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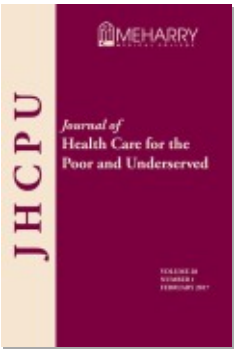

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ORIGINAL PAPER

Inadequate Cancer Screening: Lack of Provider Continuity is a Greater Obstacle than Medical Mistrust

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Abstract: **Background**. Racial minorities and low-income individuals are generally less likely to have adequate cancer screening than Whites or higher-income individuals. **Purpose**. To examine the roles of medical mistrust and lack of provider continuity in cancer screening in a low-income minority population. **Methods**. A total of 144 urban federally qualified health center patients completed a cross-sectional survey that included the Group Based Medical Mistrust Scale and questions on provider continuity and cancer-screening-history. **Results**. Breast cancer screening was associated with continuity of care but not mistrust (respectively $p = .002$, $p > .05$); colon cancer screening was not significantly associated with either factor ($p > .05$). **Conclusions**. Findings suggest that among low-income minority adults continuity of care is more strongly associated with screening than medical mistrust. Shifting focus from medical mistrust—a patient-level issue—to establishing health care homes—a system-level issue—may be a more effective strategy for reducing racial and socioeconomic disparities in cancer screening.

Key words: Mistrust, continuity of care, cancer screening, racial minorities, low income, breast cancer, colon cancer

Cancer mortality is disproportionately prevalent among racial minorities and low-income individuals.[1,2] Compared with their White counterparts, Blacks experience higher mortality for all cancers combined, and for breast and colon cancer individually.[3] Low-income individuals also experience higher mortality for breast cancer and colorectal cancer (CRC).[4,5] One major factor fueling these disparities is late-stage diagnosis, which leads to worse initial prognosis.[1]

Cancer screening reduces CRC and breast cancer mortality.[6–11] Despite this, many individuals in the U.S. do not receive screening at recommended intervals, especially

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racial minorities and low-income individuals.[2,12–14] For example, national survey data found that only 44.2% and 56.3% of individuals with an income less than 139% of the federal poverty threshold had recent CRC screening and recent mammography, respectively, compared with 65.5% and 81.8% of individuals with an income greater than 400% of the poverty threshold.[12]

There are a plethora of commonly cited potential factors associated with suboptimal cancer screening.[12,13,15–20] Two important but less well characterized proposed factors are medical mistrust (i.e., mistrust of the health care system or providers) and lack of provider continuity (i.e., having a consistent provider or health care home).[21–26] La Veist et al. showed that mistrust toward health care organizations leads to failure to take medical advice and to keep follow-up appointments,[27] while Brookhart et al. showed that provider continuity is positively associated with medical adherence.[28] Given that medical mistrust and lack of provider continuity are thought to be more common among racial minorities and low-income populations,[25,29–32] their potential role in the observed cancer mortality disparities among these groups should be explored.

Both medical mistrust and lack of provider continuity are linked to complicated structures of racial and socioeconomic discrimination, and the resulting lack of social resources and support. Thus, neither is easily ameliorated. When prioritizing one factor as a first target for intervention, an important preliminary question is: is one of these two factors more significantly linked to adequacy of cancer screening, and thus disparities in mortality? Survey data from a cross-sectional study in a low-income minority population were used to explore this question.

Methods

Overview and study design. Survey data were collected from patients at a network of urban federally qualified health centers (FQHCs) as part of a longitudinal, observational study on CRC screening behaviors. This cross-sectional analysis of baseline data was performed to investigate potential associations between cancer screening and both medical mistrust (a scale variable) and provider continuity (a binary categorical variable). Study procedures were approved by the Washington University in Saint Louis School of Medicine (Saint Louis, MO) Institutional Review Board.

Participants. Participants were recruited from the patient populations of three FQHCs in St. Louis, Missouri. Patients were eligible to participate if they spoke English and were 40 years of age or older. Participants received a $15 gift card upon survey completion.

Measures. Participants completed a baseline survey, either by interviewer-administration (69%) or on their own (31%). Outcomes of interest were ever having been screened for CRC or breast cancer as assessed by self-report. Screening measures queried were fecal occult blood testing (FOBT), flexible sigmoidoscopy, and colonoscopy for CRC and mammography for breast cancer. National Cancer Institute (NCI) CRC screening measures[33] were used in their original form to measure CRC screening and in modified form to measure breast cancer screening. The two primary independent variables were medical mistrust and provider continuity. Mistrust was evaluated using the Group-Based Medical Mistrust Scale ($\alpha = 0.877$). This scale was designed to assess mistrust

within the context of health care and racial discrimination and has been validated in Black men and women.[34,35] Individuals were categorized as having provider continuity if they answered "yes" to the question "Is there a particular doctor's office, clinic, or health center that you regularly go to when you are sick?" Additional variables of interest included age, gender, race, education level, income level, and insurance status.

Analysis. Total medical mistrust scores were calculated by summing scores for the 12 individual items generating a scale from 0 to 60, with a higher score indicating a greater level of mistrust. Medical mistrust scale scores were then assessed across groups categorized by age, race, gender, income, and insurance status using t-tests, and groups categorized by education level using ANOVA. Continuity of care was assessed across those same groups using chi-square tests. The association between medical mistrust and continuity of care was evaluated using a t-test.

American Cancer Society screening guidelines were used to identify the appropriate subpopulations for analysis of specific cancer screening modalities: mammography analysis was restricted to women ≥40 years and CRC screening analysis to men and women ≥50 years. Based on their yes/no answers to screening history questions, participants were scored as either had ever been screened or had never been screened for mammography and for any CRC screening (FOBT, sigmoidoscopy, colonoscopy). Mistrust and provider continuity were assessed across ever/never screened groups by t-tests and chi-square tests, respectively. All analyses were conducted using IBM SPSS Statistics v.22.[36]

Results

Demographic characteristics. The sample population consisted of 144 individuals (Table 1) with a mean age of 51 years (SD = 7) who were predominately Black and male (87.5% and 61.8%, respectively). Over one third (36.1%) of participants had not completed high school or attained a GED , and about one quarter (24.3%) reported education beyond high school. Participants faced considerable socioeconomic challenges. The majority (70.8%) reported a monthly income below $800 (less than $9,600 annually). A similarly large proportion (75.0%) reported having ever been homeless (i.e., ever spent longer than 24 hours on the streets or in a shelter). Uninsured participants comprised 52.1% of the sample population, with an additional 10.4% reporting that despite having insurance at the time of the survey, they had experienced a coverage gap in the previous 12-month period. Despite the high percentage of uninsured participants, 84.7% reported they had a regular health care source. This likely reflects the health center based recruitment strategy and the eligibility requirement for participants to be a patient at these centers.

Medical mistrust demographic characteristics. A total of 123 individuals had complete responses to the 12-item Group-Based Medical Mistrust Scale. Significant differences in mistrust were seen across groups by race and insurance status (Table 2). Blacks had higher mistrust scores than individuals of other races (mean(SD): 31.0(9.1) vs. 26.2(8.4); p = .04). Individuals with health insurance had higher levels of mistrust than uninsured individuals (mean(SD): 32.0(9.8) vs. 28.6(8.2); p = .04). There were

Table 1.

PARTICIPANT DEMOGRAPHICS[a]

Variable	Mean (±SD) or frequency (proportion)
Age (years)	51 (±7)
Race	
Black	126 (87.5%)
Other	18 (12.5%)
Gender	
Male	89 (61.8%)
Female	55 (38.2%)
Highest Level of Education	
< high school (HS) graduation or GED	52 (36.1%)
HS graduation or GED	55 (38.2%)
> HS graduation or GED	35 (24.3%)
Employment Status	
Unemployed (non-disabled)	71 (49.3%)
Monthly Income	
< $800	102 (70.8%)
≥ $800	33 (22.9%)
Insurance Status	
Uninsured	75 (52.1%)
Insured	64 (44.4%)

[a]N = 144. Percentages within individual demographic factors may not sum to 100% due to participant-omitted answers.

no significant differences in mistrust by gender, highest level of education, or monthly income. A selection of the most commonly endorsed mistrust statements are shown in Table 3.

Provider-continuity demographic characteristics. A total of 143 individuals responded to the provider-continuity question (Table 4). A significant difference in provider continuity was only seen across groups by insurance status. A greater percentage of individuals with health insurance had a regular provider than uninsured individuals (93.8% vs. 79.7%; $\chi^2 = 5.68$ [df = 1], p = .02). There were no significant differences in provider continuity by race, gender, highest level of education, or monthly income.

Medical mistrust vs. provider continuity. Medical mistrust and provider continuity were not significantly associated (n = 122; p = .85).

Cancer screening by medical mistrust vs. provider continuity. Among women 40 years or older who responded to the relevant survey questions, there was a significant difference in history of mammography across groups by provider continuity (n = 55, $\chi^2 = 9.75$ [df = 1], p = .002; Table 5) but not by medical mistrust (n = 45, p = .81). Specifically, women who reported continuity of medical care were more likely to

Table 2.

MEDICAL MISTRUST BY DEMOGRAPHIC CHARACTERISTICS[a]

Demographic characteristic	Sample Size	Medical Mistrust Score (mean ± SD)	p-value
Race			
Black	105	31.0 ± 9.1	.04
Other	18	26.2 ± 8.4	
Gender			
Male	78	30.1 ± 9.3	.73
Female	45	30.7 ± 8.9	
Highest Level of Education			
< HS grad or GED	44	31.8 ± 8.0	.19
HS grad or GED	47	30.2 ± 9.5	
> HS grad or GED	30	27.9 ± 9.4	
Monthly Income			
< $800	89	30.0 ± 9.1	.79
≥ $800	27	30.5 ± 9.5	
Insurance Status			
Uninsured	69	28.6 ± 8.2	.04
Insured	50	32.0 ± 9.8	

[a]Mistrust measured by the Group Based Medical Mistrust Scale with scores ranging from 0 to 60; a higher score indicates a greater level of mistrust.

Table 3.

REPONSES TO SELECTED ITEMS FROM THE GROUP BASED MEDICAL MISTRUST SCALE

Mistrust Item	Population % (n)[a]
Doctors and health care workers sometimes hide information from patients who belong to my ethnic group.	36% (49)
Doctors and health care workers treat people of my ethnic group as "guinea pigs".	25% (33)
I have personally been treated poorly or unfairly by doctors or health care workers because of my ethnicity.	22% (30)
People of my ethnic group cannot trust doctors and health care workers.	17% (23)

[a]Sample sizes for each question reflect the total number of participants who answered that question (in descending order: n = 135, 134, 136, 136). Participants who answered either "Strongly Agree" or "Agree" were included in the percentages reported above.

Table 4.

CONTINUITY OF MEDICAL CARE BY DEMOGRAPHIC CHARACTERISTICS

Demographic characteristic	Sample Size	Has a Regular Provider (proportion)	p-value
Race			
Black	125	84.0%	.24
Other	18	94.4%	
Gender			
Male	88	84.1%	.60
Female	55	87.3%	
Highest Level of Education			
< HS grad or GED	51	80.4%	.07
HS grad or GED	55	81.8%	
> HS grad or GED	35	97.1%	
Monthly Income			
< $800	102	83.3%	.13
≥ $800	33	93.9%	
Insurance Status			
Uninsured	74	79.7%	.02
Insured	64	93.8%	

Table 5.

RATES OF CANCER SCREENING BY LEVEL OF MEDICAL MISTRUST AND CONTINUITY OF CARE

	Medical Mistrust			Continuity of Medical Care		
Screening modality	Sample size	Mistrust score (mean ± SD)	p-value	Sample size	Has a Regular Provider (proportion)	p-value
Mammogram						
Ever	37	30.9 ± 9.5	.81	46	93.5%	.002
Never	8	30.0 ± 6.0		9	55.6%	
CRC Screening						
Ever	37	31.9 ± 10.1	.68	42	92.9%	.06
Never	30	30.9 ± 8.3		37	78.4%	

CRC = Colorectal Cancer

have ever received breast cancer screening than individuals without continuity of care (93.5% vs. 55.6%).

Among individuals aged 50 or older, those who had provider continuity had higher rates of CRC screening than those without continuity—92.9% of individuals with continuity had ever received CRC screening vs. 78.4% without—but the difference was not statistically significant ($n = 79$, $p = .06$). In contrast, individuals who had received CRC screening had a higher mean mistrust score than those who had not received screening (mean ± SD: ever CRC screening 31.9 ± 10.1 vs. never CRC screening 30.9 ± 8.3), but again this result was not significant ($n = 67$, $p = .68$).

Additional analyses. Race, education and income levels, and insurance status were not significantly associated with either mammography or CRC screening, and gender was also not significantly associated with CRC screening (all p values > .05).

Discussion

Key findings. The study population faced pronounced disparities—most participants were below the national poverty line, had at some point been homeless, and lacked post-secondary education. Within this population, we examined the associations of medical mistrust and provider continuity with cancer screening, and found that continuity was more strongly associated with having ever had mammography than was mistrust.

This cross-sectional survey study found that continuity of medical care, but not medical mistrust, was significantly associated with adequate breast cancer screening. That having a regular provider is important for maintaining a good standard of care is consistent with previous studies[37–39] and is conceptually logical. Patients and physicians can only develop a therapeutic relationship when they have repeated clinical encounters. Such a relationship enables the physician to gain a more complete picture of the patient's medical history and screening/preventative needs. Regular use of the same clinical office or team also creates a secure and familiar space in which the patient and provider can discuss the patient's health and health care plan in a non-emergent setting.[37–39]

Given that other studies have linked medical mistrust with inadequate care,[27,40–42] it may seem surprising that in this study population, high levels of medical mistrust were not associated with inadequate breast cancer screening. However, the interplay of mistrust, screening/preventive medicine, and patient outcomes is likely quite complicated and not easily captured using a 12-item tool. The Group Based Medical Mistrust Scale asks general questions about health care providers and the medical field, with most questions oriented toward how a group of people are treated, rather than the individual answering the questions (e.g., "people of my ethnic group"). These questions do not assess an individual patient's level of trust in a specific provider or institution, which may 1) vary significantly from their level of trust in the medical field as a whole, and 2) be much more functionally relevant for adherence to prevention guidelines.

Indeed, it would be an oversimplification to claim that provider continuity and mistrust—and their impact on quality/adequacy of care—are independent from each other. It is difficult for a patient to build trust with a provider they meet only once or a clinic they use only once, and presumably more feasible to build trust with a familiar provider one expects to see again. This idea is supported by a number of studies that

have found continuity of care is positively correlated with medical trust across sample populations and more specifically within minority subgroups.[37,43] Furthermore, in a sample of 1,031 men Carpenter et al. found that having a regular provider was associated both with greater trust and with screening for prostate cancer.[25]

Many studies have investigated the complex relationships between race, mistrust, provider continuity, and health care utilization,[23,26,27,29,30,34,41,44–47] but as a field, public health is still only beginning to understand these complex interconnections. There are a variety of mistrust measures that have been used to investigate these questions: the Medical Mistrust Index,[29] the Primary Care Assessment Survey,[48] the Stanford Trust in Physician Scale,[49] and the Group-Based Medical Mistrust Scale (used in the current study). Many of these measures ask about patients as a group or as members of specific racial or ethnic groups, providers as a whole, or the health care system as a singular entity. Some ask about a patient's experience with the health care system as a whole, or even a specific relationship between one patient and one doctor, but leave out queries concerning race and racial discrimination. To our knowledge, no studies have simultaneously asked about an individual patient's experience with an individual provider with specific reference to the role the patient's race plays in that interaction. Perhaps this is a gap in our literature that it would be important and enlightening to fill in.

However, investigating this gap could be analytically quite complex. Should the specific provider be designated as the provider/practice the individual visits most often, or whatever practice is chosen as the point of study recruitment/participation? How can individuals whose regular provider is a physician be compared with those whose regular provider is a nurse practitioner or physician's assistant, or some combination thereof? How can such a measure be standardized across both populations with and without a regular provider? Regarding the latter question, some studies have opted to only include those potential participants who do have a regular care home,[48,49] but in doing so have resigned themselves to not addressing an important side of the mistrust issue. Measuring medical mistrust by treating the entire medical field as a single entity has practical benefits in that it allows for comparison across individuals with disparate access to and interaction with medical providers. Unfortunately, the same simplicity that makes such a measure methodologically attractive may miss an important element of mistrust.

Advantages and limitations. While this study comes to a potentially important conclusion that continuity of care may be a larger driver of screening behavior than medical mistrust among low-income primary care patients, it is important to keep in mind its limitations. First, because this is a cross-sectional study, it is not possible to assess causal relationships between cancer screening behaviors and both mistrust and provider continuity. Secondly, this study relied on participant self-report for screening history and provider continuity. Although this may not always be accurate, several studies have supported the use and validity of self-report for assessing cancer screening.[33,50] Third, knowing that participants usually see the same provider at the FQHCs in this study, continuity of care was operationalized as having a usual clinic or office where care is obtained. While it can be argued that continuity and usual source of care are different concepts, there is evidence that having a regular provider at a usual source is more effective than having a usual source of care alone.[51,52] Thus, due to the way

continuity was defined in this study, the magnitude of association between continuity and cancer screening may be underestimated.

As previously noted, a more comprehensive medical mistrust measure that asks participants to evaluate their own interactions with a specific provider/practice and with the more general health care system as a whole, while also assessing the role race plays in those interactions might better characterize this complex matter. The Group Based Medical Mistrust Scale was developed and tested in African American and Latina women for the purpose of assessing medical mistrust as it relates to racial/ethnic health disparities.[34] While race and ethnicity are different concepts, the Scale uses "ethnicity" as an encompassing term for both race and ethnicity, and it has been validated among Blacks, demonstrating applicability to race. Because a predominantly African American sample, such as that in this study, is likely to over-represent those who have high mistrust, future studies might utilize quota sampling to recruit other racial/ethnic groups and thereby minimize homogeneity of the sample.

Additionally, the small sample size (n = 144) limited the study's ability to detect significant differences, draw more definitive conclusions, and adjust analyses by multiple demographic variables. This limitation was more pronounced when isolating subgroups that were eligible for mammography or CRC screening and had also completed the mistrust or provider-continuity measures. For example, almost two thirds of the sample population was male and thus not eligible for standard breast cancer screening. Despite the small sample size, this study was able to gain insight into a unique population underrepresented in published research. The demographic make-up, in particular the relatively homogeneous nature of the sample population (i.e., mostly Black, low-income) may have also contributed to the lack of expected correlation observed between demographic characteristics and cancer screening. This homogeneity also limited the study's ability to make intergroup comparisons and to expand the study's conclusions more generally outside of this specific population. In future studies, quota sampling could be used to ensure adequate representation of different subpopulations (e.g. gender, race) to allow for inter-group comparisons.

However, the demographic characteristics of the study population also add richness to our findings. While it is often the case in survey studies that the majority of participants are female,[53–55] in this study the majority were male. This allows for insights to be drawn for a population often under represented both in research and in health care utilization more generally.[56,57] The same can be said of the nearly homogeneous racial makeup, lack of higher education, and pronounced poverty of the sample population—more than 70% of participants had an annual income of less than $10,000, placing them well below the national poverty threshold. While many studies have characterized populations at high risk for inadequate medical/preventative care, this study characterized a population at the very limit of high risk and low resources. Sampling such an exceptionally high-risk and low-resource population allows this study to draw conclusions and propose future interventions targeted at those patients who are most in need. Such specific prioritization is especially important within the context of limited health care resources and health care disparities.

As the target population in this study was underserved individuals, a convenience sampling strategy was used with the sampling frame of FQHC patients. This popula-

tion may include individuals who use a specific center for routine care as well as those who are transient and do not routinely visit a specific center. It is likely that due to this sampling strategy, individuals with a usual source of care are over-represented in the sample. To address this limitation, future studies may include a community-based sampling component.

Implications for future interventions. Medical mistrust and continuity of care are both complicated systems-level issues. Medical mistrust is staggeringly complex and is inseparable from a long-standing history of institutionalized discrimination that reaches far beyond the borders of the health care field. As such, it has no clear or simple solution. While continuity of care and the dearth of health care homes is a similarly complex issue, because it is directly within the purview of the health care system, it seems more feasibly solvable by those within that system.

For some providers, it may be all too easy to dismiss individual patients' non-adherence to medical guidelines out of hand, or indeed patients themselves as mistrusting, uninformed, or non-compliant. Prioritizing providing consistent longitudinal care can re-direct this counter-productive focus on the perceived limitations of an individual patient instead into a productive improvement of the shortcomings of the health care system.[39]

This study in no way aims to minimize the importance of medical mistrust, and interventions to address this remain important. Indeed, this study's findings on mistrust are sobering (Table 3). Over a third of participants considered health care providers to be (intentionally or unintentionally) racially-biased. A quarter of patients agreed that "doctors and health care workers treat people of my ethnic group as 'guinea pigs'." These simple statistics indicate potential challenges for members of racial/ethnic minority groups and low-income individuals interacting with the health care system and should inform future effort to ameliorate mistrust and its effects.

Medical mistrust is likely a mechanism of negative patient outcomes, but it could also be considered an outcome in and of itself. It would not be unreasonable to conclude that patients who at the completion of treatment or medical encounter do not trust their provider or feel that their care was negatively affected by their race have not received the standard of care. It may be more ethically cautious to conceptualize medical mistrust as an outcome rather than a patient attribute or mechanism as that will, at least to some extent, ensure that not all responsibility will be placed on the patient. As for functional application, interventions that build better continuity of care at the systems-level, especially for high-risk populations, may improve both cancer-screening rates and trust on the interpersonal level.

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