The Role of Trust in Delayed HIV Diagnosis in a Diverse, Urban Population

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Abstract

Delayed diagnosis of HIV infection is a common problem. We hypothesized that persons with less trust in physicians and in the healthcare system would be diagnosed with lower CD4 cell counts than persons with more trust because they would delay seeking healthcare. From January 2006 to October 2007, 171 newly diagnosed HIV-infected persons, not yet in HIV primary care, were recruited from HIV testing sites in Houston, Texas, that primarily serve the under- and uninsured. The participants completed instruments measuring trust in physicians and trust in the healthcare system. Initial CD4 cell counts were obtained from medical record review. Mean trust scores for participants with CD4 cell counts 200 cells/mm^3 were compared with scores from participants with CD4 cell counts <200 cells/mm^3. We found that 51% of the cohort was diagnosed with a CD4 cell count <200 cells/mm^3. Neither trust in physicians nor trust in the healthcare system was an independent predictor of delayed diagnosis of HIV infection. In multivariate analysis, men who have sex with men and injection drug users were more likely to have early HIV diagnosis. Race/ethnicity was the only variable statistically significantly predictive of trust in physicians and in the healthcare system. Hispanics had the highest trust scores, followed by Blacks and Whites. Low trust is likely not a barrier to timely diagnosis of HIV infection.

Keywords

Trust; physicians; healthcare system; delayed diagnosis; race/ethnicity

INTRODUCTION

An estimated 232,000 Americans are HIV positive but are not yet diagnosed [1]. Unfortunately a significant proportion of this group will only be tested once they have advanced HIV disease. Klein et al found that 43% of patients had CD4 counts of less than 200 cells/mm^3 when they entered care [2]. Patients entering care in Mugavero et al's cohort had a median CD4 cell count of 238 cells/mm^3 [3]. Dybul et al found that 36% of patients

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entering their care had CD4 counts less than 200 cells/mm^3 [4]. In the cohort that Jenkins et al studied, 29% of the patients had CD4 counts less than 200 cells/mm^3 at entry to care [5]. These studies are consistent with the Centers for Disease Control and Prevention's finding that 38% of patients who tested HIV positive in 34 States received an AIDS diagnosis within a year of testing positive [6].

Clearly large numbers of HIV infected individuals are not receiving the benefits of early care for their HIV infection. Early detection of HIV infection can result in earlier treatment for HIV infection, which improves health outcomes [7]. In contrast, when the infection is discovered in an advanced stage, it becomes more difficult to treat and has a poorer prognosis [8] and incurs far greater treatment costs [9,10]. A delayed diagnosis can also result in transmission of HIV, as high-risk behaviors may continue without knowledge of one's infection. There is also strong evidence that antiretroviral treatment (ART) greatly reduces the probability of HIV transmission [11,12]. In addition, individuals with undiscovered HIV infection will not receive counseling on HIV risk reduction behaviors [6].

Trust has been shown to affect acceptance of ART, adherence to ART, and appropriate use of outpatient clinic appointments [13–15]. Trust in physicians and trust in the healthcare system are not necessarily correlated [16]. There are some suggestions that trust in physicians and the healthcare system might affect HIV testing. Based on interviews of patients, Hutchison et al listed distrust as a major reason for not having an HIV test [17]. The Massachusetts Department of Health also suggested that lack of trust in public health departments and/or healthcare systems constituted a barrier to early testing [18]. Rudy et al speculated that training counseling staff to increase patients' trust in the testing process would increase the uptake of HIV testing [19]. While speculated upon, distrust has not been demonstrated to be a barrier to early HIV testing. The US National HIV/AIDS Strategy seeks to decrease the proportion of persons who are undiagnosed from 21% to 10% by 2015 [20]. Massive HIV testing efforts are underway in a number of US cities [21–23]. If trust in physicians and/or the healthcare system is associated with delayed diagnosis, campaigns to promote HIV testing might need to target mistrust. Given the high prevalence of delayed diagnosis and its clinical and public health impact, and trust's impact on acceptance of other aspects of HIV care, we hypothesized that lower trust would be found in persons with delayed diagnosis of HIV infection. We therefore conducted a study to determine if patients diagnosed with HIV infection with more advanced disease as measured by a lower baseline CD4 cell count had lower levels of trust in the healthcare system and/or physicians than persons diagnosed earlier in their disease process.

METHODS

Subjects and Setting

The Attitudes and Beliefs and the Steps of HIV Care study (the Steps Study), was a prospective, observational cohort study. From January 2006 to October 2007 patients newly diagnosed with HIV infection and not yet in HIV primary care were recruited from publicly funded HIV testing sites in Houston: 2 county hospitals, an emergency department-based testing program, 12 community-based outpatient clinics, a VA hospital; and city-run clinics specializing in the treatment of sexually transmitted infections. Follow-up lasted 18 months. We defined "newly diagnosed" as a person diagnosed with HIV-infection within the past three months. "Not yet in HIV primary care" was defined as not having completed an outpatient medical appointment with a physician, physician assistant, or nurse practitioner specifically for treatment of HIV infection before enrollment. Participants were approached after they had received their test results (since testing was not part of the research protocol) but before linking to primary HIV care. Interviews were conducted in the field (i.e., at the

participant's place of residence or other mutually agreeable site), or in a healthcare facility. Additional details on the Steps Study are published elsewhere [24].

Measurement

All participants completed a baseline interviewer-administered survey. The Trust in the Healthcare System Scale was developed by O'Malley et al [25]. The respondents indicate how strongly they agree or disagree with each item using a five-point Likert-type scale. The range of scores is 4 to 20, with higher scores indicating more trust. Trust in physicians was assessed with a 10-item scale developed and validated by Hall et al [26]. It assesses the participant's degree of trust in physicians in general (i.e., with no reference to the participant's actual physician). The respondent is asked how strongly they agree or disagree with the statements being read, utilizing a six-point Likert-type scale. The scores range from 10 to 60, with higher scores indicating more trust.

The "CD4 cell count at diagnosis" (baseline) was the first CD4 cell count obtained after infection was diagnosed for each patient. The study did not have a laboratory component, so these values were obtained from medical record review. Medical record review was performed about 2 years after enrollment, to allow sufficient time for any medical follow-up and initial laboratory testing to occur. Early diagnosis was defined as an initial CD4 count 200 cells/mm^3, while late diagnosis was defined as an initial CD4 cell count <200 cells/mm^3.

Data Analysis

The correlation between trust scores and baseline CD4 cell count was assessed with Pearson's correlation coefficient. Mean trust scores for each scale were calculated and a Student's t-test was used to compare the mean trust scores for the early-diagnosis versus the late-diagnosis groups. Chi squared tests were used to compare demographic characteristics between the early-and late-diagnosis groups. Linear regression was employed to adjust the mean trust scores for potential confounders. Logistic regression was used to determine the predictors of high or low trust for each trust scale as well to construct a predictive model of late diagnosis. Data were analyzed using SAS (SAS Institute, Cary, NC). The study was approved by the institutional review boards of Baylor College of Medicine and The University of Texas Health Science Center at Houston. All participants provided written informed consent.

RESULTS

Two hundred thirty nine patients were approached to participate in the study and 200 agreed to enroll. The 39 patients who declined enrollment were similar in age, sex, race/ethnicity, and site of diagnosis to the 200 enrolled patients (data not shown). After enrollment, five patients were excluded because their HIV confirmatory test was negative. After medical record review, four were excluded because they were found to have been previously diagnosed, and two were excluded because they had already linked to care before the baseline survey was completed. One patient was excluded after enrollment because he moved from the Houston area and thus received medical care elsewhere. Over 80% of the remaining participants were recruited within one month of their diagnosis. Of the 188 eligible participants, 1 died before completing a baseline survey, 3 withdrew consent and 3 did not complete the trust scales in their entirety. After medical record review, 10 participants never had a CD4 cell count obtained and were excluded, leaving 171 participants in the final analysis.

Characteristics of the sample population are presented in Table 1; 68 % were male; 53% were between the ages of 30 and 50 years; 51% were non-Hispanic Black (Black); and 45.0% had not completed high school. Of note, 61% of the study sample did not identify as either a man who has had sex with men (MSM) or as an injection drug user (IDU). Just below half the participants (44%) were diagnosed in an inpatient or emergency department setting. The majority of these participants (62%) were interviewed before discharge, and an additional 23% were interviewed in the field. The remaining 15% were interviewed in an outpatient medical setting. Half of the participants (50%) diagnosed in the outpatient setting were interviewed in the field, outside of any healthcare facilities, while the other half were interviewed in an outpatient medical setting (47%) or in the hospital (3%).

The mean baseline CD4 count was 278 cells/mm^3, and 51% had CD4 counts under 200 cells/mm^3 and so were considered diagnosed late. The sample characteristics are also shown in Table 1 stratified by CD4 cell count (< or 200 cells/mm^3). The late diagnosis group was more likely to be diagnosed in an emergency room or hospital. Other baseline characteristics were not statistically significantly different between the two groups.

Results for the trust in physicians and trust in the healthcare system scales are presented in Table 2. Collectively, the participants reported high trust in physicians and the healthcare system. The mean (SD) trust in physicians score was 42.2 (8.4) with a range of scores from 14 to 58. The scale exhibited good psychometric properties with a Cronbach's alpha of 0.91. Participants with late and early diagnosis had similar scores (43.1 [7.3] and 41.3 [(9.4], respectively). The difference was not statistically significant (t=1.39, P= 0.17). The mean score for the trust in the healthcare system scale was 16.1 (3.3), with a range of 6 to 20. The scale demonstrated good psychometric properties with a Cronbach's alpha of 0.87. Participants with a CD4 cell count <200 cells/mm^3 had significantly greater trust in the healthcare system (16.7 [3.1]) than participants with higher CD4 cell counts (15.5 [3.4], t=2.32; P= 0.02).

Because there likely was colinearity between the trust variables, we created 2 separate multivariate logistic regression models of early diagnosis of HIV infection, one containing trust in physicians, and one containing trust in the healthcare system. We considered the variables in Table 1 for inclusion in the models. In both models, the only significant predictor of early diagnosis was the presence of a HIV risk factor (MSM or IDU versus neither MSM nor IDU). In the model that included trust in the healthcare system, identifying as an MSM or IDU had an adjusted odds ratio of 2.3 (95% CI 1.08–5.02, Wald X^2=4.68, P=0.03) for early diagnosis. Similarly, in the model that included trust in physicians, the adjusted odds ratio was 2.3 (95% CI 1.06–5.0, Wald X^2=4.48, P=0.03). Neither trust in physicians nor trust in the healthcare system was an independent predictor of early diagnosis of HIV infection (Wald X^2=1.42, P=0.24; Wald X^2=0.00, P=0.99, respectively).

In a linear regression model of the trust in physicians score that included gender, race/ethnicity, age, education, MSM and IDU status, and CD4 cell count, race/ethnicity was the only variable to have significant effect (Table 3). Hispanic participants were the most trustful of physicians (adjusted mean 45.1), followed by Black (adjusted mean 41.0) and then non-Hispanic White (White) participants (adjusted mean 35.1). The differences between the race/ethnicity groups were significant (Black to White P=0.01; Hispanic to White P<0.0001; Black to Hispanic P=0.01). Similar results were found in the trust in the healthcare system multivariate analysis (Table 3). In a model adjusted for the same factors as above, race was the only variable to be statistically significantly associated with trust in the healthcare system. Again, Hispanic participants had the highest trust scores (adjusted mean 17.5), followed by Black (adjusted mean 15.4) and White participants (adjusted mean 14.8). The difference between Hispanic and White participants was significant (P=0.007), as

was the difference between Black and Hispanic participants (P=0.002), while the scores of the Black and White participants were similar (P=0.5). In this adjusted multivariate model, there was no longer any difference in trust in the healthcare system by early or late diagnosis group (P=0.39). Logistic regression models of the trust variables dichotomized at the median value yielded similar results, with early or late diagnosis not predictive of trust.

We conducted a number of additional analyses to better understand our results. It is possible that dichotomizing early and late diagnosis at or < 200 cells/mm^3 obscures differences in trust. We constructed scatter plots of the trust scores and CD4 cell counts at diagnosis. There was no evidence to suggest that different cut-points would have yielded different results, and the Pearson correlation coefficients for CD4 cell count and trust in physicians and trust in the healthcare system were −0.12 (P=0.11) and −0.19 (P=0.01), respectively, which suggested that there was little explanatory power for either scale. It is noteworthy that the correlations were negative, contrary to our hypothesis. We also used 4 clinically meaningful categories of CD4 cell count results in multivariate models of trust, and did not observe any apparent trends in trust as CD4 cell counts decreased (see Table 3). It is also possible that the 10 participants excluded from the analyses because they did not have CD4 cell count results were affecting the findings. The mean trust in physician and trust in healthcare system scores for these 10 excluded participants were 40.5 (6.3) and 15.8 (2.6), not statistically different from the trust scores of the 171 participants with CD4 cell counts (t=0.64, P=0.53 and t=0.33, P=0.74, respectively). It may be that the relation of trust to HIV diagnosis is different by race, and to test this possibility we included interaction terms (race by trust) in the logistic regression analyses, but none of the interaction terms were statistically significant (data not shown). Finally, the counterintuitive finding that participants with a CD4 count <200 cells/mm^3 had higher trust in the healthcare system may be associated with the fact that participants with lower CD4 counts were more likely to have been diagnosed in an emergency room or hospital. It may be that this recent, intensive interaction with healthcare systems and providers boosted trust. The mean trust in the healthcare system and trust in physician scores did not differ by site of diagnosis, lending little support this hypothesis, however (t=0.66, P=0.51 and t=1.38, P=0.17, respectively).

DISCUSSION

We sought to investigate whether lower levels of trust in physicians and in the healthcare system are predictive of delayed HIV diagnosis, among a cohort of 171 low-income patients recently diagnosed with HIV infection. We found little evidence that trust in physicians or trust in the healthcare system was an independent predictor of delayed diagnosis of HIV infection.

Studies have found that trust is associated with acceptance of ART, adherence to ART, and appropriate use of outpatient clinic appointments [13–15]. We are not aware of any previous studies that assessed the influence of trust in physicians or in the healthcare system on delays in HIV diagnosis. Clark and colleagues sought to determine if an association existed between belief in conspiracy theories of HIV/AIDS and delayed HIV diagnosis [27]. They found conspiracy theories to be common but not associated with delays in diagnosis. Both that study and the present study were conducted in cohorts that were diagnosed with relatively advanced HIV infection.

It is not clear why we did not find an association between trust and delayed diagnosis, given the importance of trust in other aspects of HIV care. Acute medical need will, in theory, increase trust because persons in need have little alternative but to trust their providers [28]. It is possible that a new diagnosis of HIV infection is traumatic enough to result in high levels of trust, regardless of HIV disease stage. Future studies could assess trust immediately

before and after HIV testing to test this hypothesis. Such studies would be difficult to conduct, however, because they would have to include thousands of persons to have an adequate sample of persons newly diagnosed with HIV infection.

There are a number of other possible reasons for our negative findings. They could be a result of failing to measure confounders or effect modifiers, such as stigma and perceived risk of HIV infection. Because the analyses relied on baseline data from the project, they are essentially cross sectional and so causality cannot be determined. The vast majority of baseline interviews were completed before CD4 cell count results were known to the participants. However, it is theoretically possible that the participant's perception of his or her severity of illness, regardless of whether CD4 cell count results were known by the participant, influenced trust. A healthy person has the luxury of not needing to trust the healthcare system, but as severity of illness increases, the patient has little option but to trust the physicians and healthcare system as they deliver more highly technical and specialized care [28]. This phenomenon may explain our paradoxical finding that trust was higher in persons with lower CD4 cell counts, though as noted in the results section, trust did not differ by inpatient or outpatient site of diagnosis.

It is noteworthy that the subgroup considered not at highest risk for HIV infection (i.e. non-IDU, non-MSM) was large in the present study and 55% of them were diagnosed with CD4 cell counts <200 cells/mm^3. In contrast, 34% of those considered "highest risk" were diagnosed with a low CD4 cell count (P=0.12; Table 1). In adjusted analyses, the higher-risk group was over twice as likely to be diagnosed with a CD4 cell count 200 cells/mm^3. A possible explanation for this increased prevalence of late diagnosis among those not at highest risk is the belief that they were not susceptible to infection, though this is speculation. As a result they may delay diagnosis until they are ill from an opportunistic infection. Similar results were seen in the study by Clark and colleagues [27]. These findings support the implementation of routine HIV testing of adults in healthcare settings as recommended by the CDC [29].

We found that the mean trust scores differed by race/ethnicity in an unexpected pattern. Hispanics were consistently found to be most trustful of physicians and of the healthcare system, while White patients were the least trustful of both physicians and the healthcare system. Other studies have found White patients more trustful of physicians and healthcare institutions, and Black patients the least trustful [14,30]. There are several possible explanations for our findings. Differences in trust may exist between indigent White patients who use publicly funded healthcare services (such as those in our sample) and White patients who use private healthcare services. Whetten et al found that distrust was not uncommon among Whites, but concluded that distrust was similar for each racial/ethnic group within in a similar socioeconomic stratum [14]. In our multivariate models, we did not find that socioeconomic status was an independent predictor of trust. It is likely that there was not enough heterogeneity in our sample to fully adjust for socioeconomic status. In addition, less than 10% of the sample population was White (16 persons), and such a small a sample may produce unreliable results. Nonetheless, our results suggest that among the under- and un-insured, trust may not be distributed along racial/ethnic lines as one might expect.

The study has other limitations. The relatively small sample size of the study may have contributed to the negative findings. There was, however, no signal in the scatter plot data to suggest a larger study would support our hypotheses. The study sample is not representative of patients diagnosed with HIV infection in private healthcare settings or community based organizations, or of patients in different geographic areas. There was more homogeneity in the trust in the healthcare system scores than we anticipated. The scale may require

modification to increase its ability to differentiate between groups. Finally, we used general trust in physicians and trust in the healthcare system scales. Trust scales more specifically focused on trust in HIV providers and HIV healthcare facilities might have yielded different results. However, any focus on HIV specific resources would have required the participant to conjecture about their level of trust because, per protocol, the scales were administered before the participant had any experience with the HIV primary care setting. We decided to gather data based on experience rather than conjecture, but that forced us to measure more general constructs. Future research should consider measuring both general and HIV-specific constructs.

Trust in providers is an important predictor of adherence to HIV care [13–15]. To our knowledge, this is the first study to assess the influence of trust in physicians and trust in the healthcare system on delayed diagnosis of HIV infection. We found little evidence that a lack of trust resulted in delayed diagnosis of HIV infection among persons who used publicly funded healthcare systems. Delays in HIV diagnosis remain a significant problem in the continuum of HIV healthcare. This is particularly true among persons without widely recognized high-risk behaviors for acquiring HIV, i.e., MSM and IDU. Among low-income persons with undiagnosed HIV infection, we found little evidence that efforts to promote trust would reduce delayed diagnosis of HIV infection. Data from other populations using alternative methodologies are needed to corroborate or refute our findings.

Acknowledgments

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Table 1

Characteristics of 171 participants in the Steps Study, overall and stratified by late (CD4 cell count <200 mm^3) or early (CD4 cell count ≥200 mm^3) diagnosis.

	All participants	%	Late diagnosis n=87	%	Early diagnosis n=84	%	X^2-value (P-value)
Gender: n=171							1.70 (0.19)
Male	116	67.8	63	72.4	53	63.1	
Female	55	32.2	24	27.6	31	36.9	
Age: n=171							5.19 (0.07)
18–30 yrs	52	30.4	20	23.0	32	38.1	
31–50 yrs	91	53.2	53	60.9	38	45.2	
>50 yrs	28	16.4	14	16.1	14	16.7	
Race: n=171							5.66 (0.06)
Hispanic	68	39.8	42	48.3	26	31.0	
Black	87	50.9	37	42.5	50	59.5	
White	16	9.4	8	9.2	8	9.5	
Education: n=169							5.66 (0.06)
No degree	76	45.0	44	51.2	32	38.6	
High school/GED	44	26.0	24	27.9	20	24.1	
Any college	49	29.0	18	20.9	31	37.3	
Annual income: n=167							0.49 (0.78)
<$14,999	108	64.7	53	62.4	55	67.1	
$15,000–$24,999	36	21.6	19	22.4	17	20.7	
>$25,000	23	13.8	13	15.3	10	12.2	
HIV risk: n=170							2.36 (0.12)
IDU/MSM	67	39.4	29	33.7	38	45.2	
Other	103	60.6	57	66.3	46	54.8	
Diagnosis: n=171							35.4 (<0.001)
Hospital/ER	76	44.4	58	66.7	18	21.4	
Other	95	55.5	29	33.3	66	78.6	

Abbreviations: GED, graduate equivalency degree; IDU, injection drug use; MSM, men who have sex with men; ER, emergency room.

Table 2

Trust in physicians and trust in the healthcare system scores in the Steps Study, overall and comparing participants with late (CD4 cell count <200 mm^3) and early (CD4 cell count 200 mm^3) diagnosis.

	All participants n=171 mean (SD); median (25th %, 75th%)	Late diagnosis n=87 mean (SD); median (25th %, 75th%)	Early diagnosis n=84 mean (SD); median (25th %, 75th%)	t-value (P-value)
Trust in physicians	42.2 (8.4)	43.1 (7.3)	41.3 (9.4)	1.39 (0.17)
	44 (38, 48)	45 (39, 48)	43 (37, 47)	
Trust in healthcare system	16.1 (3.3)	16.7 (3.1)	15.5 (3.4)	2.32 (0.02)
	16 (14, 19)	17 (15, 20)	16 (13, 18)	

Median (25th%, 75th%) values are shown for descriptive purposes. P-value is from Student's t-test. P-values from non-parametric tests were similar. Sample trust in physicians items include, "I completely trust doctors' decisions about which medical treatments are best," "I have no worries about putting my life in the hands of doctors," and "All in all, I trust doctors completely." Sample trust in the healthcare system items include, "How willing are you to put your life in the hands of the healthcare system?" and "How much do you trust the healthcare system to give you the best possible care?"

Table 3

Multivariate linear regression analysis of mean trust in the healthcare system and trust in physicians scores in the Steps Study.

	Trust in the healthcare system (adjusted mean score)	F-value (P-value)	Trust in physicians (adjusted mean score)	F-value (P-value)
Gender		0.01		0.27 (0.63)
Male	15.9	(0.93)	40.9	
Female	15.9		40.1	
Age		0.51		0.11 (0.90)
18–30 yrs	15.7	(0.60)	40.0	
31–50 yrs	15.7		40.5	
>50 yrs	16.4		40.9	
Race		6.04		8.87 (0.0002) [†]
Hispanic	17.5	(0.003 [*])	45.1	
Black	15.4		41.0	
White	14.8		35.1	
Education		0.01		0.33 (0.72)
No degree	15.9	(0.99)	41.3	
High school/GED	15.9		40.3	
Any college	16.0		39.5	
Annual income		0.11		0.09 (0.92)
<$14,999	16.0	(0.90)	40.1	
$15,000–$24,999	15.7		40.6	
>$25,000	16.2		40.8	
HIV risk factor		0.31		0.02 (0.89)
IDU/MSM	16.1	(0.58)	40.6	
Other	15.7		40.1	
CD4 count (cells/mm^3)		1.01		0.27 (0.85)
<50	16.3	(0.39)	41.1	
50–199	16.5		40.6	
200–499	15.6		40.8	
>500	15.3		39.4	

Abbreviations: GED, graduate equivalency degree; IDU, injection drug use; MSM, men who have sex with men; ER, emergency room.

[*] For the pairwise comparisons between the race/ethnicity groups: Black to White, F=0.48; P=0.49; Hispanic to White, F=7.42; P=0.007; Black to Hispanic, F=9.75; P=0.002.

[†] P values for the pairwise comparisons between the race/ethnicity groups are: Black to White, F=6.38; P=0.01; Hispanic to White, F=16.8; P<0.0001; Black to Hispanic, F=6.90; P=0.01.