The Influence of Trust in Physicians and Trust in the Healthcare System on Linkage, Retention, and Adherence to HIV Care

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Abstract

Lack of trust by the patient in the physicians or the healthcare system has been associated with poorer health outcomes. The present study was designed to determine if trust in physicians and the healthcare system among persons newly diagnosed with HIV infection was predictive of patients' subsequent linkage, retention, and adherence to HIV care. 178 newly diagnosed HIV infected patients were administered the trust-in-physicians and trust-in-healthcare system scales. Median trust-in-physicians and trust-in-healthcare system scales. Median trust-in-physicians and trust-in-healthcare system scores were compared for all the mentioned subsequent linkage, retention, and adherence to HIV care. Univariate logistic regression using the trust-in-physician scale confirmed significant association with retention in care (p=0.04), which persisted in multivariate analyses (p=0.04). No significant association was found between trust-in-physicians and linkage to care or adherence to antiretroviral therapy. Trust in the healthcare system was not associated with any of the outcomes. Patients with higher trust in physicians were more likely to be retained in HIV care. Trust at diagnosis may not be a barrier to better clinical outcomes, either because trust changes based on subsequent interactions, or because trust is not a determining feature. Interventions to improve retention in care could include improving trust in physicians or target persons with low trust in physicians.

Introduction

A NTIRETROVIRAL THERAPY (ART) has drastically improved the morbidity and mortality associated with HIV.^{1,2} To maximally benefit from ART, patients with HIV must be diagnosed as early as possible, linked to HIV care, retained in care, prescribed ART, and adhere to ART and have an undetectable HIV load.^{3–5} Unfortunately, among the patients aware of their HIV status, fewer than three-quarters are linked to care in a timely manner and further less than two-thirds are retained in HIV care.⁶ As a result, the U.S. Centers for Disease Control and Prevention estimates that of the 1.2 million people in the United States live with human immunodeficiency virus (HIV) infection, only 30% currently have viral suppression.⁷

A lack of trust by the patient in the physicians or the healthcare system has been associated with poorer health status, decreasing adherence to medications, and a tendency to not follow recommendations for lifestyle modification and avoidance of risky behaviors.^{8–14} Distrustful patients tend to

be less satisfied with their healthcare overall and to have shorter relationships with their doctor. 8

Few studies have assessed the influence of trust on linkage and adherence to HIV healthcare. A retrospective cohort study published by Bodenlos et al. evaluated the attitudes of the patient toward their HIV healthcare provider and attendance at healthcare appointments. Patients with positive attitudes toward their healthcare provider were more likely to attend their healthcare appointments.¹⁵ Whetten et al.¹⁶ interviewed 611 HIV-infected individuals to assess whether higher trust in healthcare providers and the government was related to better healthcare utilization in the past and better health outcomes at the time of interview. Higher trust in healthcare providers was associated with increased outpatient visits and reduced emergency room visits in the past 9 months; and increased likelihood of taking antiretroviral therapy, and improved mental and physical health at the time of the interview. Distrust in the healthcare system was found to be a barrier to service use and consequently diminished the quality of healthcare outcomes.¹⁶

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However, both of these studies enrolled persons already in care, and studies of a newly diagnosed cohort are lacking. In addition, none of these studies were prospective in nature and instead determined if current trust levels were associated with past behaviors. Few studies have assessed trust and then prospectively followed patients to ascertain whether they link and adhere to HIV care, and no study to our knowledge has assessed patients at or near the time of diagnosis of HIV infection.¹⁷ As a result, little is known about the influence of trust on persons who recently learned that they are infected with HIV.

We conducted a prospective cohort study of persons newly diagnosed with HIV infection. Previous analyses of that cohort demonstrated that neither trust in physicians nor trust in the healthcare system predicted delayed HIV diagnosis.¹⁸ The present analysis of that cohort study was designed to determine if trust in physicians and trust in the healthcare system were predictive of patients' subsequent linkage, retention, and adherence to HIV care. We hypothesized that patients with higher trust in physicians and the healthcare system were more likely to be successfully linked, retained, and adhere to HIV care.

Methods

Design, subjects, and procedures

From January 2006 to October 2007, subjects newly diagnosed with HIV infection and not yet in HIV outpatient care were recruited from publically funded healthcare testing sites in Houston, Texas. Participants completed an intervieweradministered survey in English or Spanish, and provided consent for medical record review and follow-up surveys for the next 18 months.

To be eligible, persons had to be diagnosed with HIV infection within the past 90 days and could not have yet completed an outpatient visit with a physician, physician assistant, or nurse practitioner specifically for the treatment of HIV infection. Patients were enrolled from the site of HIV diagnosis and prior to establishing outpatient HIV care. The baseline survey was completed at the time of enrollment. Sites of recruitment were public facilities primarily serving uninsured patients in Houston, Texas. Inpatients were recruited from the Ben Taub General Hospital, the Lyndon B. Johnson General Hospital, and the Michael E. DeBakey Veterans Affairs (VA) Medical Center. Sites of outpatient enrollment were the DeBakey VA outpatient clinics, the Ben Taub General Hospital Emergency Department, Harris Health System Community Health Centers (12 free-standing community based clinics for uninsured persons), and the City of Houston's sexually transmitted infections clinics.

Patients were surveyed every 3 months in follow-up for up to 18 months. Participants were contacted between these interviews to confirm continued enrollment and update contact information.

Healthcare utilization (medical visits and ART use) was initially assessed by self-report, and confirmed by medical record review. The study interviews, conducted every 3 months, included questions about if and where patients obtained general and HIV-specific medical care. Patients' selfreported ART use and clinic attendance was then confirmed by medical record review. In addition, we searched for clinic attendance for all patients, regardless of whether they completed follow-up interviews, in four of the five public HIV clinics in Houston, which account for about 60% of the HIV primary care in Houston, and 90% of the HIV primary care for uninsured patients in the area. All self-reported health care use and ART use was confirmed by medical record review. CD4+ T cell count and HIV viral load data were also gathered from medical record review.

Trust variables and outcomes

Two scales were used to measure trust during the baseline interview. The first scale assessed the degree of trust a person had in physicians. This scale reflects global beliefs about one's willingness to be placed into the care of physicians in general. Because patients had not yet entered HIV care, we could not assess trust in the patient's personal physician. Trust in physicians was measured via a modified 10-item scale (Table 1) developed and validated by Hall et al.¹² The participant was asked how strongly they agreed or disagreed with each statement, utilizing a 6-point Likert-type response scale instead of the original 5-point response scale, to try to increase the range of responses. The scores thus could range from 10 to 60, with higher scores indicating greater trust.

The second trust variable, trust in the healthcare system, was measured with an instrument modified from the Patient Attitudes Concerning Trust (PACT) scale (Table 1) originally developed by O'Malley et al.^{19,20} The participants indicated how strongly they agreed or disagreed with each statement, using a 5-point Likert-type response scale. The

TABLE 1. TRUST IN PHYSICIANS AND TRUST IN HEALTHCARE SYSTEM QUESTIONNAIRES

Trust in Physicians, based on Hall et al.¹²

- a. In general, doctors care about their patient's health just as much as, or more than their patients do.
- b. Sometimes doctors care more about what is convenient for them than about their patient's medical needsc. Doctors are extremely thorough and careful
- d. I completely trust doctor's decisions about which medical treatments are best
- e. Doctors are totally honest in telling their patients about all of the treatment options available for their conditions.
- f. Sometimes doctors do not pay full attention to what patients are trying to tell them
- g. Doctors always use their very best skill and effort on behalf of their patients
- h. I have no worries about putting my life in hands of doctors
- i. A doctor would never mislead you about anything
- j. All in all, I trust doctors completely

Trust in Healthcare System, based on O'Malley et al.^{18,19}

- a. How much do you trust the healthcare system?
- b. How willing are you to put your life in the hands of healthcare system?
- c. How confident are you in the healthcare system's ability to care for your health?
- d. How much do you trust the healthcare system to give you the best possible care?

range of scores is from 4 to 20, with higher scores indicating greater trust.

Alcohol use was assessed with the CAGE questionnaire, and a positive response on any two of the four items was considered heavy alcohol use.²¹ Depression was assessed with the Center for Epidemiologic Studies Depression Scale (CES-D) questionnaire.²² Scores greater than or equal to 16 signified high risk for depression.²² CD4 cell count at diagnosis was assessed from medical record review, and was the first available result available for the patient.

Outcomes included linkage to care, retention in care, ART initiation, adherence to ART, and achieving an undetectable viral load. Linkage to care was defined as having completed at least one outpatient visit for HIV primary care within 90 days of diagnosis.²³ Retention in care was defined as having completed at least one visit for HIV primary care in each of 3 or 4 quarter years in the year after diagnosis.²⁴ Based on treatment recommendations at the time,²⁵ ART initiation within 1 year of diagnosis was assessed for patients with a baseline CD4+ T cell count less than 350 cells/mm³ and was dichotomized. Adherence to ART was assessed by average responses on a visual analogue scale of adherence, using all available follow up reports for the participant. The adherence score was then dichotomized at equal to or greater than 95% or less than 95%.²⁶ Virologic suppression was defined as HIV viral load <400 copies/mL (the lower limit of detection in the clinical laboratory at the time of the study) for patients with an indication for ART within the first 12 months.

Data analysis

Missing viral load measures for patients with an indication for ART²⁵ were considered treatment failures for the analysis. Death before an outcome was completed was also considered failure for that outcome. The trust variables were continuous but not normally distributed, so nonparametric tests were used to compare the median trust scores for participants who achieved and did not achieve the outcomes. A univariate nonparametric Kruskal–Wallis test was used to investigate associations between trust scores and baseline characteristics of the cohort. Significant associations found on univariate analysis between the trust scores and the outcome variables were adjusted for baseline characteristics associated with trust scores at a level of p < 0.1 using multivariate logistic regression. We considered p < 0.05 to be statistically significant.

Data were analyzed using SAS (SAS Institute, Cary, NC). The study was approved by the institutional review boards of Baylor College of Medicine and of The University of Texas Health Science Center at Houston. All participants provided written informed consent.

Results

Two-hundred thirty-nine patients were approached for enrollment before 200, the planned enrollment total, agreed to enroll. No differences in demographic characteristics were noted between the 200 participants who were enrolled and the 39 who declined enrollment. After enrollment, five participants were excluded because their HIV confirmatory test was negative, four were excluded because they were found on medical record review to have been previously diagnosed, two were excluded because they had already linked to HIV care before the baseline survey was completed, and one was excluded because he was transferred out of Houston for medical care.

Of the remaining 188 participants, one died before completing a baseline survey, five withdrew consent, and four did not complete trust scales, leaving 178 participants in the present analysis. Eighty-one percent of participants were surveyed within 1 month of receiving their HIV diagnosis.

Demographic characteristics of the 178 participants are presented in Table 2. Of note, 68% of the participants were male, 52% were non-Hispanic black, 39% were Hispanic, and 10% were non-Hispanic white patients. Approximately 44% of the participants did not complete high school, 67% had an annual income below \$15,000, and 59% did not have traditional HIV risk factors [were neither men who have sex with men (MSM) nor intravenous drug user (IDU)]. Approximately half of the participants had a CD4 cell count at diagnosis less than 200 cells/mm³ (49.7%). Sixty-seven percent of the patients screened positive for depression, and over a quarter of the patients admitted to illicit drug and alcohol misuse, highlighting the high prevalence of psychiatric co-morbidity in this population. The median (25th, 75th percentile) trust in physicians score was 44 (38, 48), while the median (25th, 75th percentile) trust in the healthcare system score was 16 (14, 19).

In the univariate analyses (Table 2), participants with lower trust in physician scores were more likely to be females (p=0.06), more likely to be non-Hispanics (p<0.01) and report high school or higher education (p=0.03). There was no association between age, income, HIV risk factor, baseline CD4 cell count, presence of depression, or reported alcohol and substance use and trust in physicians score. Participants with lower trust in the healthcare system scores were more likely to be non-Hispanics (p<0.01) and report high school or higher education (p=0.05). There was no association between age, gender, income, HIV risk factor, baseline CD4 cell count, presence of depression, or reported alcohol and substance use and trust in healthcare system score.

Of the 178 participants in the analysis, 139 (78.1%) were successfully linked to care within 90 days of diagnosis, 93 (52.2%) were retained in care at 12 months, and 91 (80.5%) of the 113 participants with CD4 < 350 initiated ART. Of the patients on ART, 51 (57.9%) reported \geq 95% adherence to ART, but only 41 (36.3%) of the 113 participants with an indication for ART achieved undetectable viral load by 1 year.

Trust in healthcare system did not predict any of the outcome variables (Table 3). Trust in physicians did not predict linkage to care, use of ART, adherence to ART, or virologic suppression (Table 3). The median trust in physicians score for persons retained in HIV healthcare was 45, while the median score for persons not retained in HIV healthcare was 43 (p=0.02) (Table 3; Fig. 1). A univariate logistic regression model of the trust in physician score confirmed significant association with retention in care with the odds of retention increasing 1.25 times for each 5-unit increase in trust score (95% confidence interval, 1.03, 1.50; p=0.04).

Multivariate logistic regression using the trust-in-physician scale and adjusting for gender, race/ethnicity, and education confirmed the significant association with retention in care, with the odds of retention increasing 1.24 times for each

	Participants (%)	<i>Trust in Physicians</i> <i>Score Median</i> (25 th , 75 th percentile)	<i>Trust in Healthcare System</i> <i>Score Median</i> (25 th , 75 th percentile)
All participants	178 (100%)	44 (38, 48)	16 (14, 19)
Sex (n=178) Male Female	122 (68.5%) 56 (31.5%)	p = 0.06 45 (38, 48) 42 (37.5, 45.5)	<i>p</i> =0.18 16 (14, 20) 16 (13, 18)
Age, years (n = 178) 18-30 31-50 >50	58 (32.6%) 94 (52.8%) 26 (14.6%)	P = 0.80 44 (37, 47) 44 (38, 48) 43.5 (39, 49)	p = 0.59 16 (15, 19) 16 (14, 19) 18 (13, 20)
Race/ethnicity (n = 178) Hispanic African American White	68 (38.2%) 92 (51.7%) 18 (10.1%)	p < 0.01 47 (44, 50) 42 (36.5, 46.5) 38 (31, 43)	p < 0.01 18 (16, 20) 16 (13, 18) 16 (13, 17)
Education $(n = 176)$ No degree High school or GED Any college	78 (44.3%) 48 (27.3%) 50 (28.4%)	p = 0.03 45 (40, 50) 42 (37.5, 46.5) 42 (35, 47)	p = 0.05 17.5 (15, 20) 16 (13, 18.5) 16 (14, 18)
Annual income (<i>n</i> =174) <\$14,999 \$15,000-\$24,999 >\$25,000	115 (66.1%) 34 (19.5%) 25 (14.4%)	p = 0.79 44 (39, 47) 41.5 (34, 50) 43 (33, 50)	p = 0.51 16 (15, 19) 16 (13, 18) 16 (13, 19)
HIV risk factor (n = 177) IDU or MSM Other	72 (40.7%) 105 (59.3%)	p = 0.68 43 (38, 47.5) 44 (39, 48)	<i>p</i> =0.99 16 (14, 19.5) 16 (14, 19)
CD4 cell count, $/\text{mm}^3$ ($n = 167$) <200 cells 200–349 cells \geq 350 cells	83 (49.7%) 30 (18.0%) 54 (32.3%)	p = 0.12 45 (39, 48) 47 (39, 50) 42.5 (37, 45)	p = 0.11 17 (14, 20) 17 (13, 20) 16 (13, 17)
CES-D Depression Scale $(n=176)$ Positive (≥ 16) Negative (< 16)	117 (66.5%) 59 (33.5%)	<i>p</i> =0.11 46 (37, 50) 43 (39, 47)	<i>p</i> =0.11 17 (15, 20) 16 (14, 19)
Any substance use in the last 6 months $(n = 177)$ Present	48 (27.1%)	p = 0.29 41.5 (38, 47.5)	p = 0.37 16 (13, 19)
Absent Heavy alcohol use $(n = 176)$	129 (76.9%)	$\begin{array}{c} 44 \ (38, 48) \\ p = 0.27 \\ 42 \ (22, 47) \end{array}$	p = 0.37
Positive CAGE (≥2) Negative CAGE (<2)	42 (23.9%) 134 (76.1%)	42 (38, 47) 44 (38, 48)	16 (13, 19) 16 (14, 19)

TABLE 2. BASELINE CHARACTERISTICS AND TRUST SCORES OF 178 PARTICIPANTS IN THE STEPS STUDY

5-unit increase in trust score (95% confidence interval, 1.02, 1.52; p = 0.04).

Discussion

In this prospective observational cohort study of persons newly diagnosed with HIV infection, we demonstrated that higher trust in physicians predicted more successful retention in HIV care. To our knowledge, this is the first prospective study to assess the impact of trust in physicians and trust in the health system on the continuum of HIV care in persons newly diagnosed with HIV infection. We found that trust in physicians at the time of diagnosis was not significantly associated with other steps in the HIV care continuum, and trust in the healthcare system was not associated with any steps in the continuum.

The trust-in-physician score for our cohort compared favorably to the national sample used for validating the trust-inphysician scale. In that study, with a possible range in scores from 11 to 55, the mean score was 33.5, or very close to the mid-point. That sample was a telephone-based sample of adults with health insurance.¹² Our sample had a median trust in physician score of 44, which is about 10 points higher, within a similar possible range of scores (10 to 60). Our sample has been recently diagnosed with HIV infection, and thus is more acutely dependent on physicians, which has been associated with higher trust.¹¹ Unfortunately there are no national data for comparison for the trust-in-healthcare scale.

Trust may not have a pervasive impact throughout the steps of HIV care. Most of the outcomes we assessed were not associated with trust in physicians or the healthcare system measured shortly after HIV diagnosis. Events before, at, or after diagnosis and related to or unrelated to the encounter in which HIV was diagnosed could affect trust. In a previous examination of this same cohort, we found that neither trust in physicians nor trust in the healthcare system

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TABLE 3. THE ASSOCIATION OF TRUST IN PHYSICIANS
and Trust in Healthcare System Scores
AT HIV DIAGNOSIS WITH OUTCOMES DURING
NEXT YEAR AMONG PARTICIPANTS IN STEPS STUDY

Outcome	Trust in Physicians Score median (25 th , 75 th percentile)	Trust in Healthcare System Score median (25 th , 75 th percentile)
Linked to care $(n = 178)$ Yes $(n = 139)$ No $(n = 39)$	p = 0.23 44 (38, 48) 42 (38, 48)	<i>p</i> =0.79 16 (14, 19) 16 (14, 19)
Retained in care $(n=178)$ Yes $(n=93)$ No $(n=85)$	<i>p</i> =0.02 45 (40, 49) 43 (37, 46)	<i>p</i> =0.30 16 (14, 19) 16 (14, 19)
ART use, if baseline CD4 cell count $<350 \text{ /mm}^3$ ($n=113$) Yes ($n=91$) No ($n=22$)	p = 0.17 46 (39, 50) 43 (39, 47)	<i>p</i> =0.88 17 (14, 20) 17 (15, 19)
Adherence to ART, if on ART (<i>n</i> =88) 95–100% (<i>n</i> =51) <95% (<i>n</i> =37)	p = 0.14 46 (39, 50) 44 (41, 48)	<i>p</i> =0.15 18 (14, 20) 16 (13, 19)
HIV viral load suppression, if baseline CD4 cell count <350 /mm ³ (n = 113)	<i>p</i> =0.42	<i>p</i> =0.36
<400 copies /mL $(n=41)$ ≥400 copies /mL $(n=72)$	47 (40, 49) 44 (39, 48)	18 (15, 20) 17 (14, 20)

predicted delayed HIV diagnosis, as indicated by lower initial CD4 cell counts.17

In the present analyses, we did not see a relationship with linkage to care, which is perhaps most suggestive that trust at baseline is not of critical importance, as that is the first step in the continuum and most proximate to our measurement of the participant's trust. Those results could have been affected by the relatively limited sample size, since only 39 participants did not link to care within 90 days.

Other studies have found that trust is associated with acceptance of ART, adherence to ART, and appropriate use of outpatient clinic appointments.^{27,28} It is possible that we

FIG. 1. Retention in care stratified by trust in physicians. The figure shows proportion retained in care stratified into three groups, according to the participant's baseline trust in physicians scale score: 10 to 30 (n=19), 31 to 45 (n=93), and 46 to 60 (n=69).

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did not see an association with trust and ART adherence and viral load suppression in our data because trust at diagnosis may be no longer relevant once one is in care and prescribed ART. These more downstream steps in the continuum could have been influenced by later interactions with physicians and the healthcare system. Negative results also could have been due to our assessing trust in physicians in general. We could not assess trust in the patient's HIV physician because, by definition, the patient did not have one yet. Low trust in physicians in general may not be a major barrier to HIV testing or linkage to initial HIV care, but, after that, may be an important component for being retained in HIV care in the first year after diagnosis.

Stutterheim et al. in their qualitative study²⁹ highlighted that around 60% of the people accessing HIV care experienced some negative interaction with their healthcare provider. Further, Magnus et al. found that HIV-infected patients reporting poor retention in HIV care were more likely to report negative experiences with doctors or nurses not always listening carefully to them and not always explaining things to them. Patient perception of provider willingness to care for patients with HIV and their sense of stigma has also been associated with poor retention in HIV care.³⁰

Trust in physician has been correlated with improved patient reported satisfaction in their care,³¹ which in turn has been associated with improved retention in HIV care.³² A trusting relationship could help patients feel welcomed and cared for and reduce the perceived stigma associated with accessing HIV as well as improve patient satisfaction with care. Based on these and other data, the US Department of Health and Human Services Panel on Antiretroviral Guidelines for Adults and Adolescents recommends establishing a trusting patient-provider relationship to improve medication adherence, retention in HIV care, and improve long-term health outcomes.^{27,28,33} To our knowledge, interventions to improve trust in physicians have not been developed or tested. An alternative strategy to intervening to improve trust is to identify persons with low trust and then delivering retention interventions, such as enhanced personal contact,³⁴ to these patients.

While it includes physicians, the healthcare system is broader and includes hospitals, clinics, insurers, and other entities. We did not find a significant association between trust in the healthcare system and the outcome variables of



interest. The study by Whetten et al.¹⁶ included a population that overly represented minority and poor patients, similar to our population. It also found no association between trust in the healthcare system and both HIV clinic visits and ART adherence. Together, these negative results suggest that patients are able to set aside mistrust of the healthcare system, though they are influenced by trust in physicians.

The prospective nature of the study also allows us to highlight the cohort's progress in the continuum of HIV care. Seventy-eight percent of the patients were successfully linked to care within 90 days of diagnosis, 52% were retained in care at 12 months, and 81% of the 113 participants with CD4 < 350 initiated ART. Of the patients on ART, 58% reported $\geq 95\%$ adherence to ART, but only 36% of the 113 participants with an indication for ART achieved undetectable viral load by 1 year. These results are not dissimilar to national estimates.⁸ The US DHHS treatment guidelines now recommend ART for all patients infected with HIV.³³ Newer integrase strand transfer inhibitors, simpler dosing regimens, and improved side effect profiles lead us to expect better adherence and improved viral load suppression rates than we observed in this study. Nonetheless, the results are sobering.

There are certain limitations of our study. Trust in healthcare systems may be idiosyncratic to a given location, limiting the generalizability of our findings on that construct. The study sample is relatively small, and some persons were lost to follow-up despite aggressive tracking. We do not have data on why some participants had lower trust in physicians and the healthcare system than others. Trust was assessed at baseline and any change in trust over the next 12 months was not accounted for in the study. Trust may be a confounder for unmeasured constructs, such as resiliency, skepticism, or others. Finally, our study was conducted in a public healthcare facility in Houston, and an over-represented minority, underprivileged, and indigent population may not be representative of the persons living with HIV in the U.S.

This prospective cohort study of persons newly diagnosed with HIV infection found that patients with higher trust in physicians were more likely to be successfully retained in HIV care in the first year after diagnosis. It was previously demonstrated that better retention in HIV care in the first year has been associated with higher rates of ART initiation and improved survival.^{26,35,36} Qualitative research would be helpful to develop an understanding of trust in physicians and the healthcare system and of the correlates of retention in HIV care among persons newly diagnosed with HIV infection. Based on our results, one component of interventions designed to improve early retention in care might have a focus on improving trust in physicians.

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Author Disclosure Statement

The authors report no real or perceived vested interests that relate to this article (including relationships with pharmaceutical companies, biomedical device manufacturers, grantors, or other entities whose products or services are related to topics covered in this article) that could be construed as a conflict of interest.

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