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Behavioral Evidence of HIV Testing Stigma

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Abstract

To avoid HIV testing stigma, people may engage in non-stigmatized behaviors to conceal their interest in HIV testing. We examined 165,828 outpatient visits in a 2002-2007 national survey to explore whether people receiving an HIV diagnostic test, compared to people receiving non-stigmatized, diagnostics tests (mammography and blood pressure testing), listed their interest in testing more frequently as a non-primary reason for visit, listed a greater number of reasons for visiting the clinic, and listed more reasons for visit unrelated to the testing performed. Among people who reported HIV testing as a reason for visit, 42.39% requested HIV testing as a non-primary reason for visit (mammography: 13.77%; blood pressure: 18.01%), and on average listed more reasons for visiting the clinic. The odds of requesting additional unrelated services for HIV testing patients was almost 5 times that of patients requesting blood pressure tests and over 20 times the odds of mammography patients. Together, we interpret these results as initial behavioral evidence of people's avoidance of HIV stigma in health care settings. We hope that this manuscript serves as a call to action for future research exploring causal relationships between health service usage and HIV stigma.

INTRODUCTION

Over 1 million people are currently living with HIV/AIDS in the United States, and an estimated 25% of these people are unaware that they are HIV positive [1, 2]. Researchers have proposed that increasing HIV testing will help to reduce the number of people who are unaware of their positive status and to curb the HIV epidemic [3, 4].

However, potential stigmatization is one reason why people avoid testing for HIV [5-9]. The act of HIV testing itself is stigmatizing as it suggests that a person might be infected, and this stigma can be compounded if the tester receives a positive diagnosis. Receiving a positive diagnosis for HIV/AIDS can have dramatic effects on a person's life, including leading to the loss of employment, loss of friendship, family ties, housing, dismissal from school, and denial of health/life insurance and health care [10].

People may seek psychological cover, or the ability to conceal one's motivations, as an attempt to reduce HIV stigma and be able to test for HIV. A person might seek psychological cover by engaging in a non-stigmatized behavior in order to cover an interest in engaging in a stigmatized behavior. For example, donating blood may provide a psychological cover for HIV testing by allowing people to appear as if they are solely interested in giving blood, a non-stigmatizing behavior [11, 12], while also receiving HIV testing results. When visiting a clinic, people might seek psychological cover by bundling non-stigmatized services with HIV testing in an attempt to reduce the likelihood that others know that they are interested in testing for HIV [13].

This paper explores the hypothesis that people testing for HIV attempt to seek psychological cover to avoid the stigma associated with HIV testing. Building on qualitative research suggesting the effects of HIV stigma on HIV prevention decisions and behaviors, this paper seeks to provide initial support to show behavioral manifestations of stigma avoidance and presents a call for research to explore this topic.

METHODS

Data

The National Hospital Ambulatory Medical Care Survey (NHAMCS) is a nationally representative probability sample of visits to hospital emergency and outpatient departments in non-federal hospitals conducted annually by the Center for Disease Control and Prevention (CDC). In this analysis, subjects were taken from the 2003-2007 NHAMCS Outpatient data. Between 2002 through 2007, a total of 165,828 visits were recorded. Of these, only patients who either requested HIV testing, a mammogram, or blood pressure testing were chosen. This resulted in a total of 1,309 observations. Patients self-reported up to a total of 3 reasons for visit. We categorized them as having requested a specific test if it was listed as any of these 3 reasons. Reasons listed were ordered by importance.

Analysis

We sought to quantify observed differences between patients who requested and received HIV testing from those who requested blood pressure testing or mammography. We inferred that these observed differences between the groups could be due to the existence of perceived stigma by patients towards HIV testing. In quantitative terms, we examined three specific outcomes and quantified significant differences between the three groups. First, the likelihood of putting the requested test as their primary reason of visit was measured among the three groups. Next, we compared the probability of listing more than one reason for visit between the three groups. Finally, an independent physician who was blinded to the purpose of the study rated a list of NHAMCS reasons for visits for each of these groups as being related or unrelated to needing HIV testing, blood pressure testing, or mammography. From this list, we quantified the probability of having requested these non-related reasons for visit for each of the 3 subgroups (i.e., reporting reasons for visit that were unrelated to any of the tests). For example, glucose tests, X-ray, bone density tests, and others were considered unrelated to HIV testing but pregnancy testing, rectal exams, and urine culture tests were considered related. In all three questions, we employed logistic regression adjusting for age, race, gender, and method of payment (used as a surrogate measure for socioeconomic status) as covariates. Age was categorized into 4 categories: children (< 18 years old), young adult (18-34 years old), adult (35-64 years old), and senior (>64 years old). Race was differentiated as white and nonwhite. Methods of payment were grouped into self-paying patients, patients on Medicaid, and all others.

We hypothesize that if patients felt a strong stigma towards HIV testing, the HIV testing group would be less likely to have reported HIV testing as their primary reason for visit (compared to the mammogram group putting mammograms as their primary reason for visit or the blood pressure test group putting blood pressure testing as their primary reason for visit). We also would expect that the HIV testing group would be more likely to list multiple reasons for visit as compared to the other groups. Finally, we hypothesized that the HIV testing group would have a higher percentage of reasons for visit that were unrelated to the testing procedure. A combination of all three of these observed events would provide initial behavioral evidence of people's avoidance of HIV stigma in a health care setting.

RESULTS

Table 1 shows the demographic differences between patients listing HIV, blood pressure, or mammography testing as their reason for visit. Demographic profiles between the three groups were significantly different. The p-values for Pearson's chi-square tests for the association between reason for visit group and age group, gender, race, and payment type were all less than 0.0001. Because each covariate category was associated with the groups, we incorporated all of them into the logistic regression models.

Table 2 shows results of the logistic regression with primary reason for visit as the outcome. Conditioned on having included a reason for visit as mammography, blood pressure test, or HIV testing, patients in the mammography group had 3.5 times the odds of listing mammography as their primary reason for visit compared to patients in the HIV testing group. Patients in the blood pressure testing group also had a higher chance of listing blood pressure as their primary reason for visit. Age groups, gender, race, and method of payment were all significant predictors across groups.

Table 3 shows the results for the probability of having multiple reasons for visit. Both the mammography and the blood pressure test groups had lower odds of putting down multiple reasons for visit than the HIV testing group.

Table 4 displays the results of reason for visit as being related or unrelated to mammography, blood pressure testing, and HIV testing. Pronounced differences existed between the mammography, blood pressure, and HIV groups. For the HIV testing group, we estimated the odds of listing a reason for visit that was unrelated was almost 5 times that of the blood pressure testing group and over 20 times the odds of the mammography group.

DISCUSSION

The present study provides initial support suggesting that people seek psychological cover to avoid the stigma associated with HIV testing. Compared to visits where people reported visiting the clinic for a mammography or blood pressure diagnostic test (non-stigmatized services), those who reported visiting a clinic for an HIV diagnostic (stigmatized) test were less likely to list that reason as their primary reason for visit, more likely to list a larger number of services as their reason for visit, and more likely to have requested a larger number of services that were unrelated to the performed mammography, blood pressure, or HIV testing. The odds of requesting unrelated services for patients who received HIV testing was almost 5 times that of patients who received blood pressure tests and over 20 times the odds of patients who received mammography testing.

The data presented are used to show that behavior might be used as a method for measuring stigma. Stigma is typically measured through qualitative work and self-report scales, such as an assessment of people's perceptions of the stigma associated with HIV [14, 15]. For example, based on previous HIV scales, Sayles, et al., (2008) developed a multidimensional assessment of internalized HIV stigma among sociodemographically diverse people living with HIV [16]. While these stigma scales have helped develop a body of stigma literature and have documented the existence of stigma, finding behavioral manifestations of stigma could help to support and extend stigma literature. To document behavioral evidence of stigma avoidance, we adapted psychological hypotheses of how people would behave if they were experiencing stigma, and measured whether people were behaving according to those hypotheses when visiting a clinic for a stigmatized test versus non-stigmatized test, controlling for additional factors.

Reducing the stigma associated with seeking services is important for increasing health service utilization, and for reducing health care expenditures from people requesting unneeded services to conceal their interest in receiving stigmatized services. While some effects of seeking psychological cover to avoid stigma may be desirable, such as giving blood in order to receive HIV testing results, others are less desirable, such as requesting unnecessary services to conceal an interest in receiving an HIV test.

The implications of this study are that funds are possibly being spent on unnecessary services for people to avoid HIV stigma and conceal their interest in HIV testing. It is important to reduce health care costs and make services more cost-effective for a growing population in need of health care, and awareness of people's decisions and behavioral strategies to avoid experiencing stigma might help to reduce the likelihood of providing unneeded health services to these patients.

The limitations of this study are due primarily to the observational nature of the design. First, multiple alternative explanations may exist for each hypothesis. While each analysis we conducted may have valid alternative explanations by itself, we attempted to address these alternatives by 1) showing that the HIV testing group consistently behaved in a stigma-avoiding manner under multiple hypotheses, and 2) using non-stigmatized services as controls for HIV testing. Next, it is possible that NHAMCS data were not accurately coded. Data were compiled as a result of physicians requesting information from patients, inputting this information on the form, and sending the form for coding and evaluation. It is possible that through this process, reasons for visit were incorrectly reported, or listed in the incorrect order. However, the CDC has attempted to address this problem by training health providers on methods of reporting and stating that providers should report reasons for visits in patients' own words. Third, it is possible that our sample is limited as patients who want to avoid stigma might be using home-based testing kits or testing at community locations not affiliated with NHAMCS. Finally, the present methods are novel and therefore have not been validated or tested against other existing measures of stigma. This study therefore does not aim to conclusively demonstrate behavioral evidence of HIV testing. Instead, the study serves to demonstrate a novel (but not yet validated) method for measuring stigma as initial support for behavioral evidence of HIV stigma. We hope that this study can be used as a catalyst for additional exploration of this topic.

CONCLUSIONS

The present findings suggest 1) researchers can measure behavioral manifestations of stigma avoidance, and 2) that people seek psychological cover to mask their interest in receiving an HIV test. To conceal their interest in testing for HIV, people may be requesting and receiving additional, often unnecessary, services. The total financial cost associated with people's avoidance of stigma and use of unnecessary services is unknown.

We hope that this manuscript serves as a call to action for future research exploring causal relationships between health service usage and HIV stigma. While primarily qualitative work has documented the existence of HIV stigma and the role that it plays in people's mental health and well being, attempts to measure stigma more objectively (such as through avoidance of stigmatized health services) can build upon the existing frameworks by providing more insights as to how stigma impacts decision making, as well as attempting to document the financial burden associated with people's desire to avoid stigma. In this paper we have attempted to shed light on the possibility that the stigma associated with HIV could lead people to avoid HIV testing (or to request additional non-stigmatized services). Future research might explore stigmatized services other than HIV testing (such as services for other sexually transmitted infections or mental health services) to see if people seek

psychological cover to avoid the stigma associated with those services. Understanding the role that stigma plays in people's lives and the way people react to stigma may provide information on how to improve interventions and health services delivery.

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Table 1

Demographics Breakdown by groups' reasons for visiting the clinic

	HIV Percent (n)	Blood Pressure Percent (n)	Mammography Percent (n)	Pearson's Chi-square
Age *				617.03
0-17	11.96 (11)	1.75 (15)	0.28 (1)	
18-34	59.78 (55)	9.01 (7)	2.48 (9)	
35-64	27.17 (25)	56.37 (482)	72.45 (263)	
> 65	1.09 (1)	32.87 (281)	24.79 (90)	
Gender *				205.39
Male	38.04 (35)	40.35 (345)	0 (0)	
Female	61.96 (57)	59.65 (510)	100 (363)	
Race *				56.01
White	64.13 (59)	65.03 (556)	85.95 (312)	
Non-White	35.87 (33)	34.97 (299)	14.05 (51)	
Payment *				165.46
Self-pay	7.61 (7)	9.59 (82)	4.68 (17)	
Medicaid	68.48 (63)	23.63 (202)	9.09 (33)	
Other	23.91 (22)	66.78 (571)	86.23 (313)	

Covariates broken down by groups. Percentage (Number of Visits).

* p-value < 0.001

Table 2

Logistic Regression on Reason for Visit as Primary versus Non-Primary Reason

Factor (Reference Group)	Odds Ratio	95% CI – Low	95% CI – High
Mammography (HIV)	3.496	3.454	3.539
Blood Pressure (HIV)	1.791	1.770	1.811
Child (Young Adult)	0.646	0.634	0.659
Adult (Young Adult)	1.224	1.213	1.235
Senior (Young Adult)	1.055	1.045	1.065
Male (Female)	1.269	1.262	1.275
White (Non-White)	1.544	1.537	1.552
Medicaid (Other)	1.094	1.087	1.101
Self-pay (Other)	0.566	0.562	0.571

Table 3

Logistic Regression on listing multiple reasons for visit

Factor (Reference Group)	Odds Ratio	95% CI – Low	95% CI – High
Mammography (HIV)	0.157	0.155	0.159
Blood Pressure (HIV)	0.687	0.679	0.694
Child (Young Adult)	0.831	0.817	0.846
Adult (Young Adult)	0.843	0.837	0.849
Senior (Young Adult)	1.240	1.230	1.250
Male (Female)	0.853	0.849	0.856
White (Non-White)	0.720	0.717	0.722
Medicaid (Other)	1.592	1.584	1.600
Self-pay (Other)	2.092	2.077	2.106

Table 4

Logistic Regression on listing additional reasons for visit that were unrelated to mammography, blood pressure testing, and HIV testing

Factor (Reference Group)	Odds Ratio	95% CI – Low	95% CI – High
Mammography (HIV)	0.049	0.049	0.050
Blood Pressure (HIV)	0.215	0.213	0.218
Child (Young Adult)	0.406	0.398	0.415
Adult (Young Adult)	0.916	0.909	0.924
Senior (Young Adult)	1.292	1.282	1.303
Male (Female)	0.813	0.809	0.816
White (Non-White)	0.672	0.669	0.675
Medicaid (Other)	1.301	1.294	1.308
Self-pay (Other)	0.930	0.923	0.937