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RESEARCH ARTICLE

Mistrust of Health Care Organizations is Associated with Underutilization of Health Services

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Purpose. We report the validation of an instrument to measure mistrust of health care organizations and examine the relationship between mistrust and health care service underutilization.

Methods. We conducted a telephone survey of a random sample of households in Baltimore City, MD. We surveyed 401 persons and followed up with 327 persons (81.5 percent) 3 weeks after the baseline interview. We conducted tests of the validity and reliability of the Medical Mistrust Index (MMI) and then conducted multivariate modeling to examine the relationship between mistrust and five measures of underutilization of health services.

Results. Using principle components analysis, we reduced the 17-item MMI to 7 items with a single dimension. Test–retest reliability was moderately strong, ranging from Pearson correlation of 0.346–0.697. In multivariate modeling, the MMI was predictive of four of five measures of underutilization of health services: failure to take medical advice ($b = 1.56$, $p < .01$), failure to keep a follow-up appointment ($b = 1.11$, $p = .01$), postponing receiving needed care ($b = 0.939$, $p = .01$), and failure to fill a prescription ($b = 1.48$, $p = .002$). MMI was not significantly associated with failure to get needed medical care ($b = 0.815$, $p = .06$).

Conclusions. The MMI is a robust predictor of underutilization of health services. Greater attention should be devoted to building greater trust among patients.

Key Words. Trust, mistrust, help seeking, underutilization, measurement, scale, factor analysis, principle components analysis

Mistrust plays an important role in the process of care. Several studies have commented on the influence of trust/mistrust in health services (Caterinicchio 1979; Thorne and Robinson 1988; Thom and Campbell 1997; Thom et al. 1999a, b; LaVeist, Nickerson, and Bowie 2000; Hall et al. 2001), yet there is a lack of empirical research on mistrust in medical care settings and its impact on utilization of health services. Pearson and Raeke's (2000) review of the literature on mistrust in health care concluded that one impediment to

advancing this literature has been the lack of a generalized measure of mistrust in health care that is suitable for inclusion in both patient-based and community studies. Research on mistrust has progressed since Pearson and Raeke's (2000) literature review (Leisen and Hyman 2001; Hall et al. 2002; Thom et al. 2002; Rose et al. 2004; Shea et al. 2008), but the limitations they describe remain. The Trust in Physicians Scale (TIPS) is the most widely used measure of trust within medical care settings. It assesses patients' level of trust of their individual physician (Thorne and Robinson 1988; Anderson and Dedrick 1990). The TIPS is limited in that it is applicable only to patients who have a physician as their primary source of care. It is not applicable to the medically uninsured, those who do not have a usual source of health, or for individuals whose usual source of care is not a physician. However, over the past few decades there have been important changes in the dominant modes of medical care delivery (Mechanic and Schlesinger 1996). Patient's interactions with the medical care system have become less focused on an individual physician. With the emergence of HMOs, managed care, and other similar systems of health care delivery, increasingly, the patient–provider relationship is with an organization or nonphysician health care provider rather than an individual physician (Mechanic and Schlesinger 1996).

Low-income and minority patients are more likely to rely on clinics or emergency rooms as their usual source of care. And some preventive health services, such as mammography or even flu shots, are typically conducted by a technician that the patient does not have an ongoing relationship with. While the TIPS has been deployed productively in several published studies, there remains a need for an additional measure that can assist in expanding the literature on mistrust in health care beyond the limitations of the TIPS. In this paper, we report on the validation of an instrument to measure mistrust of health care organizations. We then use that measure to examine the relationship between mistrust and race disparities in health care service underutilization.

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METHODS

We conducted a telephone survey of a random sample of residents of Baltimore City, MD. We sampled households and selected the household member age 18 or older who had the most recent birthday (Salmon and Nichols 1983). Baltimore City has 167 telephone exchanges (first 3 numbers of a telephone number) within two area codes, 410 and 443. The 45 exchanges that were associated exclusively with cellular phones were excluded. Another 23 exchanges were excluded because they are exclusively owned by large businesses or institutions, such as universities, large corporations, or government entities.

The remaining 99 exchanges were entered into a database with all possible combinations of the last 4 digits (0001–9,999). This generated a sampling frame of 989,901 telephone phone numbers. We selected a 1 percent random sample (9,899). Power calculations determined we required a sample of 367 respondents. Trained interviewers called each telephone number, documenting those that were disconnected or not in service, those who did not speak English, those who refused, and those who agreed to enroll in the study. For the telephone numbers answered by an answering machine, a message was left and each number was called back a minimum of two times (Xu, Bates, and Schweitzer 1993; Koepsell et al. 1996). The interviewers made contact (talked with an eligible respondent) with 783 people; 401 completed the baseline interview (51.2 percent), and 382 refused.

The average baseline interview lasted approximately 15 minutes. Participants were told that they would be called back in approximately 3 weeks and an appointment to facilitate callbacks. Of the 401 completed baseline interviews, 327 (81.5 percent) completed the follow-up interview. All analyses are based on the 401 respondents from the baseline survey with the exception of the analysis of test–retest reliability, which is based on the 327 respondents for whom we had complete data. Follow-up interview was also done over the telephone and lasted approximately 12 minutes. Respondents were compensated U.S.$20 for their participation. The interviewers obtained oral informed consent. The study was approved by the Institutional Review Board at the Johns Hopkins Bloomberg School of Public Health.

MEASURES

Race (African American versus white) and gender (male versus female) were specified in the analysis as binary variables. Income was specified as a

continuous variable in eight groupings, and education was categorized into four categories (less than high school, high school graduate, some college, and college graduate or more). Age was grouped in to six categories. Insurance status is specified as a set of four binary variables (Medicare, Medicaid, private insurance, and uninsured). In regression models, privately insured is the comparison category. Medical mistrust was assessed using the Medical Mistrust Index (MMI), a 17-item scale, which uses Likert-type response with the following response codes: "strongly disagree," "disagree," "agree," and "strongly agree."

The 17 items that comprise the MMI came from a set of focus groups with patient/participants in a study of race differences in utilization of cardiovascular invasive procedures (LaVeist et al. 2003). Without prompting, study participants consistently reported mistrust as an important barrier to receipt of care. Based on these interactions the first version of the MMI was created. The measure was further refined by a review of the literature on mistrust of societal institutions and mistrust of health care (Mechanic and Schlesinger 1996; Pearson and Raeke 2000). The items in the 17-item scale are displayed in Table 2. Additionally, we asked respondents if in the last 12 months they had failed to take their physician's advice; failed to keep a follow-up appointment; failed to seek medical care when they felt they needed it; failed to fill a prescription; or postponed or delayed seeking care they felt they needed. Each question was specified in our analysis as a binary variable denoting an affirmative response.

Analysis Strategy

We examined internal consistency reliability and test–retest reliability for the MMI. Analysis of the internal consistency included the Cronbach α coefficient, item-to-total correlation, and factor analysis. We also performed factor analysis (principle components analysis) to determine whether scale psychometrics can be used to produce a more parsimonious scale. Once the most parsimonious scale was determined we created an index by averaging across the items to create an index ranging from 1 to 4. We then examined validity of the MMI. Validity refers to the degree to which there are systematic differences between the information obtained in response to the questions relative to the meaning of the concept they were intended to measure, or related measures about a similar concept. Because there is no exact criterion measure, we used two related measures, the TIPS (Anderson and Dedrick 1990; Thom

et al. 1999b) and the Generalized Trust Scale (GTS), a subscale of the Trust Inventory (Couch, Adams, and Jones 1996). We anticipate that there will be an inverse correlation between MMI and the other trust measures. Finally, we specified a set of multivariate regression models to examine the effect of mistrust of medical care on utilization of needed health services.

RESULTS

The sample has a mean age of 47.3 with respondents evenly distributed across each age category. Nearly 15 percent of the sample are under age 25, and 19.6 percent are older than 65. The modal age category is 45–54. Twenty-eight percent of the sample are male. The sample reflects the ethnic distribution of Baltimore, MD; 69 percent are African American, 25 percent are white, and 5.7 percent are Hispanic or Asian American. Nearly 24 percent reported incomes below U.S.$10,000, and 25 percent reported incomes above U.S.$50,000. Just below 75 percent of respondents had at least a high school education, and 22.1 percent were college graduates. Nearly 51 percent had private insurance, and nearly 24 percent were uninsured (Table 1).

In the first set of analyses we assess internal consistency for the 17-item MMI (see Table 2). Items 5 and 7–11 were reverse coded so that for each item a higher score indicated greater mistrust. We conducted principal components analysis (assuming the factors would be oblique). The results are displayed in Table 2. The analysis resulted in a two-factor solution. Items that did not load on a factor at 0.5 or greater were dropped from the scale.

Seven of the 17 items loaded above 0.5. The remaining items loaded more strongly on the second factor. However, only one of the items that loaded on the second factor had a factor loading at or above 0.5. The first factor explained over 40 percent of the variance and the second factor explained about 12 percent. The first factor accounted for a substantial proportion of the variance relative to the second factor. Also a review of the Scree plot and the eigenvalue coupled with the fact that only one item loaded above 0.5 led to the conclusion that the second factor was not robust. Thus, we settled on a single-factor solution with the seven items that loaded on factor 1. All further analysis was conducted on the seven-item version of the scale. The computed reliability coefficient (Chronbach α) was 0.76 for the seven items.

In Table 3 we present analysis of the test–retest reliability for each item and the seven-item scale. The table shows the correlation between the same item for the baseline and follow-up survey. Pearson correlations among the

Table 1: Demographic Profile of the Sample

Variable	*%*
Age (years)	
Younger than 25	14.9
25–34	12.1
35–44	17.4
45–54	21.7
55–64	14.4
65 or older	19.6
Sex	
Female	71.3
Male	28.7
Race	
White	25.2
Black	69.1
Other	5.7
Income	
<U.S.$5,000	8.7
U.S.$5,000–U.S.$9,999	15.2
U.S.$10,000–U.S.$14,999	11.5
U.S.$15,000–U.S.$24,999	12.9
U.S.$25,000–U.S.$34,999	13.8
U.S.$35,000–U.S.$49,999	12.9
U.S.$50,000–U.S.$59,000	8.1
U.S.$60,000 or more	16.9
Education	
Less than high school graduate	25.6
High school graduate	32.7
Some college	19.6
College graduate	22.1
Health insurance	
Medicaid	32.9
Medicare	21.9
Private	50.9
Uninsured	23.9

individual items ranged from 0.346 to 0.500. Test–retest correlation for the full scale was 0.697. All correlations were significant at $p<.0001$.

Using Pearson correlation, we examined scale validity of the MMI by testing for an association between the MMI and related measures, the TIPS and GTS. We selected the TIPS because is it an established measure of trust used in health care research and the GTS because it is an established measure of trust as a general personality characteristic. The MMI was significantly correlated with TIPS (corr $= -0.232$, $p<.0001$) and the GTS (corr $= -0.151$, $p=.006$). Additionally, we examined the association between the MMI and

Table 2: Assessment of Internal Consistency and Mean Distribution of 17-Item Medical Mistrust Index Items

Question	*Factor 1*	*Factor 2*	*Mean*	*Standard Deviation*	*Item-to-Scale Correlation*
(1) You 'd better be cautious when dealing with health care organizations	0.612	0.285	2.93	0.660	0.445
(2) Patients have sometimes been deceived or misled by health care organizations	0.719	0.157	2.70	0.664	0.561
(3) When health care organizations make mistakes they usually cover it up	0.657	0.138	2.63	0.663	0.493
(4) Health care organizations have sometimes done harmful experiments on patients without their knowledge	0.658	0.228	2.54	0.665	0.491
(5) Health care organizations don't always keep your information totally private	0.591	0.261	2.51	0.646	0.427
(6) Sometimes I wonder if health care organizations really know what they are doing	0.658	0.217	2.70	0.609	0.498
(7) Mistakes are common in health care organizations	0.573	0.228	2.67	0.590	0.414
(8) I trust that health care organizations will tell me if a mistake is made about my treatment	−0.463	0.386			
(9) Health care organizations often want to know more about your business than they need to know	0.483	0.430			
(10) The patient's medical needs come before other considerations at health care organizations	−0.390	0.489			
(11) Health care organizations are more concerned about making money than taking care of people	0.418	0.020			
(12) Health care organizations put the patient's health first	−0.369	0.329			
(13) Patients should always follow the advice given to them at health care organizations	−0.401	0.434			
(14) I typically get a second opinion when I am told something about my health	0.378	0.430			
(15) I trust that health care organizations check their staff's credentials to make sure they are hiring the best people	−0.382	0.311			
(16) They know what they are doing at health care organizations	0.194	0.195			
(17) I trust that health care organizations keep up with the latest medical information	−0.403	0.544			
Eigenvalues (% of variance)	2.87 (40.97)	0.86 (12.27)			

Table 3: Test–Retest Reliability Correlating Survey Respondent's Response for Each Item at Baseline with Their Response at Follow Up for the Seven-Item Medical Mistrust Index

Question	*Correlation between Waves 1 and 2*
(1) You'd better be cautious when dealing with health care organizations	Corr = 0.500 $p = .000$
(2) Patients have sometimes been deceived or misled by health care organizations	Corr = 0.398 $p = .000$
(3) When health care organizations make mistakes they usually cover it up	Corr = 0.567 $p = .000$
(4) Health care organizations have sometimes done harmful experiments on patients without their knowledge	Corr = 0.474 $p = .000$
(5) Health care organizations don't always keep your information totally private	Corr = 0.364 $p = .000$
(6) Sometimes I wonder if health care organizations really know what they are doing	Corr = 0.346 $p = .000$
(7) Mistakes are common in health care organizations	Corr = 0.451 $p = .000$
Scale	Corr = 0.697 $p = .000$

several demographic variables. The MMI was correlated with race (corr = -0.183, $p = .01$) and education (corr = 0.115 $p = .02$); however, we did not find a significant relationship between the MMI and gender (corr = -0.56, $p = .26$).

In Table 4 we examine the effect of mistrust on a set of measures of health services underutilization. Each model was adjusted for race, sex, age, education, income, and health insurance. Model 1 shows that mistrust is associated with failure to take medical advice such that a higher score on the MMI leads to greater odds of having failed to take medical advice in the last 12 months. Likewise, mistrust is a predictor of each measure of health services underutilization, with the exception of failing to seek needed care, which has a p-value of .06. Higher mistrust scores lead to greater odds of underutilization of health services. The consistency of the positive association between mistrust and underutilization across the various measures suggests that the finding is robust. Tests for interactions between the MMI and race, gender, and education failed to find a significant interaction.

DISCUSSION

Factor analysis of the 17-item MMI revealed the presence of one factor with seven items. The low eigenvalue and variance explained of the second factors

Table 4: Logistic Regression of Mistrust and Utilization of Health Services Regressed on Medical Mistrust Index (MMI) and Controls

	Model 1 Failed to Take Medical Advice β (p)	*Model 2 Failed to Keep Follow-Up Appointment (p)*	*Model 3 Failed to Get Needed Care (p)*	*Model 4 Postponed Seeking Needed Care (p)*	*Model 5 Fail-to-Fill Prescription (p)*
MMI	1.56 (.00)	1.11 (.01)	0.815 (.06)	0.939 (.01)	1.48 (.002)
Race	0.384 (.27)	0.499 (.18)	0.086 (.81)	0.005 (.98)	0.230 (.53)
Female	0.733 (.06)	0.092 (.80)	0.310 (.396)	0.468 (.152)	− 0.027 (.94)
Income	0.013 (.88)	− 0.195 (.02)	− 0.002 (.98)	0.019 (.81)	− 0.180 (.05)
Education	0.381 (.02)	0.110 (.51)	0.330 (.06)	− 0.010 (.95)	0.180 (.29)
Age	− 0.068 (.54)	− 0.233 (.03)	0.014 (.91)	0.052 (.61)	− 0.097 (.397)
Medicaid	0.845 (.04)	0.188 (.64)	0.409 (.35)	0.516 (.17)	− 0.043 (.92)
Medicare	0.016 (.97)	− 0.475 (.26)	− 0.632 (.148)	− 0.817 (.03)	− 0.628 (.15)
Uninsured	− 0.246 (.55)	− 0.68 (.85)	0.665 (.08)	0.660 (.05)	− 0.50 (.23)
Constant	− 6.85	− 2.89	− 4.640	− 3.843	− 4.180

indicated that the second factor was not robust. Thus, we concluded that the more parsimonious seven-item factor solution was robust. Accordingly, we used the seven-item scale to test the association between mistrust and five measures of underuse of health services. The scale had reasonable test–retest reliability. Item-to-item correlations between baseline and 3-week follow up ranged between 0.346 and 0.567. And, the test–retest correlation for the overall scale was 0.69. This suggests that mistrust is a stable construct in the absence of new experiences that influence (either negatively or positively) one's attitude regarding trust. Moreover, the MMI was correlated with the TIPS and the GTS, suggesting that the scale has good construct validity. It is instructive that the MMI was correlated with the TIPS and the GTS, but that the correlations were not very strong. This further suggests that the MMI is distinct from the TIPS, measuring a related but different aspect of mistrust.

Most of the research on patient trust has centered on the provider–patient interaction, as the provider has traditionally been the gateway for patients into the medical care system. However, there also needs to be a focus on patient trust of the larger health care system. It may be that patient mistrust is less focused on a specific individual or aspect of the care system. That is, it may be that mistrust emanating from patient experiences in one aspect of the health care system would lead to general mistrust of health care. This may explain why patients who have never participated in a clinical trial and therefore have no personal experience with clinical trials may be less willing to consent to participate when asked (Williams et al. 2004; Braunstein et al. 2008). They may have developed mistrust from other encounters with the health care system that leads to broader mistrust of other aspects of health care.

Conceptually, mistrust of the medical care system contributes to delay in care seeking, which complicates the care process and often worsens patient outcomes. Delays in seeking care can lead patients to initiate care at later stages of disease progression, increasing the costs of treatment. Moreover, as racial/ethnic minorities report more mistrust of health care, mistrust may be an explanation for disparities in health care utilization and adherence. And there may be race differences in the magnitude of the effect of medical mistrust on health services use. Unfortunately, the relatively small sample of whites in our study made multivariate analysis within stratified samples underpowered so we are not able to test this hypothesis. Additional research on mistrust and health care disparities can aid in explicating this possibility. If this hypothesis is borne out, efforts to garner greater trust among minorities may be a fruitful approach to the reduction and elimination of racial/ethnic health care disparities.

As research on mistrust in health care progresses, this may lead to promising avenues for improving the patient experience in health care. One can envision health care organizations reaching out to residents within their service area who have not been patients to determine whether the organization has established a mistrustful relationship with segments of their potential patient base. Not only could such efforts have implications for profitability, but they could also advance national health policy priorities to improve access to care.

Medical mistrust is also a potentially important predictive variable. We have demonstrated its association with delay in care seeking, nonadherence, and failure to keep appointments. But these findings are suggestive of other interesting hypotheses that go beyond health services utilization, such as studies regarding the ways in which patients go about assigning trust to individuals and organizations and how trust might impact health and illness behavior. For example, are patients who have more medical encounters more or less trustful of the health care system? Do patients in managed care organizations have more or less trust of the health care system? What are the health system characteristics associated with increasing or decreasing patient trust of health care systems? What can health care organizations do to engender trust? The creation of a validated measure of medical mistrust will make it possible to design studies to address these and other hypotheses.

Interpretation of the findings should take into account limitations of the study. While our sample is representative of Baltimore, it would be beneficial to test the psychometric properties of the MMI in other community settings, including rural communities and other regions of the country. Our sample is predominantly African American. As such we are not able to comment on the generalizability of the findings beyond that population. As we did not conduct cognitive interviews, we are not able to determine whether there is variation among respondents in their interpretation of the term "health care organization" used in the MMI items. Also, we envisioned the MMI to be used in patient populations as well as community settings; however, this study is based on a community sample. It would also be valuable to examine the measure in hospital-based settings or among patients who have regular interaction with health care settings.

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