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Mistrust of Healthcare Organizations is Associated with Underutilization of Health Services

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ABSTRACT

Purpose

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

Methods

We conducted a telephone survey of a random sample of households in Baltimore City, Maryland. We surveyed 401 persons and followed up 327 (81.5%) three 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's correlation of .346-.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 ($b=.939$, $p=.01$), and failure to fill a prescription ($b=1.48$, $p=.002$). MMI was not significantly associated with failure to get needed medical care ($b=.815$, $p=.06$).

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 (1,2,3,4,5,6,7), 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 (8) review of the literature on mistrust in healthcare concluded that one impediment to advancing this literature has been the lack of a generalized measure of mistrust in healthcare that is suitable for inclusion in both patient-based and community studies. Research on mistrust has progressed since Pearson and Raeke's literature review (9-13), 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 (6, 14). 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 (15). Patient's interactions with the medical care system have become less focused on an individual physician. With the emergence of HMO's, managed care and other similar systems of healthcare delivery, increasingly, the patient-provider relationship is with an organization or non-physician healthcare provider rather than an individual physician (15).

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 healthcare beyond the limitations of the TIPS. In this paper, we report on the validation of an instrument to

measure mistrust of healthcare organizations. We then use that measure to examine the relationship between mistrust and race disparities in healthcare service underutilization.

Methods

We conducted a telephone survey of a random sample of residents of Baltimore City, Maryland. We sampled households and selected the household member age 18 or older who had the most recent birthday (16). Baltimore City has 167 telephone exchanges (first 3 numbers of a telephone number) within two area codes, 410 and 443. The forty-five 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 (0001-9999). This generated a sampling frame of 989,901 telephone phone numbers. We selected a one 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 (17,18). The interviewers made contact (talked with an eligible respondent) with 783 people; 401 completed the baseline interview (51.2%), 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%) 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 $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 vs. white) and gender (male vs. 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 employs 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 (19). 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 healthcare (8, 15). The items in the 17-item scale are displayed in Table 2. Additionally, we

asked respondents if in the last twelve 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's alpha coefficient, item-to-total correlation and factor analysis. We also performed factor analysis (principle components analysis) to determine if 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 one to four. 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. Since there is no exact criterion measure, we used two related measures, the Trust in Physicians Scale (3, 14) and the Generalized Trust Scale, a subscale of the Trust Inventory (20). 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% of the sample is under age twenty-five and 19.6% are over age sixty-five. 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% are African American, 25% are white and 5.7% are Hispanic or Asian American. Nearly 24% reported incomes below $10,000 and 25% report incomes above $50,000. Just below 75% of respondents had at least a high school education and 22.1% were college graduates. Nearly 51% had private insurance and nearly 24% 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 .5 or greater were dropped from the scale.

Table 2

Seven of the 17 items loaded above .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 .5. The first factor explained over 40% of the variance and the second factor explained about 12%. 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 eiganvalue coupled with the fact that only 1 item loaded above .5 lead to the conclusion that the second factor was not robust. Thus, we settled on a single factor solution with the 7-items that loaded on Factor 1. All further analysis was conducted on the 7-item version of the scale. The computed reliability coefficient (Chronbach's Alpha) was .76 for the seven items.

In Table 3 we present analysis of the test-retest reliability for each item and the 7-item scale. The table shows the correlation between the same item for the baseline and follow-up survey. Pearson's correlations among the individual items ranged between .346 and .500. Test-retest correlation for the full scale was .697. All correlations were significant at p<.0001

Table 3

Using Pearson's correlation, we examined scale validity of the MMI by testing for an association between the MMI and related measures, the Trust in Physician Scale (TIPS) and Generalized Trust Scale (GTS). We selected the TIPS because is it an established measure of trust used in healthcare 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=-.232 p< .0001) and the GTS (corr=-.151 p=006). Additionally, we examined the association between the MMI and several demographic variables. The MMI was correlated with race (corr=-.183 p=.000) and education (corr=.115 p=.02); however, we did not find a significant relationship between the MMI and gender (corr=-.56 p=.26).

In Table 4 we examine the effect of mistrust on a set of measures of health services under-utilization. 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 under-utilization, with the exception of failing to seek needed care which has a p-value of .06. Higher mistrust scores lead to greater odds of under-utilization of health services. The consistency of the positive association

between mistrust and under-utilization 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.

Table 4

Discussion

Factor analysis of the 17-item MMI revealed the presence of one factor with 7-items. The low eigenvalue and variance explained of the second factors indicated that the second factor was not robust. Thus, we concluded that the more parsimonious 7-item factor solution was robust. Accordingly, we used the 7-item scale to test the association between mistrust and five measures of under-use of health services. The scale had reasonable test-retest reliability. Item-to-item correlations between baseline and 3-week follow up ranged between .346-.567. And, the test-retest correlation for the overall scale was .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 healthcare 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 healthcare system would

lead to general mistrust of healthcare. 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 (22, 23). They may have developed mistrust from other encounters with the healthcare system that leads to broader mistrust of other aspects of healthcare.

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 healthcare, mistrust may be an explanation for disparities in healthcare 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 multiviate analysis within stratified samples under-powered so we are not able to test this hypothesis. Additional research on mistrust and healthcare 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 healthcare disparities.

As research on mistrust in healthcare progresses this may lead to promising avenues for improving the patient experience in healthcare. One can envision healthcare organizations reaching out to residents within their service area who have not been patients to determine if the organization has established a mistrustful relationship with segments of their potential patient-base. Not only could such efforts have implications for profitability, but 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, non-adherence, 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 healthcare system? Do patients in managed care organizations have more or less trust of the healthcare system? What are the health system characteristics associated with increasing or decreasing patient trust of healthcare systems? What can healthcare 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 generalizabilty of the findings beyond that population. As we did not conduct cognitive interviews, we are not able to determine if there is variation among respondents in their interpretation of the term "healthcare 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 healthcare settings.

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Table 1. Demographic profile of the sample.		
Variable		Percent
Age	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	Less than $5,000	8.7
	$5000-$9999	15.2
	$10,000-$14,999	11.5
	$15,000-$24,999	12.9
	$25,000-34,999	13.8
	$35,000-49,999	12.9
	$50,000-$59,000	8.1
	$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

Table 2. Assessment of internal consistency and Mean distribution of 17-item Medical Mistrust Index Items					
Question	Factor 1	Factor 2	Mean	Std. Dev	Item-to-Scale Correlation
1) You'd better be cautious when dealing with healthcare organizations.	.612	.285	2.93	.660	.445
2) Patients have sometimes been deceived or mislead by healthcare organizations.	.719	.157	2.70	.664	.561
3) When healthcare organizations make mistakes they usually cover it up.	.657	.138	2.63	.663	.493
4) Healthcare organizations have sometime done harmful experiments on patients without their knowledge.	.658	.228	2.54	.665	.491
5) Healthcare organizations don't always keep your information totally private.	.591	.261	2.51	.646	.427
6) Sometimes I wonder if healthcare organizations really know what they are doing.	.658	.217	2.70	.609	.498
7) Mistakes are common in healthcare organizations.	.573	.228	2.67	.590	.414
8) I trust that healthcare organizations will tell me if a mistake is made about my treatment.	-.463	.386			
9) Healthcare organizations often want to know more about your business than they need to know.	.483	.430			
10) The patient's medical needs come before other considerations at healthcare organizations.	-.390	.489			
11) Healthcare organizations are more concerned about making money than taking care of people.	.418	.020			
12) Healthcare organizations put the patient's health first.	-.369	.329			
13) Patients should always follow the advice given to them at healthcare organizations.	-.401	.434			
14) I typically get a second opinion when I am told something about my health.	.378	.430			
15) I trust that healthcare organizations check their staff's credentials to make sure they are hiring the best people.	-.382	.311			
16) They know what they are doing at healthcare organizations.	.194	.195			
17) I trust that healthcare organizations keep up with the latest medical information.	-.403	.544			
Eigenvalues (% of variance)	2.87 (40.97)	.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 7-item Medical Mistrust Index	
Question	Correlation between waves 1 and 2
1) You'd better be cautious when dealing with healthcare organizations.	Corr = .500 P= .000
2) Patients have sometimes been deceived or mislead by healthcare organizations.	Corr = .398 P= .000
3) When healthcare organizations make mistakes they usually cover it up.	Corr = .567 P= .000
4) Healthcare organizations have sometimes done harmful experiments on patients without their knowledge.	Corr = .474 P= .000
5) Health care organizations don't always keep your information totally private.	Corr = .364 P= .000
6) Sometimes I wonder if healthcare organizations really know what they are doing.	Corr = .346 P= .000
7) Mistakes are common in healthcare organizations.	Corr = .451 P= .000
Scale	Corr = .697 P= .000

Table 4. Logistic regression of mistrust and utilization of health services regressed on MMI and controls					
	Model 1	Model 2	Model 3	Model 4	Model 5
	Failed to take medical advice β (*p*)	Failed to keep follow-up appointment β (*p*)	Failed to get needed care β (*p*)	Postponed seeking need care β (*p*)	Fail to fill prescription β (*p*)
MMI	1.56 (*p*=.00)	1.11 (*p*=.01)	.815 (*p*=.06)	.939 (*p*=.01)	1.48 (*p*=.002)
Race	.384 (*p*=.27)	.499 (*p*=.18)	.086 (*p*=.81)	.005 (*p*=.98)	.230 (*p*=.53)
Female	.733 (*p*=.06)	.092 (*p*=.80)	.310 (*p*=.396)	.468 (*p*=.152)	-.027 (*p*=.94)
Income	.013 (*p*=.88)	-.195 (*p*=.02)	-.002 (*p*=.98)	.019 (*p*=.81)	-.180 (*p*=.05)
Education	.381 (*p*=.02)	.110 (*p*=.51)	.330 (*p*=.06)	-.010 (*p*=.95)	.180 (*p*=.29)
Age	-.068 (*p*=.54)	-.233 (*p*=.03)	.014 (*p*=.91)	.052 (*p* =.61)	-.097 (*p*=.397)
Medicaid	.845 (*p*=.04)	.188 (*p*=.64)	.409 (*p*=.35)	.516 (*p*=.17)	-.043 (*p*=.92)
Medicare	.016 (*p*=.97)	-.475 (*p*=.26)	-.632 (*p*=.148)	-.817 (*p*=.03)	-.628 (*p*=.15)
Uninsured	-.246 (*p* =.55)	-.68 (*p*=.85)	.665 (*p*=.08)	.660 (*p*=.05)	-.50 (*p*=.23)
Constant	-6.85	-2.89	-4.640	-3.843	-4.180