

# **HIV STIGMA AMONG HEALTH CARE TEAM MEMBERS**

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#### **ABSTRACT**

**Background:** Despite the advent of treatment for HIV, people living with HIV are still experiencing HIV-related stigma: prejudice, stereotyping and discrimination by health care members across the globe. Stigma increases barriers to care, decreases access to care, and decreases the quality of life for the person living with HIV.

**Aims and Objectives:** To describe stigma among health care team members in regards to people living with HIV.

Design: Prospective, cross-sectional survey

**Methods:** Two hundred and forty-two health care providers were recruited from one major hospital in the Southeastern United States to complete the Health Care Provider HIV/AIDS Stigma Scale (HPASS). HPASS is a validated instrument consisting of 30 items measuring prejudice, stereotyping, and discrimination. Data were collected via an online survey.

**Results:** This study found that stereotyping exists and is demonstrated by varied health care team members. Front-desk nurses recorded the highest degree of stereotyping patients with HIV in comparison to other health care members.

**Conclusion:** This study showed that stigma still exists within health care delivery and further emphasized the need for self-evaluation, education, and training for all health care team members.

#### INTRODUCTION

#### Relevance to clinical practice

- All health care personnel should conduct a self-assessment on possible personal stigma demonstrated towards patients with HIV
- Continuing education discussions and presentations for health care providers should incorporate education on understanding by minimizing stigma against these patients

What does this paper contribute to the wider global clinical community?

- The paper provides evidence that stigma still exists among health care providers
- Combatting stigma related to HIV requires an

awareness among health care providers to eradicate biases present.

• Culturally appropriate training specifically targeting the areas of prejudice, stereotyping and discrimination should be made a priority focus for all health care professionals and other clinical or hospital staff

The crisis regarding human immunodeficiency virus (HIV) and acquired immune deficiency syndrome AIDS began in 1981 in a culture full of fear, ignorance, and stigma both socially and in the world of health care providers (Bowen, 2013). Thirty-six years later, people living with HIV(PLWH) still experience health care provider based stigma associated with this disease as well as negative outcomes worldwide (Belyaeva *et al.*, 2015; Coetzee, Kagee, & Vermeulen,

2011; Courtenay-Quirk *et al.*, 2006; Eaton *et al.*, 2015; Ekstrand *et al.*, 2013; Feyissa *et al.*, 2012; Kalichman *et al.*, 2009; Meyerson *et al.*, 2014; Mills *et al.*, 2006; Mundt & Briggs, 2016; Rutledge *et al.*, 2011). The World Health Organization (WHO) (2015) reported that approximately 1.1 million people died of HIV related illness.

Not all regions in the world have legal mechanisms to protect a patient's privacy. In the United States, unless a person is self-disclosing, the stigmatizing attribute of an HIV positive diagnosis is only visible to persons who have access to that protected health information (PHI). Virtually every individual with access to PHI across the continuum of the health care delivery has the potential to stigmatize patients with HIV. Both clinical and support staff who have access to PHI may be perceived correctly or incorrectly by PLWH as stigmatizing in their actions, attitudes, or behaviors. PLWH may see this as happening either consciously or unconsciously, but the net effect is that PLWH experience the negative effects of the stress engendered by stigma (Herek & Capitanio, 1998; Relf & Rollins, 2015). These negative effects include increased barriers to care (Kinsler et al., 2007), decreased access to care (Meyerson et al., 2014), and an increased incidence of HIV related health issues (Major & O'Brien, 2005) with a commensurate decreased quality of life (Reece et al., 2007).

Research that explores correlations between stigma and the use of HIV services or the effects of stigma on HIV prevention and treatment programs is limited (Li *et al.*, 2013). Moreover, there are only a few standardized stigma measurement tools currently available. There is also a lack of standardized instruments to measure HIV/AIDS-related stigma, which greatly reduces the ability for researchers to identify the multiple facets of stigma. The rationale for measuring these subscales of HIV stigma is to advance strategies to eliminate or mitigate the negative effects of HIV stigma. The purpose of this study was to identify and measure specific types of stigma among health care providers in regards to PLWH.

#### **BACKGROUND**

Provider-based HIV stigma is a significant deterrent to access of care. Evidence suggests that provider-based HIV stigma discourages subsequent follow up and access to care for urgent needs among PLWH (Feyissa *et al.*,

2012). Provider based stigma affects access across all health care settings (Kinsler *et al.*, 2007). Providers may actively discriminate against PLWH by making themselves unavailable for routinely provided services or may be unwilling to refer PLWH to other providers and facilities (Yannessa, Reece & Basta, 2008). Providers endorsing stigmatizing ideas and attitudes about PLWH, with or without intent, participate in the creation of a mistrust of health care professionals. This in turn is demonstrated by decreased healthcare utilization and access by PLWH (Eaton *et al.*, 2015).

Biasness of the healthcare providers is also reflected at the structural and institutional level. It is reported that 20% of the population infected with HIV is unaware of it (Meyerson *et al.*, 2014), and that trends of infection rates are skewing towards rural and non-metropolitan areas (Sison *et al.*, 2013). Nevertheless, providers may exclude entire populations of rural PLWH by centering comprehensive provision of care only in urban centers (Yannessa *et al.*, 2008). These logistics create other barriers to care including transportation and increased financial burden in keeping appointments with providers who are sometimes hours away and may require the patient to miss days from work (Coetzee *et al.*, 2011).

#### Decreased Access to Care and Barriers to Care

Access is a term used for a broad set of concerns that center on the degree to which PLWH are able to obtain needed services from the health care system. Access is a function that extends beyond insurance coverage or proximity of providers since neither act as a guarantee that PLWH will find and receive the care they require to maintain or improve their health status (Kim *et al.*, 2014).

Barriers to care in settings in which providers stigmatize PLWH tend to be multifaceted and interrelated. Meyerson *et al.* (2014) identified poor protection of confidentiality as a significant barrier to care. PLWH are also afraid of being identified at clinics known for treatment of HIV (Coetzee *et al.*, 2011). One solution is to provide HIV care in primary settings and remove the potential for stigma by integrating HIV care with care of other patients. The problem is that primary care providers can stigmatize PLWH by declining to provide these services (Famoroti, Fernandes & Chima, 2013).

Alternately, they may decline to provide the services by citing that they are not accepting any new patients at that time (Yannessa et al., 2008). Economic factors also play a role in provider-based stigma. Kinsler et al. (2007) reported that PLWH are more likely to lack insurance coverage and many live in poverty. Health care providers are more likely to provide services if they are certain of some measure of payment for services (Sison et al., 2013).

# **Decreased Quality of Life**

Quality of life indicators for PLWH have been described in nine dimensions: overall function, life satisfaction, health worries, financial worries, medication worries. HIV mastery, disclosure worries. provider trust, and sexual function (Holmes & Shea, 1997). Therefore, when a health care provider engages in discrimination, stereotypes, or prejudices, PLWH may experience a decreased quality of life. Negative effects of HIV stigma are associated with depression (Kalichman et al., 2009), PLWH may be twice as likely to decrease highly active antiretroviral therapy (HAART) compliance and utilization of social supports such as AIDS service organizations and drug assistance programs (Corless et al., 2013; Reece et al., 2007; Relf & Rollins, 2015; Smit et al., 2012). HIV related stigma is a key influence on the health status of PLWH (Rutledge et al., 2011).

Parker & Aggleton (2003) specifically address stigma as it applies to HIV/AIDS and advance the concept of stigma as a dynamic and constantly changing social process. From this perspective, stigma is not an individual attribute or consequence of individual behavior, but a cultural phenomenon applied to entire groups of people. It involves the marking of differences between groups or categories of people.

The multiplicity of definitions and concepts of stigma make understanding its origins and effects, difficult and creates a divide between conceptualization and research models, evidence, and interventions. Deacon (2006) argues for a more coherent theory of stigma. She calls for a revisiting and re-evaluation of theories of stigma by developing a definition of stigma that captures the influences from for both psychological and social dimensions.

Earnshaw & Chadoir (2009) sought to clarify and refine the conceptualization of stigma, and further developed a

conceptualization of HIV stigma. There are three components in their framework: stigma, mechanisms, and outcomes. Their framework begins with the assumption that HIV is a stigma- a 'mark' that is socially devalued. They argue that this 'mark' impacts people in society based on the way in which people react to the knowledge that someone is HIV infected or not. Once a person has been 'marked', the process moves to the mechanisms stage. The mechanisms include prejudice, stereotypes, and discrimination. They may lead to various outcomes that are oftentimes injurious. Earnshaw & Chadoir suggested that prejudice is experienced as emotions, stereotypes as cognition and discrimination as actions.

In this study, prejudice is defined as negative emotions and feelings that the uninfected feel toward the infected. This prejudice in turn creates a social distance and separation between individuals with a perceived stigmatizing attribute and those that would endorse those prejudices (Earnshaw & Chaudoir, 2009). Stereotypes are defined as negative thoughts or beliefs about PLWH (Earnshaw & Chaudoir, 2009). Discrimination is a behavioral response to prejudicial reactions toward PLWH (Wagner et al., 2014).

#### **METHODS**

#### **Design and Setting**

This was a descriptive study using a survey of health care providers and staff in a large nonprofit health system in Southeast United States. The health system has more than 2800 employees and over 300 physicians representing 34 different medical specialties. The study was approved by the authors' University Internal Review Board (IRB) and the IRB of the regional health care system.

#### **Participants**

Participants included physicians, nurse practitioners, physician's assistants, registered nurses, medical assistants, and front desk staff members. A total of 256 responded during the 4- week time frame.

#### **Instrument**

The health care provider HIV/AIDS Stigma scales (HPASS) measures specific behaviors, cognitions, and affects that characterize HIV stigma mechanisms perpetrated or endorsed by health care providers (Wagner *et al.*, 2014). The 30-item HPASS has a 6-point Likert scale (1=strongly disagree, 6=strongly agree). The internal consistency reliability of the instrument is Cronbach's  $\alpha$ =0.94. There are three subscales. Cronbach's alphas for the subscales are stereotyping (11 items, Cronbach's  $\alpha$ =0.87), discrimination (6 items, Cronbach's  $\alpha$ =0.92), and prejudice (13 items, Cronbach's  $\alpha$ =0.91). In addition to the HPASS, demographic data were collected including age, education level, and occupation. Other questions included previous provision of care to PLWH (yes or no) and non-professional contact with knowledge of PLWH (yes or no).

#### **Data Collection**

Interested participants were given a secure external link that connected them to an electronic survey where they were provided four sequential pages including an informed consent, a demographics questionnaire, the HPASS instrument, and an optional gift card drawing for twenty \$25 Visa gift cards as incentive.

### **Data Analysis**

Due to incomplete data, only 242 surveys were included in the final analysis. Descriptive statistics were used to analyze all study variables (age, education level, types of providers, previous prevision of care to PLWH, and contact with PLWH outside of work setting). Analysis of variance (ANOVA), least significant difference (LSD) post hoc test was used to test for differences between groups on the three subscales of the HPASS survey: stereotyping, discrimination and prejudice. Data were analyzed with SPSS version 23 (IBM Corp, Armonk, NY, USA). A significance level of p < 0.05 was used for all analyses.

#### **RESULTS**

The majority of the sample was in the 36-45 year age range category. Most (79.8%) participants were female. Data were not collected on ethnicity. The majority (n=201, 83.1%) of participants reported having previously provided services to PLWH while only 22.3% reported knowing PLWH in a non-professional setting. Table 1 provides a descriptive demographic data for the study.

Table 1: Frequencies and Percentage for Demographic Characteristics of the Sample

Characteristics	Frequency $n = 242$	%	
Gender			
Male	49	20.2	
Female	193	79.8	
Age			
Less than 25	16	6.6	
26-35	60	24.8	
36-45	76	31.4	
46-55	49	20.2	
56-65	34	14.0	
66-75	7	2.9	
Highest Education			
High School/GED	15	6.2	
Some College	50	20.7	
Associate	60	24.8	
Bachelors	71	29.3	
Masters	20	8.3	
Doctorate	26	10.7	
Occupation			
Front Desk Staff	59	24.4	
Medical Assistant	48	19.8	
Nurse	101	41.7	
Nurse Practitioner/Physician's Assistant	10	4.1	
Physician	24	9.9	

Results from the ANOVA demonstrated significant differences between groups for stereotyping subscale (F = 2.60, df = 4,237; p = 0.037), and prejudice subscale (F = 3.40, df = 4,237; p = 0.005) but not for the others. Table 2 shows the ANOVA results for the subscales.

Table 2: One-way ANOVA on Differences between Occupational Subgroups and Measured Stigma Subscales

		Sum of Squares	df	Mean Square	F	Sig.
Stereotyping	Between Groups	702.998	4	175.750	2.598	0.037
	Within Groups	16030.444	237	67.639		
	Total	16733.442	241			

Discrimination	Between Groups	287.044	4	71.761	1.943	0.104
	Within Groups	8755.225	237	36.942		
	Total	9042.269	241			
Prejudice	Between Groups	1611.155	4	402.789	3.796	0.005
	Within Groups	25144.829	237	106.096		
	Total	26755.983	241			

Multiple comparisons using LSD post hoc test showed differences among the groups on the stereotyping subscale and prejudice subscale. For the stereotyping subscale, front desk staff members had a higher mean score (M=31.85, SD=9.06) than nurses (M=28.63, SD=7.87). Likewise, for the prejudice subscale, comparisons between front desk staff had a higher mean score on the prejudice subscale (M=38.02, SD=11.12) than nurses (M=32.40, SD=10.81) as a group.

Providers who were less than 25 years old had a higher mean score on the stereotyping subscale (M=30.69, SD=9.99) than those who were 36-45 years old (M=26.43, SD=6.6). Likewise, for the prejudice subscale, younger providers (less than 25) were more prejudiced (M=39.19, SD=13.14) than all other age groups

## DISCUSSION

This study found that the stereotyping in HIV is demonstrated across the spectrum of health care delivery and is most pronounced among front desk staff. Providers with these stereotypes may not assess or educate patients about preventable HIV-risk behaviors such as unprotected sex, or suggest available HIV preexposure prophylaxis prevention medicine. The undiagnosed infection rates are now reported at 14% for sexually active individual's age of 13 years and older on average nationwide (Centers for Disease Control and Prevention, 2014). It would therefore be prudent for the health care system to initiate a system-wide standard of care to screen all sexually active individuals that report unprotected sex or other high HIV-risk behaviors in order to offer serologic screening as a minimum level of care.

Another important finding related to stereotypes

prejudice held by front desk staff to ward PLWH. Frontdesk support staff is, more often than not, the first point of contact for all PLWH when they access health care. As the point of first contact, they set the tone for the entire experience of PLWH as they navigate the complicated health care delivery model. This emphasizes the importance for them to be aware of their biases towards PLWH.

Lin et al., (2012) conducted a randomized study (n=1760) about health care providers' empathy levels in caring for PLWH. The study reported that younger medical providers and less educated providers tended to avoid providing care to PLWHA. In our study, we did not evaluate empathy level. However, our study found that prejudice was more likely among younger providers, in the age subgroup of less than 25 yearsold, in comparison to other age subgroups.

PLWH report experiencing barriers to care as feelings of being judged (stereotyping), fear of prejudice, and emotional responses ranging from futility to frustration and even anger (Zukoski, Thorburn & Stroud, 2011). Virtually all nurses, advanced nurse practitioners/physician assistants, and physicians are educated in communication and empathetic interactions. This education enables health care providers to deliver care in an empathetic and nonjudgmental manner. They are provided education in part to ensure access to care is maintained through positive patient experience. However, "front-desk staff" nurses may not get this same training as other health care providers. This study emphasizes the need to provide similar education to front-desk staff to clarify any stereotypes and biases toward PLWH, and further emphasize mechanism of convey empathy towards the patients. These positive interactions may encourage access to care.

#### LIMITATIONS

There are several limitations to this study. First, the study used a non-probability self-selecting sample and as such may not represent the population of health care providers. Second, the study relies on self-report and may reflect bias based on a desire to give socially acceptable answers on the questionnaire. Third, the study was performed in a predominantly rural area of the Southern United States, which may be unique and unaccounted for cultural influences. Fourth, the small sample size of the physician's group and the combination of nurse practitioner and physician's assistant subgroup may not adequately represent measures of stigma in theses subgroups.

#### CONCLUSION

Decades earlier HIV was treated as a fatal acute illness and PLWH were subject to open and blatant discrimination along with the prejudices and stereotypes that were engendered by fear and ignorance of this disease. HIV is considered a condition that stigmatizes those that are infected. It is a stigma that is unseen unless it is disclosed. The net outcomes of provider-based HIV stigma may be decreased access to care, increased barriers to care, and decreased quality of life. This study is the first application of the HPASS in a hospital setting. Until health care providers are able to demonstrate a

reduction of stereotyping, discrimination and prejudice as it relates to HIV, PLWH may not seek care. Thus, there is a strong need to educate all employees. Health care organizations should implement a standardize evaluation and training for every health care provider.

#### **Relevance to Clinical Practice**

Combatting stigma related to HIV requires awareness among health care providers to overcome their biases. A program should be adopted for all providers to assess their own biases about PLWH. Culturally appropriate training specifically targeting the areas of prejudice; stereotyping and discrimination should be made a priority focus for all health care professionals and other clinical or hospital staff.

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