available data, over 50% of people report having discriminatory attitudes towards people living with HIV.^[33]

Defining H/A Stigma - Develop a comprehensive conceptual framework for H/A stigma that incorporates both the socio-cognitive and the structural aspects of stigma as well as captures the effects of pre-existing and overlapping stigma related to poverty, race, gender, sexual orientation, etc.^[32]

The four challenges:

1. Defining,
2. Measuring,
3. Assessing impact of, and
4. Reducing stigma – among others has hampered local and global efforts to address H/A stigma.

Goffman defined stigma as “an attribute that is deeply discrediting,” and that reduces the bearer “from a whole and usual person to a tainted, discounted one”. He established that society stigmatizes on the basis of what is constitutes as “difference” or “deviance,” and results in a “spoiled identity”. The social label of deviance compels stigmatized individuals

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to view themselves and others to view the stigmatized as discredited or undesirable. This, in turn, limited the scope of stigma reduction interventions to strategies that might increase the empathy and altruism towards as well as reduce the anxiety and fear of PLHAs among the general population or individual based interventions to assist PLHAs to cope with perceived or experienced. Some people living with HIV and other key affected measurement and reduction interventions identified in this review either implicitly or explicitly utilizes a socio-cognitive conception of stigma.^[20]

Parker and Aggelton argue that “It is especially important to think of stigma as a social and cultural phenomenon linked to actions of whole groups of people in the developing world, where bonds and allegiances to families, village, and neighbourhood, and community abound”. Theorizing stigma in this way also highlights the necessity of power – social, economic, or political power – to enable a community to move from individual level perceptions to collectively identify an undesirable difference/attribute, construct stereotypes, and ultimately, to act on the negative stereotype by discriminating against the stigmatized.^[5-6]

Stigma and discrimination also makes people vulnerable to HIV. Those most at risk to HIV continue to face stigma and discrimination based on their actual or perceived health status, race, socioeconomic status, age, sex, sexual orientation or gender identity or other grounds.^[25]

Populations are shunned by family, peers and the wider community, while others face poor treatment in educational and work settings, erosion of their rights and psychological damage. These all limit access to HIV testing, treatment and other HIV services.

At that time very little was known about how HIV is transmitted, which made people scared of those infected due to fear of contagion. This fear, coupled with many other reasons, means that lots of people falsely believe:^[25]

- HIV and AIDS are always associated with death.
- HIV is associated with behaviours that some people disapprove of (such as homosexuality, drug use, sex work or infidelity).
- HIV is only transmitted through sex, which is a taboo subject in some cultures.
- HIV infection is a result of personal irresponsibility or moral fault (such as infidelity) that deserves to be punished.
- Inaccurate information about how HIV is transmitted which creates irrational behavior of misperceptions of personal risk.

Research by the International Center for Research on Women (ICRW) outlines the possible consequences of HIV- related stigma as:^[26]

- Loss of income and livelihood
- Loss of marriage and childbearing options
- Poor care within the health sector
- Withdrawal of care giving in the home
- Loss of hope and feelings of worthlessness
- Loss of reputation.

HIV Stigma And Key Affected Populations:^[11]

- Men who have sex with men.

- People who inject drugs.
- Sex workers.

Forms of HIV Stigma:^[7]

Two forms:

1. Internalized Stigma/Self stigma
 2. Externalized Stigma
- Governmental Stigma
 - Restrictions on entry travel and stay
 - Healthcare stigma
 - Employment stigma
 - Community and Household level Stigma

Internalized/ Self Stigma: It has an equally damaging effect on the mental well- being of people living with HIV or from key affected populations. This fear of discrimination breaks down confidence to seek help and medical care. Self stigma and fear of a negative community reaction can hinder efforts to address the HIV epidemic by continuing the wall of silence and shame surrounding the virus. Negative self judgement resulting in shame, worthlessness and blame represents an important but neglected aspect of living with HIV. Self stigma affects a person ability to live positively, limits meaningful self agency, quality of life, adherence to treatment and access to health services.

Externalized Stigma

- a. **Governmental Stigma** - A countries discriminatory laws, rules, and policies regarding HIV can alienate and exclude people living with HIV re-enforcing the stigma surrounding HIV and AIDS.
- b. **Restriction on entry, travel and stay** - Deportation of people living with HIV has potentially life-threatening consequences if they have been taking HIV treatment and are deported to a country that has limited treatment provision. Alternatively, people living with HIV may face deportation to a country where they would be subject to even further discrimination- a practice that could contravene international human rights law.
- c. **Healthcare stigma** - Healthcare professionals can medically assist someone infected or affected by HIV, and also provide life-saving information on how to prevent it. However, HIV-related discrimination in healthcare remains an issue and is particularly prevalent in some countries. It can take many forms, including mandatory HIV testing without consent or appropriate counselling. Health providers may minimize contact with, or care of, patients living with HIV, delay or deny treatment, demand additional payment for services and isolate people living with HIV from other patients.^[7] People from key affected populations may face additional discrimination in healthcare settings. Discriminatory attitudes held by health providers may also lead them to make judgements about a person's HIV status, behaviour, sexual orientation or gender identity, leading individuals to be treated without respect or dignity. These views are often fuelled by ignorance about HIV transmission routes among healthcare professionals. These experiences may leave people living with HIV and people from key affected populations too afraid to seek out healthcare services, or be prevented from accessing them- for instance, if a nurse refuses to treat a sex worker after finding out

about their occupation. It also prevents many people from key affected populations being honest with healthcare workers if they're a sex worker, have same-sex relations, or inject drugs, meaning they are less likely to get services that could help them.

- d. **Employment stigma** - In the workplace, people living with HIV may suffer stigma from their co-workers and employers, such as social isolation and ridicule, or experience discriminatory practices, such as termination or refusal of employment.^[8] Evidence from the people living with HIV stigma index suggests that, in many countries, HIV-related stigma and discrimination are as frequently or more frequently a cause of unemployment or a denial of work opportunity as ill health.
- e. **Community and household level stigma** - Community-level stigma and discrimination towards people living with HIV can force people to leave their home and change their daily activities.^[9] In many contexts, women and girls often fear stigma and rejection from their families, not only because they stand to lose their social place of belongings, but also because they could lose their shelter, their children and their ability to survive. The isolation that social rejection brings can lead to low self-esteem, depression, and even thoughts or act of suicide. Women with older husbands and from household's with lower economic status were significantly more likely to experience stigma and discrimination from their husbands family as well as from friends and neighbours.^[10] Stigma and discrimination can also take particular forms within community groups such as key affected populations. For example, studies have shown that within some lesbian, gay, bisexual, transgender and intersex (LGBTI) communities there is segregation between HIV-positive and HIV-negative, where people associate predominantly with those of the same status.^[11-13]

Relationship of HIV/AIDS related Stigma to Prevention & Treatment Programs.^[26]

Stigma & HIV risk behavior

While H/A stigma is widely invoked as a major facilitator of the epidemic, only a few studies have demonstrated an association between stigma and increased risk behaviour. Presumed HIV-negative or unknown status individuals in China holding greater stigmatizing attitudes were more likely to be engaged in high risk behaviour. To develop prevention programs that effectively reduce risk behaviour, more rigorous investigation that better delineates the relationship between stigmatizing attitudes and HIV risk behaviour is needed. In particular, the role of social inequalities as well as overlapping stigmas (such as those related to homosexuality) in mediating the relationship between H/A stigma and risk behaviour must be examined.

Stigma & Biomedical Prevention:^[21]

Novel biomedical interventions to prevent HIV infection, such as adult male circumcision, pre-exposure prophylaxis, microbicides, and vaccines, represent immense potential to limit the spread of the epidemic. As many of these technologies are still being tested or are in development, little is known about how they will effect and be affected by H/A stigma. Others are more circumspect about the potential benefits of promoting circumcision on H/A stigma, citing the

possible contamination of male circumcision by the stigma of female genital mutilation as well as the long history of social power imbalance in the promulgation of circumcision among populations^[27]. As biomedical prevention interventions are rolled out in the future, a detailed understanding of how H/A stigma will affect uptake and use of the interventions is critical to ensure population level effectiveness

Stigma, Testing, & Treatment

H/A stigma is documented as a barrier to uptake of HIV testing and treatment services in numerous settings, particularly in resource limited countries^[28-30]. In a study of HIV testing and stigma in South Africa, individuals who were not tested for HIV exhibited significantly greater stigmatizing attitudes towards PLHA.^[17-19] In a study of 112 patients receiving antiretroviral therapy in Botswana two years before the implementation of universal access to treatment, 69% of patients did not disclose their HIV status to their family and a majority of those who reported delaying testing for HIV did so due to fear of H/A stigma. Access to therapy triggers a 'virtuous social cycle' by treating these individuals and alleviating their visible signs of disease, enabling them to return to a socially and financially productive lives, and sparking interest in testing and treatment among others in the community^[14-16]. In theory, widespread scale-up of treatment access may turn HIV into a treatable and chronic (rather than deadly) disease, increase uptake of testing, and thereby, ultimately reduce H/A stigma.^[22]

Treatment Adherence:^[35]

Treatment adherence means taking the correct dose of your medications every time, exactly as prescribed by health care provider or recommended by pharmacist. To successfully halt HIV replication and keep viral load suppressed, HIV meds need to be maintained at high enough levels in the blood, 24 hours a day. If the drug levels become too low, drug resistance may occur.

HIV drug resistance can cause meds to stop working properly and may limit future treatment options. It is also possible to transmit drug-resistant HIV to other people, making it harder for them to treat their own infection.

When selecting a new HIV medication or starting meds for the first time, look at lifestyle to see if there are any potential adherence obstacles. Here is a list of questions for you to consider when discussing adherence and making treatment decisions with your health care provider:

- Does your daily schedule change a lot?
- What is your typical eating schedule each day?
- Do you have a difficult time swallowing pills?
- Are you taking other medications?
- What side effects can you tolerate?
- What happens if you miss a dose?

Today, there are several once-daily fixed-dose regimens contained in one pill. While the option of only taking one pill a day sounds appealing, these regimens may not allow for a missed dose because the doses are further apart than twice-daily doses. Missing a once-daily dosed pill could also cause drug resistance.

There are certain situations that have been found to affect adherence.^[23]

Attitude: People who feel most strongly that their medication

is doing them good typically have an easier time adhering to their regimens.^[31]

Adherence Tips and Tools:^[27]

Adherence problems aren't something to be ashamed of. It's important to discuss any fears or challenges you have with your health care provider.

There are also many tips and tools you can use to help you better adhere to HIV treatment:

1. **Practice with jellybeans or M&Ms:** Think of it as an experiment to see if you can adhere to a treatment regimen. Practice for two weeks and talk with your health care provider about any challenges you faced along the way.
2. **Keep your meds next to something you use regularly:** If you see your meds near something you use on a daily basis, it can help tremendously. Examples include your coffee pot, your alarm clock or your toothbrush.
3. **Sign up for a reminder service:** Many AIDS service organizations and pharmacies have a free program that will call to remind you to take your medications. You can also find free reminder services online that will send you a text message or email every day at the times you specify.
4. **Program your cell phone:** Set an alarm on your phone at various times of the day and night. People may be less likely to ask about your cell phone ringing than if you've set an alarm on a watch or other device.
5. **Travel with extra doses:** If you travel frequently, always bring your meds in your carry-on luggage, and bring a few extra doses in case of flight delays and cancellations.
6. **Stay on schedule:** Some people have more trouble remembering to take their medication on their days off work or school, or other times when their schedule is different than usual. You may need additional support remembering your medication on days like this.
7. **Organize your meds:** One-week, two-week and one-month pillboxes are available to help you lay out your meds in advance. Many people with HIV use these affordable and handy organizing devices. Some pharmacies will sort out your daily dose of meds and organize and package them in blister packs rather than putting them into pill bottles.
8. **Meds on the go:** If you find that you regularly need to take your meds on the go, check out portable pocket-sized pill cases. Some even have built-in timers.
9. **Plan ahead:** Make sure that you regularly refill your prescriptions so you don't run out of your medications

Adherence to Antiretroviral Therapy:^[35]

Adherence to ART can be influenced by a number of factors, including the patient's social situation and clinical condition, the prescribed regimen, and the patient-provider relationship. Poor adherence is often a consequence of one or more behavioural, structural, and psychosocial barriers (e.g., depression and other mental illnesses, neurocognitive impairment, low health literacy, low levels of social support, stressful life events, busy or unstructured daily routines, active substance use, homelessness, poverty, nondisclosure of HIV serological status, denial, stigma, and inconsistent access to medications due to financial and insurance status). Characteristics of one or more components of the prescribed

regimen can affect adherence. Once-daily regimens including those with low pill burden (even if not one pill once daily), without a food requirement, and few side effects or toxicities, are associated with higher levels of adherence. Single-tablet regimens (STR) that include all antiretroviral in one pill taken once daily are easier for people to use^[34]. However, data to support or refute the superiority of a STR versus a once-daily multi-tablet regimen (MTR), as might be required for the use of some soon-to-be-available generic-based antiretroviral (ARVs) regimens, are limited. There are demonstrated beneficial effects on viral suppression in switch studies, in which persons on MTR are randomized to stay on MTR or switch to STR. Whether an STR is beneficial in treatment-naive patients is not known, with at least one large observational cohort study showing benefit of once-daily STR versus once-daily MTR, but only when switches for simplification of MTR were considered failures. Comparisons of these regimens are hampered since not all drugs and classes are available as STR.

Characteristics of the clinical setting can also have important structural influences on the success or failure of medication adherence. Settings that provide comprehensive multidisciplinary care (example: by case managers, pharmacists, social workers, and mental health and substance abuse providers) support patients' complex needs, including their medication adherence-related needs. Drug abuse treatment programs are often best suited to address substance use and may offer services that promote adherence, such as directly observed therapy (DOT).^[35]

Aim and Objectives

AIM

The present study is aimed to identify the influence of stigma on HIV patients and barriers to non-adherence of AntiRetroviral therapy (ART).

Objectives

To identify the influence of stigma in HIV/AIDS patients and also to identify the barriers of non adherence for Anti Retroviral Therapy

METHODOLOGY

Study Design: Cross-sectional observational study was conducted.

Study Period: The study was conducted within a time period of 6 months i.e., from 1st September 2018 to February 28th 2019.

Study Site: The study was conducted in ART PLUS center of Government General Hospital, Guntur, a tertiary care teaching hospital.

Sample Size: A total of 250 patients who met the inclusion criteria were taken into the study.

Materials used

- Patient consent form.
- Pre tested standardized questionnaire.

Inclusion criteria

- Patients who are diagnosed with HIV/AIDS.
- HIV patients who are receiving ART treatment.
- Patients who are concerned to participate in the study

- & willing to give informed consent.
- Those who can understand English / local language.
- Patients of either gender & age > 21 years.

Exclusion criteria

- Patients with organic mental disorders.
- Pregnant women

Statistical Analysis

Chi-square test was performed with a confidence interval of 95% between gender variable and others by using SPSS Version 17.

RESULTS

Table 1 Stigma VS no of Patients

Stigma	NO OF PATIENTS (N=250)								P Value
	MALE n=102 n (%)		FEMALE n=138 n (%)		OTHER n=10 n (%)		TOTAL PERCENT n (%)		
	N	W	N	W	N	W	N	W	
Talkin G Badly	29 (11.6)	73 (29.2)	33 (13.2)	105 (42)	9 (3.6)	1 (0.4)	71 (28.4)	179 (71.6)	<0.001
Family & Friend S	47 (18.8)	55 (22)	54 (21.6)	84 (33.6)	4 (1.6)	6 (2.4)	105 (42)	145 (58)	0.55
Avoidi NG Collea Gues	29 (11.6)	48 (19.2)	15 (6)	44 (17.6)	0 (0)	7 (2.8)	44 (17.6)	99 (39.6)	0.31
Avoidi NG									0.42

N W- NOT WORRIED, W- WORRIED

A P value (<0.05) was considered to be statistically significant

Table 2 Opinion about Health Care Workers Treating HIV Positive Person Vs No of Patients

Opinion about health care workers treating hiv positive Person	No of Patients (N=250)				P Value
	Male n=102 n (%)	Female n=138 n (%)	Others n=10 n (%)	Total Percent n (%)	
Hesitant	16 (6.4)	13 (5.2)	2 (0.8)	31 (12.4)	0.2627
Not Hesitant	86 (34.4)	125 (50)	8 (3.2)	219 (87.6)	

A P value <0.05 was considered to be statistically significant

Table 3 Attending Regularly For Check Up Vs No Of Patients

Attending Regularly For Check UP	No of Patients (N=250)				P Value
	Male n=102 n (%)	Female n=138 n (%)	Others n=10 n (%)	Total Percent n (%)	
YES	102 (40.8)	135 (54)	10 (4)	247 (98.8)	0.4386
NO	0 (0)	3 (1.2)	0 (0)	3 (1.2)	

A P value of <0.05 was considered to be statistically significant

Table 4 Reasons for Attending Regularly For Check Up Vs No of Patients

Reasons for attending regularly For check up	No of Patients (N=248)				P Value
	MALE n=102 n (%)	FEMALE n=138 n (%)	OTHERS n=10 n (%)	TOTAL PERCENT n (%)	
Fear of the Progression	74 (29.83)	93 (37.5)	3 (1.20)	170 (68.53)	0.0681
Treatment will reduce	43 (17.33)	51 (20.56)	10 (4.03)	104 (41.92)	

Disease Providing You confidence	34 (13.70)	44 (17.74)	6 (2.41)	84 (33.85)	0.3866

A P value <0.05 was considered to be statistically significant

Table 5 Reasons for Not Attending Regularly Vs No of Patients

Reasons for not attending Regularly	No of Patients (N=3)				P Value
	Male n=0 n (%)	Female n=3 n (%)	Others n=0 n (%)	Total Percent n (%)	
Feeling Ashamed To attend Hospital Work /Business Transport Is Difficulty Forgetting Follow No support From Family Others	0 (0)	0 (0)	0 (0)	0 (0)	0.0681
	0 (0)	1 (50)	0 (0)	1 (33.33)	
	0 (0)	2 (50)	0 (0)	2 (66.67)	
	0 (0)	0 (0)	0 (0)	0 (0)	
	0 (0)	0 (0)	0 (0)	0 (0)	
	0 (0)	0 (0)	0 (0)	0 (0)	

A P value of <0.05 was considered to be statistically significant

DISCUSSION

A cross-sectional observational study was carried out on “stigmata of stigma and culprits of non-adherence that influence the HIV patients receiving art treatment”.250 patients met the inclusion criteria and were included in the study. The data obtained was tabulated and analysed. Our study found out that patients were mostly worried about talking badly about them 179 (71.6%) followed by family and friends avoiding 145 (58%) them due to HIV and they were not worried about family and friends avoiding them due to HIV 105 (42%) followed by talking badly 167 (28.4%) about them. Association between the gender was analysed using chi-square test and was found to be (* p= <0.0001) extremely significant. Our study also revealed that health care professionals were mostly not hesitant 219 (87.6%). Association between the genders was analysed using chi-square test and was found to be (* p= 0.2627) not significant. We tried to assess the regularity of patients for check-up and found out that patients were attending regularly 249 (99%) for the check-up. Association between the gender was analysed using chi-square test and was found to be (* p= 0.4386) not significant. We also found that most of the patients attended regularly 249 (99%) for the check up and the reasons for attending regularly were fear of progression 170 (68.53%) followed by treatment will reduce disease 104 (41.92%). Association between the gender was analysed using chi-square test and was found to be (* p= 0.3866) not significant. Our study also revealed that most of the patients attended regularly 249 (99%) for the check- up but only 2 patients didn't attend the check up regularly and the reasons were work/business 1 (50%) and transport is difficult 1 (50%). Association between the gender was analysed using chi-square test and was found to be (* p= 0.0681) not significant.

CONCLUSION

The present study concluded that most of the patients worrying about their HIV status was mainly because of the disease and avoidance from family and friends but few patients were not

worried because of family and friends support and knowing there is cure for HIV. Our study also concluded that most of the patients were adherent to the ART therapy and were regularly attending for check-up. The reasons for attending regularly were because of fear of progression of HIV and treatment will reduce the disease followed by confidence provided by the treatment and few patients didn't attend regularly for check-up because of work followed by difficulty in transport.

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