Association Between Prior Experiences of Discrimination and Patients' Attitudes Towards Health Care Providers Collecting Information About Race and Ethnicity

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BACKGROUND: Previously, we reported a high level of comfort among Californians for collecting race/ethnicity information by health care providers (HCPs). However, minorities were less comfortable providing race/ethnicity information and were more worried than non-Hispanic whites about the potential misuse of this information.

OBJECTIVE: To determine if perceived experiences of discrimination (both in general and in medical care) were associated with comfort providing race/ethnicity information, and conversely, to worry about providing the information.

DESIGN AND PARTICIPANTS: Telephone survey of 480 Californians, including 101 whites, 98 Asians, 173 Hispanics, 82 blacks, and 26 multiracial individuals.

MEASUREMENTS: Comfort level giving HCPs information about race/ethnicity (measured on a 1–10 scale, with text anchors of “very uncomfortable” at 1 and “very comfortable” at 10), worry that the information could be used to discriminate against patients, and worry that the information could be used to find undocumented immigrants. Worry was measured using a four-point Likert scale— not worried at all, a little worried, somewhat worried, and very worried. Respondents were also asked about perceived discrimination in general and perceived discrimination in medical care.

RESULTS: Compared to whites, Hispanics (Beta-coefficient (BC) = -1.16, SE=0.51) and Mandarin/Cantonese-speaking Asians (BC=-1.40, SE=0.65) reported significantly less comfort giving HCPs information about their race/ethnicity, while blacks (BC=0.70, SE=0.16), Hispanics (BC=0.91, SE=0.18), and multiracial individuals (BC=0.63, SE=0.24) were significantly more worried that race/ethnicity information could be used to discriminate against them. Adjusting for perceived experiences of discrimination in general

and in medical care partially explained the higher discomfort and worry among minorities.

CONCLUSIONS: Perceived experiences of discrimination are associated with greater discomfort and worry about providing race/ethnicity data. Health care institutions should consider how they can address the public's concerns about possible misuses of data.

KEY WORDS: race; data collection; discrimination.

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Experts and organizations have recommended that health care providers (HCPs) systematically collect information on patient's race and ethnicity (race/ethnicity) to understand the populations they serve, to allow examination of differences in quality of care, and to develop targeted programs to eliminate disparities.^{1–4} In prior studies, we reported a high level of support among patients at a general internal medicine clinic and among California residents for HCPs collecting race/ethnicity information so that the information could be used to monitor disparities.^{5,6} However, these same studies found that racial and ethnic minorities were significantly more uncomfortable than whites about providing race/ethnicity data and had more worries about potential misuse of data.^{5,6}

It is unclear what explains the greater discomfort and worry among minorities. We hypothesized that the discomfort and worry among racial and ethnic minorities could be due to a general distrust of HCPs or government agencies, or could be due to previous experiences with discrimination or mistreatment in the health care system. Some studies have shown that minorities perceive greater discrimination in medical care.^{7–11} It is plausible that minorities may perceive or experience more discrimination in health care, and that these experiences lead to greater distrust of HCPs and more concerns about HCPs collecting race/ethnicity information. The objective of this study is to determine if perceived experiences of discrimination explain the greater discomfort and worry among minorities about providing race/ethnicity data to HCPs.

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METHODS

Data Collection and Sample

Data are from a study we conducted in California which was primarily focused on individuals' preferences and attitudes about reporting race, ethnicity, and language data to health-care providers.⁶ The survey was conducted by the RAND Corporation in Santa Monica, California. Because of budgetary constraints, it was not possible to conduct a random digit dialing telephone survey with oversampling of minorities. Instead, we obtained lists of potential phone numbers from Survey Sampling International (SSI), a commercial vendor whose lists contain race/ethnicity data and cover 46% of California's households. Because we sought to have our final participant group contain a high proportion of Asians and Hispanics with limited English proficiency, we used data from the 2000 United States Census to identify census tracts in which >50% of households were Asian, > 75% of households were Hispanic, >50% of households were black, and >75% of households were white. For each of these four eligibility categories, SSI then created a pooled list of all phone numbers in their database from eligible census tracts. All numbers were called at least once. Once contact was made with the selected respondent, the interviewer determined what language the respondent felt most comfortable speaking. The survey was conducted in English, Spanish, Cantonese, and Mandarin because these are the languages most commonly spoken in California.¹² Those who did not speak one of the four study languages fluently were excluded.

Of the 3501 phone numbers, 1,595 were non-working numbers or businesses; 771 numbers were called but not answered, and it could not be determined whether they were a working household number. Of the 1135 numbers answered by a household member, 131 were ineligible because they did not speak one of the four study languages or were unable to complete the interview because of physical or mental difficulties (N=33). A total of 141 people refused to be interviewed, and 286 were scheduled to be called at a later time but were never interviewed (427 non-participants). The cooperation rate (excluding phone numbers of unknown eligibility from the denominator) was 50.8%, and the overall response rate (including phone numbers of unknown eligibility in the denominator) was 39.6%.¹³ A total of 577 people were interviewed. Of the 577 respondents, five individuals were excluded because they were missing key demographic information; 92 were excluded because they were missing information on one or more of the main variables of interest for this study- comfort level, worry, or perceived discrimination. Minorities were significantly more likely than whites to be missing information on comfort level, worry, or perceived discrimination, which is why we restricted the sample only to individuals who completed the entire interview. This yielded a final sample of 101 whites, 98 Asians, 173 Hispanics, 82 blacks, and 26 multiracial individuals (total n=480).

Study Variables

The main dependent variables of interest for this analysis were comfort level and worry of respondents. We asked respondents to rate how comfortable they would be giving information about their race/ethnicity to the registration staff at a hospital

or clinic. Comfort level was recorded using a 1–10 scale, with text anchors of "very uncomfortable" at 1 and "very comfortable" at 10.

Respondents were also asked how worried they were about potential misuse of race/ethnicity data in three scenarios; we asked if they were (1) worried that the information could be used to discriminate against them, (2) worried that the information could be used to discriminate against others, and (3) worried about the information being used by the government to find undocumented immigrants. Worry was measured using a four-point Likert scale- not worried at all, a little worried, somewhat worried, and very worried. Only the results for scenarios 1 and 3 are presented, because the results for worrying about others were similar to, but weaker than the results for worrying that the information could be used to discriminate against the respondent.

To assess participants' perceptions of discrimination, we first asked about experiences of discrimination in general, "Thinking about your race or ethnicity, how often have you felt treated badly or unfairly because of your race or ethnicity." Responses included "Never," "Rarely," "Sometimes," "A lot," "All the time." Next, we asked more specifically about perceived discrimination in medical care: "Was there ever a time when you would have gotten better medical care if you had belonged to a different race or ethnic group?" Responses were "yes" or "no." These questions are the same as questions asked in the Commonwealth Fund 2001 Health Care Quality Survey^{8,10} and in the 2003 California Health Interview Survey.⁹

To assess race/ethnicity, we asked respondents to describe their race and/or ethnicity using any terms they wanted. Up to four terms were recorded verbatim. This was the primary information we used to classify respondents' race/ethnicity; we also asked respondents whether they considered themselves Hispanic or Latino. For this analysis, individuals were categorized as non-Hispanic white (White), non-Hispanic black (Black), non-Hispanic Asian (Asian), or non-Hispanic multiracial (multiracial). Anyone who considered themselves Hispanic or Latino, was categorized as Hispanic, regardless of their race. We also collected data on age, sex, education, nativity, and self-reported overall health. US-born individuals were those born in the US, Puerto Rico, or other US territories. All others were classified as foreign-born. Information on health insurance was not collected; however, indicators of health care utilization (having a regular doctor, number of hospitalizations, and number of visits to the doctor) were not included in the regression models because they were not significantly associated with comfort or worry.

Statistical Analysis

For this paper, we wanted to examine the potential mediators in the causal pathway between race/ethnicity and comfort or worry. To do this, we first, we compared differences in comfort and worry by race/ethnicity, perceived discrimination in general, perceived discrimination in medical care and several other demographic variables. Each of the three outcomes, comfort, worry about self, and worry about the government, was modeled as a continuous variable. Comfort ranged from 1–10 (10 = most comfortable). Worry about self and worry about the government ranged from 1–4 (4 = very worried). Differences in comfort or worry were compared using t-tests (across two category variables) or f-tests from one-way ANOVAs (for 3

+category variables). Next, for each of these three outcomes (comfort, worry about self, and worry about the government) three linear regression models were fitted. In our baseline model (Model 1), we determined the association between race/ethnicity and comfort or worry, after adjustment for age, sex, education, nativity, and self-rated health. To investigate potential mediators between race/ethnicity and comfort or worry, models were fitted by first adding perceived discrimination in medical care and then adding the perceived discrimination in general. Only the final model, which includes both discrimination variables, is shown. Perceived discrimination in medical care was yes or no, and perceived discrimination in general was categorized as never (referent), rarely, sometimes, and a lot/all the time.

Due to small sample sizes and initial analyses showing similarities in attitudes, we collapsed Mandarin and Cantonese-speaking Asians into one group and English and Spanish-speaking Hispanics into one group. However, attitudes differed markedly between English-speaking Asians and Mandarin/Cantonese-speaking Asians, so these groups were kept separate in regression models.

Data analysis was performed using Stata version 9.1 (College Station, Texas). Two-tailed tests were used for all analyses, and a final p-value of 0.05 was used to determine statistical significance.

RESULTS

Thirty-six percent of participants identified as Hispanic, 21% as white, 20% as Asian, 17% as black, and 5% as belonging to more than one race/ethnicity (Table 1). Respondents were mostly female (62%) and their mean age was 47 years.

Table 1. Characteristics of Sample

Race/Ethnicity (N, %)	
White	101 (21.0)
Black	82 (17.1)
Hispanic/Latino	173 (36.0)
Asian	98 (20.4)
Multiracial	26 (5.4)
Female, %	61.7
Age, years (mean $\pm$ Standard Deviation)	47 $\pm$ 17
Education, %	
Less than High School	25.4
High School Graduate	23.3
Some College	22.1
College Graduate	29.2
U.S.-born (%)	56.9
Self-reported overall health (%)	
Excellent	12.5
Very Good	30.0
Good	28.8
Fair	23.8
Poor	5.0
Has regular doctor, %	78.3
Number of physician visits in last year, %	
0	14.8
1	13.5
2-3	32.7
≥ 4	39.0

Note: 25 cases ended interview before these demographic questions, five additional cases refused to answer one item: regular doctor (five cases)

As described previously,⁶ the majority of respondents (61%) reported a high comfort level (comfort level ≥ 8 on a 10 point scale) for giving registration staff information about their race/ethnicity. However, Hispanics and Asians (both English and non-English speakers) were significantly less comfortable than whites telling registration staff about their race/ethnicity (Table 2, Column 2). On a scale of 1-10, whites reported a comfort level of 8.3 (SD $\pm$ 2.7) compared to 7.1 for English-speaking Hispanics ($p < 0.05$), 6.7 for Spanish-speaking Hispanics ($p < 0.01$), 7.3 for English-speaking Asians ($p < 0.05$), and 6.5 for Mandarin/Cantonese-speaking Asians ($p < 0.01$). Comfort was also significantly lower among those who reported general experiences of discrimination compared to those who did not ($p < 0.001$ across all groups) and among those who perceived discrimination in health care ($p < 0.001$).

Twenty-six percent of our sample reported perceptions of discrimination in general sometimes, a lot, or all the time. (Table 2, Column 1). Perceptions of general discrimination were significantly higher among all racial/ethnic groups (P -value < 0.001) (except for English-speaking Asians) than in whites (Fig. 1). In bivariate analysis, perceptions of discrimination in general were significantly associated with comfort and worry about providing race/ethnicity information (Table 2). Overall, thirty-two percent of respondents perceived discrimination in medical care (Table 2, column 1). Perceived discrimination in medical care was higher among all racial/ethnic groups compared to whites (Fig. 1, P -value < 0.001). Among those who perceived discrimination in medical care, comfort levels providing race/ethnicity information were lower and worry about misuses of the information was higher (Table 2).

In multivariate analysis, Hispanics (Beta-coefficient = -1.16, SE=0.51) and Mandarin/Cantonese-speaking Asians (Beta-coefficient = -1.40, SE=0.65) were significantly less comfortable telling registration staff about their race/ethnicity compared to whites, independent of age, sex, education, self-rated health, and nativity (Table 3, Model 1). None of the socio-demographic variables or self-rated health was significantly associated with comfort.

While perceived discrimination in medical care was not independently associated with comfort level, adjusting for perceived discrimination in medical care attenuated the lower comfort level of Hispanics (Table 3, Model 2). Respondents who perceived discrimination in general, sometimes or rarely, were significantly less comfortable reporting race/ethnicity information than those who had never been treated badly/unfairly (Table 3, Model 2). Having had experiences of discrimination in general or in medical care seemed to explain some of the lower comfort levels for Hispanics and Mandarin/Cantonese-speaking Asians; after adjusting for experiences of discrimination, these groups were no longer significantly less comfortable reporting their race/ethnicity than whites.

Black, Hispanic, and multiracial individuals were significantly more worried than whites that the information on race/ethnicity could be used to discriminate against them (Table 4, Model 1), independent of socio-demographics. Individuals with fair or poor self-reported health were also significantly more worried than those with excellent/very good/good health that race/ethnicity information could be used to discriminate against them (Beta coefficient = 0.35, P -value <0.01) (Table 4, Model 1). Increasing age and being a college graduate were associated with less worry (Table 4, Model 1).

Table 2. Bivariate Association Between Race/Ethnicity, Prior Experiences of Discrimination, and Attitudes about Collection of Race/Ethnicity Data Collection

N=480	N (%)	Comfort level giving registration clerk race/ethnicity information, range 1–10* mean (SD)	Worry that race/ethnicity information could be used to discrimination against respondent, range 1–4† mean (SD)	Worry that race/ethnicity information could be used by government to find undocumented immigrants, range 1–4‡ mean (SD)
Race/Ethnicity				
White	103 (21.5)	8.3 (2.7)	1.5 (0.9)	2.2 (1.2)
African American	82 (17.1)	8.0 (2.6)	2.3 (1.2) [§]	2.4 (1.4)
Hispanic, English- speaking	35 (7.3)	7.1 (3.4) [§]	2.2 (1.1)	2.6 (1.2)
Hispanic Spanish- speaking	136 (28.3)	6.7 (3.5)	3.2 (1.1)	3.7 (0.7)
Asian, English-speaking	43 (9.0)	7.3 (3.0) [§]	1.9 (1.0) [§]	2.3 (1.2)
Asian, Mandarin/ Cantonese- speaking	55 (11.5)	6.5 (2.7)	2.0 (1.1)	1.7 (1.0)
Multi-racial	26 (5.4)	7.4 (3.5)	2.4 (1.1)	2.5 (1.4)
General experiences of discrimination				
Never	229 (47.7)	7.9 (1.2)	2.0 (1.2)	2.5 (1.3)
Rarely	125 (26.0)	7.1 (3.0)	2.3 (1.2)	2.6 (1.2)
Sometimes	93 (19.5)	6.5 (3.2)	2.8 (1.1)	3.1 (1.1)
A lot	27 (5.6)	6.2 (3.8)	3.0 (1.2)	3.0 (1.3)
All the time	6 (1.3)	9.7 (0.82)	3.0 (1.3)	2.0 (1.5)
Perceived discrimination in medical care				
No	325 (67.7)	7.7 (2.9)	2.0 (1.2)	2.4 (1.3)
Yes	155 (32.3)	6.8 (3.4)	3.0 (1.1)	3.1 (1.1)

*Comfort level measured on a 10 point scale; 1 = very uncomfortable and 10 = very comfortable. †,‡Worry measured on a 4 point scale; 1 = not worried and 4 = very worried. Race/Ethnicity: each group compared to non-Hispanic whites. All other comparisons are across the whole group

[§] $P < 0.05$, ^{||} $P < 0.01$

Individuals who perceived discrimination in medical care were more likely to be worried that race/ethnicity data could be used to discriminate against them than those who did not perceive discrimination (Table 4, Model 2, Beta coefficient = 0.59, P -value<0.01). There was also a strong linear trend for the association between perceived discrimination in general and worry (Table 4, Model 2). Those who perceived discrimination sometimes or a lot/all the time were significantly more worried than those who said they had never experienced discrimination in general (p -value <0.01). While perceived discrimination in general and in medical care partially mediated the higher worry among black, Hispanic, and multiracial individuals, these experiences did not completely explain the higher worry among these groups.

Only Hispanic respondents were significantly more worried than whites that race/ethnicity information could be used by the government to find undocumented immigrants (data not shown, unadjusted Beta coefficient = 1.03, P -value<0.01). Perceived discrimination in general and in medical care were independently associated with higher worry about the government using race/ethnicity information to find undocumented immigrants (data not shown). However, adjustment for perceived discrimination explained little of the significantly higher worry among Hispanics (adjusted Beta coefficient = 0.87, P -value<0.01).

DISCUSSION

We have found that perceptions of experiencing discrimination in medical care and, in general, are associated with greater discomfort and worry about providing race/ethnicity information. Although perceptions of discrimination in medical care and in general were significantly associated with attitudes, perceptions of discrimination only partially explained the

higher discomfort and worry among blacks, Hispanics, and Mandarin/Cantonese-speaking Asians. In a prior study, we found that providing a rationale for collecting these data somewhat decreased peoples' concerns. However, the results of the present paper suggest that it may be difficult to assuage the concerns of some individuals because their concerns are at least partially based on past experiences of discrimination.

We found much higher levels of perceived discrimination than prior studies, especially among whites, blacks and Hispanics.^{8,9} In this study, 6% of whites, 31% of blacks, 32% of English-speaking Hispanics, and 54% of Spanish-speaking Hispanics perceived discrimination in medical care. The Commonwealth Fund 2001 Health Care Quality Survey, a national cross-sectional telephone survey, is the largest prior study of reported discrimination in healthcare to include sizable samples of both Hispanics and Asians. Respondents were asked whether there was ever a time when they thought they would have received better medical care had they

Figure 1. Percent of respondents who reported general experiences of discrimination and perceived discrimination in medical care.

Table 3. Racial and Ethnic Differences in Comfort Level* Telling Registration Staff About Race/Ethnicity, using Multivariate Linear Regression

	Model 1	Model 2
	Beta coefficient [Standard error]	Beta coefficient [Standard error]
Race		
Non-Hispanic white	Referent	Referent
Black	-0.27 [0.46]	0.13 [0.47]
Hispanic	-1.16 [†] [0.51]	-0.83 [0.53]
Asian, English-speaking	-0.65 [0.59]	-0.49 [0.60]
Asian, Mandarin/ Cantonese-speaking	-1.40 [†] [0.65]	-1.23 [0.65]
Multiracial	-0.81 [0.67]	-0.60 [0.68]
Increasing age	0.01 [0.01]	0.01 [0.01]
Education		
Less than high school (referent)		
High School graduate	-0.38 [0.43]	-0.32 [0.42]
Some college	-0.39 [0.46]	-0.29 [0.45]
College graduate	-0.07 [0.46]	0.13 [0.45]
Born outside the United States	-0.42 [0.40]	-0.44 [0.40]
Self reported overall health		
Good/Very Good/Excellent (referent)		
Fair/Poor	0.03 [0.32]	0.13 [0.32]
Perceived discrimination in healthcare		
No (referent)		
Yes		-0.009 [0.37]
General experiences of discrimination		
Never (referent)		
Rarely		-0.85 [†] [0.35]
Sometimes		-1.35 [†] [0.43]
A lot/All the time		-0.98 [0.61]

*Comfort level measured on a 10 point scale; 1 = very uncomfortable and 10 = very comfortable.

[†]P-value <0.05; [‡] P-value <0.01

belonged to a different race/ethnic group. Sixteen percent of African Americans, 15% of Hispanics, 13% of Asians and 1% of whites reported this perception.⁸ The percent of Asians reporting discrimination is similar in our sample, where 17% of Mandarin/Cantonese-speaking Asians and 12% of English-speaking Asians reported discrimination. The percentages reporting discrimination in CHIS 2003 were also lower- 3% for whites, 13% for African Americans and Hispanics, and 7% for Asians.⁹ Respondents in our survey may have been influenced by the context of the questionnaire, which focused on race/ethnicity, collection of data, and possible misuse of data. This focus may have influenced respondents to think about race/ethnicity in more detail, and hence recall more instances where they may have experienced discrimination.

Although the data are not shown, we also examined the association of trust with comfort and worry. As in other studies¹⁴⁻¹⁷, a very high proportion of our sample reported trust in doctors (80.0%) and hospitals (72.5%); surprisingly we did not find significant differences in trust by race/ethnicity. We found that general physician and hospitals trust was not associated with comfort or worry about race/ethnicity data collection. The single-item we used to measure global trust may not have captured the dimensions of trust that are associated with concerns about race/ethnicity data collection. Others have found that negative experiences with the healthcare system and perceived discrimination account

for the majority of racial/ethnic differences in level of healthcare trust¹¹ and in satisfaction with care.¹⁸ Our findings also suggest that it may be better to ask patients about personal experiences of discrimination or mistreatment in healthcare, rather than using global trust items, when trying to determine what accounts for racial/ethnic differences in specific healthcare-related attitudes.

There are several limitations to our study. The cross-sectional nature of our data does not allow us to infer causality in the association between negative experiences with the healthcare system and comfort or worry. It is possible that individuals who are less comfortable and more worried about providing race/ethnicity data are also more likely to perceive discrimination. In addition, people who have negative attitudes toward answering questions about their race/ethnicity or who have had more experiences with discrimination may have been less likely to participate in the survey. Minority respondents were also more likely than whites to refuse to answer questions on comfort, worry, and discrimination. Individuals who refused to answer questions about comfort, worry, and discrimination, may have been those who had more concerns about race/ethnicity and discrimination. In this analysis, only individuals who completed the entire interview were included in this analysis. As a result, these results may overestimate people's comfort level, while underestimating the proportion of people in the general population who experience discrimination and the proportion that worry about providing information about

Table 4. Racial and Ethnic Differences in Worry* that Information About Race/Ethnicity could be used to Discriminate Against Respondent, using Multivariate Linear Regression

	Model 1	Model 2
	Beta coefficient [Standard error]	Beta coefficient [Standard error]
Race		
Non-Hispanic white	Referent	Referent
Black	0.70 [†] [0.16]	0.55 [†] [0.16]
Hispanic	0.91 [†] [0.18]	0.80 [†] [0.18]
Asian, English-speaking	0.31 [0.21]	0.32 [0.21]
Asian, Mandarin/ Cantonese-speaking	-0.10 [0.23]	-0.13 [0.23]
Multiracial	0.63 [‡] [0.24]	0.57 [‡] [0.24]
Increasing age	-0.01 [†] [0.003]	-0.01 [†] [0.003]
Education		
Less than high school (referent)		
High School graduate	-0.17 [0.15]	-0.16 [0.15]
Some college	-0.26 [0.16]	-0.26 [0.16]
College graduate	-0.40 [‡] [0.16]	-0.45 [†] [0.16]
Born outside the United States	0.26 [0.14]	0.21 [0.14]
Self reported overall health		
Good/Very Good/Excellent (referent)		
Fair/Poor	0.35 [†] [0.11]	0.28 [†] [0.11]
Perceived discrimination in healthcare		
No (referent)		
Yes		0.42 [†] [0.13]
General experiences of discrimination		
Never (referent)		
Rarely		0.19 [0.12]
Sometimes		0.30 [‡] [0.15]
A lot/All the time		0.53 [‡] [0.21]

*Worry measured on a 4 point scale; 1 = not worried and 4 = very worried.

[†]P-value <0.01; [‡]P-value <0.05

their race/ethnicity. The results of our study are limited to residents of California and may not be generalizable to the rest of the country, though our rationale for choosing California was because of the population's racial/ethnic diversity.

This study suggests that perceived discrimination in medical care and perceived discrimination in general are associated with greater discomfort and worry about providing race/ethnicity data. Many organizations advocate the collection of race/ethnicity data as a way to address disparities.^{1,4} However, HCPs should consider how they can address the public's concerns about possible misuses of data. Efforts to overcome the public's concerns about the provision of these data may need to acknowledge patients' perceptions of discrimination and mistreatment in the health care system, while also reassuring individuals that these issues are being addressed.

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Conflict of Interest: None disclosed.

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