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'Because I Don't know': uncertainty and ambiguity in closed-ended reports of perceived discrimination in US health care

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'Because I Don't know': uncertainty and ambiguity in closed-ended reports of perceived discrimination in US health care

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ABSTRACT

Objective: Surveys often ask respondents to assess discrimination in health care. Yet, patients' responses to one type of widely used measure of discrimination (single-item, personally mediated) tend to reveal prevalence rates lower than observational studies would suggest. This study examines the meaning behind respondents' closed-ended self-reports on this specific type of measure, paying special attention to the frameworks and references used within the medical setting.

Design: Twenty-nine respondents participated in this study. They were asked the widely used question: 'Within the past 12 months, when seeking health care do you feel your experiences were worse than, the same as, or better than people of other races?' We then conducted qualitative interviews focusing on their chosen response and past experiences. Descriptive analyses focus on both the quantitative and qualitative data, including a comparison of conveyed perceived discrimination according to the different sources of data.

Results: To identify discrimination, respondents drew upon observations of dynamics in the waiting room or the health providers' communication style. Our respondents were frequently ambivalent and uncertain about how their personal treatment in health care compared to people of other races. When participants were unable to make observable comparisons, they tended to assume equal treatment and report 'same as' in the close-ended reports.

Conclusion: Respondents' responses to single-item, closed-ended questions may be influenced by characteristics specific to the health care realm. An emphasis on privacy and assumptions about the health care field (both authority and benevolence of providers) may limit opportunities for comparison and result in assumptions of racial parity in treatment.

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Introduction

Research on racial discrimination in health care is voluminous. Observational, laboratory, and matched studies report racial differences in access to and quality of care in a variety of

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health care arenas (e.g. Chin et al. 2007; Smedley, Stith, and Nelson 2003). These studies show that, for example, Black patients receive fewer pain prescriptions than other patients with similar ailments (Meghani, Byun, and Gallagher 2012), racial/ethnic minorities have less access to both acute and preventive treatment for stroke (Cruz-Flores et al. 2011), and minority patients' post-acute trauma care and rehabilitative care is not comparable to that provided to White patients (Haider et al. 2013). In sum, national data from 2011 document lower quality of care for various racial and ethnic minorities compared to Whites: Black and Hispanic patients lag behind on 40% of all measures, American Indians/Alaska Natives on 30% of all measures, and Asians on 25% of all measures (though the latter group also experienced better quality of care in some areas). These data also indicate that racial and ethnic inequity in quality of care and access to care did not change overall between 2002 and 2011 (Agency for Healthcare Research and Quality 2013).

At the same time, studies have examined patients' perceived discrimination in health care and despite the consistent evidence of pervasive disparities in access to, type of, and quality of care, self-reports of discriminatory treatment vary greatly. The percentage of respondents reporting unfair treatment in health care ranges from rather high – 63% for Blacks (Bird and Bogart 2001), 40% for non-Hispanic Whites (Peek et al. 2011), 13% for Latinos, and 9% for Asian/Pacific Islanders and American Indians (e.g. for review see Shavers et al. 2012) – to rather low – 1% for Blacks (D'Anna, Ponce, and Siegel 2010), less than 1% for non-Hispanic Whites (D'Anna, Ponce, and Siegel 2010), 2% for Latinos (D'Anna, Ponce, and Siegel 2010; Purnell et al. 2012), 3% for Asian/Pacific Islanders, and 8% for American Indians (for review see Shavers et al. 2012).

Part of this variability may be due to differences in the questions posed to respondents. Previous research has documented potential pitfalls associated with different types of question wording that assess perceived racial discrimination generally (Brown 2001; Lewis, Cogburn, and Williams 2015; Williams et al. 2012) and in health care more specifically (Kressin, Raymond, and Manze 2008; Shavers et al. 2012). For example, Hausmann, Jeong, Bost and Ibrahim (2010) document the percentage of Blacks and Whites who perceive discrimination in health care according to differing survey questions. They find that the percentage of respondents who perceive discrimination fluctuates by question type with personally mediated questions yielding much lower prevalence rates than general measures of racism in health care (i.e. personal experience with versus global measure of discrimination), 42% versus 74% for Blacks, respectively, and 6% versus 40% for Whites, respectively. These studies indicate that evidence of discrimination based on personally mediated questions – and especially single-item personally mediated questions – is the most divergent from evidence based on observational studies. Personally mediated discrimination is the perception that one has personally experienced unfair treatment, intentional or unintentional and/or includes oversight and commission (in this case, while seeking health care) (Jones 2000).

The discrepancy between studies of racial discrimination in health care quality (e.g. Shavers et al. 2012) and patients' personally mediated reports of discrimination raises questions about criterion validity. Employing self-reports through surveys to measure discrimination in general has been cautioned because these measures can lead to under- or over-estimates of the occurrence of actual discrimination, (Krieger 1990; National Research Council 2004; Quillian 2006) and there is evidence that respondents specifically under-report discrimination within health care settings (e.g. Krieger 1990; Krieger and

Sidney 1996; Kressin, Raymond, and Manze 2008). However, survey-based self-reports of discrimination continue to be pervasive in health care research, largely because this method yields a greater sample size, allowing for generalizability of findings to specific populations and the reduction of investigator influence (Shavers et al. 2012).

In this paper, we are concerned with understanding the meaning behind respondents' closed-ended self-reports of perceived discrimination within the medical setting. We use a mixed-methods approach to explore patient responses to questions proposed for inclusion in the 2009 National Health and Nutrition Examination Survey (NHANES). We explore the frameworks and references patients use to identify discrimination within the health care setting (LaVeist, Rolley, Diala 2003; Lauderdale et al. 2006; Casagrande et al. 2007) when reporting their perception of discrimination in a single-item, personally mediated survey question. Exploring these issues will help to clarify the meaning behind responses to a widely used questionnaire module, and can provide guidance to researchers about the appropriate interpretation of survey responses.

Measuring discrimination through questionnaires

There is no consensus on how best to ask about perceived discrimination and the actual concept/experience captured by different survey-based measures of discrimination (Lewis, Coghburn, and Williams 2015). All available measures of perceived discrimination can be affected by survey mode (mail, telephone, electronic) (Kemnick Pintor et al. 2015), subjectivity (Smith 2002; Williams, Neighbors, and Jackson 2003; National Research Council 2004; Pager and Shepherd 2008; Pascoe and Smart Richman 2009), social desirability bias (Smith 2002; Harrell, Hall, Taliaferro 2003; National Research Council 2004; Williams and Mohammed 2009), and recall bias (Swim, Cohen, and Hyers 1998; Smith 2002; Williams and Mohammed 2009). However, recent reviews note that under- and over-reporting may be especially sensitive to specific aspects of the construction of indicator questions. Survey researchers have several options when developing questionnaires or choosing which question(s) to utilize. Options exist regarding level of analysis, use of a one-stage versus two-stage approach, timing of attribution, timeframe of discrimination, and number of items included in the measure.

Level of analysis

Questions about perceived discrimination can involve assessing personally mediated or group-level discrimination (i.e. general racism). The goals of both approaches differ. Questions regarding personally mediated discrimination seek to determine the prevalence of people who perceive that they have personally experienced unfair treatment while seeking health care. Survey questions regarding group-level perceptions of racism in health care seek to determine the sample's perceptions of inequality in health care apart from one's personal experience with racial inequality (LaVeist, Nickerson, and Bowie 2000; Lillie-Blanton et al. 2000; Hausmann et al. 2010). In this paper, we are concerned with measures that focus on personally mediated discrimination.

One-stage, two-stage, and attribution

Researchers must also decide whether to employ a single- or two-stage approach and they must also make decisions about the timing of attribution. Questionnaire developers may

specifically ask about race in the question, commonly referred to as a one-stage question with early attribution. Alternatively, they may use a two-stage approach, which delays attributing race as the cause (Shariff-Marco et al. 2011). A two-stage approach asks whether one has experienced one or a number of events with a follow-up question inquiring about several sociodemographic characteristic(s) (gender, sexual orientation, race/ethnicity) that may have prompted the experience or event (e.g. 'In your day-to-day life, how often do any of the following things happen to you? Being treated with less respect, being called names or insulted', etc.) and only after these items are respondents asked to what they attribute the discrimination ('Your ancestry or national origins, your gender, your race') (Williams et al. 1997). The issue of early or late attribution centers on whether unfair treatment should be explicitly tied to race. Scholars suggest that by directly tying unfair treatment to race in the stem of the question, racial discrimination is measured (Brown 2001; Chae et al. 2008; Krieger 2012) while the use of the more neutral language in the two-stage late attribution measure does not specifically assess racial discrimination which makes the latter weaker in explaining racial differences in health (Krieger 2012).

On one hand, the one-stage approach leads to higher reports of perceived racial discrimination with some suggesting this is reason to believe this approach is superior (Brown 2001; Chae et al. 2008; Shariff-Marco et al. 2011; Krieger 2012) though there are arguments to the contrary (Gomez and Trierweiler 2001; Williams and Mohammed 2009). On the other hand, the single-stage approach could be more susceptible to vigilant response bias (sensitivity to discrimination) (Gomez and Trierweiler 2001; Williams and Mohammed 2009). The single-stage approach also involves higher cognitive demand, requiring respondents to think about whether discrimination has occurred while simultaneously having to determine if the discrimination is due to race. Both approaches are correlated with health problems (for review see: Pascoe and Smart Richman 2009; Williams and Mohammed 2009; Lewis, Cogburn, and Williams 2015).

Timeframe of discrimination

Measures of discrimination in health care may ask if a respondent 'has ever experienced' unfair treatment. An alternative is to include a specified timeframe in which the discrimination has occurred. The latter approach minimizes recall bias related to the timing of health care visits and experiences (Kressin, Raymond, and Manze 2008). In this study the timeframe is within the past 12 months.

Number of items

Regardless of whether a researcher uses a one or two stage approach, he/she must also decide upon single versus multiple items. Some measures of discrimination in health are taken from scales that have multiple items asking about discrimination in several domains but only have one question that asks specifically about unfair treatment in health care (Krieger 1990; Sims et al. 2009). This is a single-item measure. Other indexes of discrimination in health combine multiple items, with anywhere from 3 to 10 questions focusing on discrimination in health care combined into a scale (e.g. Bird and Bogart 2001; Green 1995; McNeilly et al. 1996; Lillie-Blanton et al. 2000; Facione and Facione 2007; Hausmann et al. 2010). Using one global question as the measure of discrimination in health care may lead to issues of construct validity when compared to measures based on multiple items (Shavers et al. 2012).

Single-item measures of discrimination in health care

Here, we investigate one specific type of survey question – the personally mediated, one-stage, single-item – because it is one of the most commonly used measures for assessing perceived discrimination in health care, and is used in some of the most widely referenced national longitudinal studies of health care in the United States. The specific measure of interest is a part of the Behavioral Risk Factor Surveillance System (BRFSS) Reactions to Race module (Centers for Disease Control 2009), a measure often used in previous research (e.g. Crawford, Jones, Richardson 2008; Hausmann et al. 2008; Hausmann et al. 2009; Peek et al. 2011; Grandner et al. 2012; Kaphingst et al. 2012; Purnell et al. 2012; Zuckerman et al. 2012; MacIntosh et al. 2013; Benjamins and Whitman 2014) and one of the most frequently used surveys for measuring perceived discrimination in health care (for review see Shavers et al. 2012). Because of its wide use, this question has the potential to guide a lot of decision-making and understanding around the topic of perceived discrimination in health care. For this reason we focus on this question. It poses the question: ‘Within the past 12 months, when seeking health care do you feel your experiences were worse than, the same as, or better than people of other races.’ The measure benefits from a defined time span (past 12 months). There is also little attributional ambiguity written into the question: respondents are asked to think of differential treatment directly tied to their race.

Yet, with a comparative question, respondents may face two main issues. First, respondents who are asked to report on discrimination using this type of measure encounter the challenge of addressing a counterfactual (Goldman 1976; Berkman 2004). That is, to evaluate their experience to others, respondents must determine what would have happened if one of their defining characteristics was different. This issue is specific to uncertainty based on the hypothetical comparison they are asked to make. Race is such a dominant status indicator that it informs nearly all social experiences, making it difficult for minorities to abstractly determine the counterfactual experience of being White (Kaufman and Cooper 1999). If there has been no defining, overt act of discrimination, minority respondents may have to draw upon a common short hand to deal with this comparative ambiguity: they may base responses on the treatment they observe others’ receiving within the same institutional settings (Major, Quinton, and McCoy 2002). The availability of these types of observations and, therefore, comparisons may represent an important substitution for the counterfactual.

Second, the covert discrimination dominant in the post-Civil Rights era affects how respondents understand and respond to questions about unfair treatment in all institutional contexts. Because discrimination is often enacted in subtle and institutional forms, many are unaware of its presence and its effect on their lives (National Research Council 2004; Kressin, Raymond, and Manze 2008). For example, Gee (2002) did not find an association between reported perceived discrimination and institutional discrimination (measured as redlining and residential segregation), but in multilevel models both were independently associated with negative health outcomes. The amount of transparency of institutional practices and the respondent’s level of familiarity with institutional practices can also affect the degree to which they detect institutional discrimination.

Assessing perceived discrimination within the health care setting

The health care setting may make both of the previously discussed measurement issues particularly salient. In research on unequal treatment within the medical system, racial discrimination generally refers to a difference between the quality and quantity of care that a subgroup receives and the quality and quantity of care they would receive if they were members of the dominant group (Quillian 2006). Although a recent study of discrimination finds little evidence of attributional ambiguity among minority respondents (Williams et al. 2012), the issues associated with the counterfactual and ambiguity (and by ambiguity we mean ambiguity in general – not knowing how one’s treatment compares to others because there is little frame of reference for knowing how others are treated when accessing health care) could be elevated in health care because the medical setting values patient privacy and thereby limits individuals’ ability to compare themselves to others (Feeley et al. 2014). Furthermore, the social organization and corporatization of medical care obfuscates clinical practices, which could thereby exacerbate problems with recognizing institutional discrimination (Conrad and Schneider 2008).

The salience of these issues within the health care setting could help to explain why Lillie-Blanton et al. find that only 19% of the public identifies racism as a major problem in the medical system, and consider discrimination in health care less of a problem than in other domains such as housing, education, and the work place (Lillie-Blanton et al. 2000). Using results from a 1999 and 2010 survey that examined awareness of racial and ethnic disparities in health, Benz, Espinosa, Welsh and Fontes (2011) find that awareness of racial disparities did not show great improvement, moving from 55% to 59% among White, Black, and Hispanic respondents. The health care setting therefore serves as a unique context for the formation of perceptions of unequal treatment.

Despite these challenges, perceptions of discrimination in health care are important to study (regardless of how (in)accurately perceptions reflect reality) because perceptions may shape individuals’ behaviors and attitudes (Pager and Shepherd 2008). Though some research shows no association between perceived discrimination and health (e.g. Banks and Dracup 2006; Casagrande et al. 2007; Burgess et al. 2008; Hausmann et al. 2008), other research shows an association, dependent on the health outcome (e.g. Blanchard and Lurie 2004; Trivedi and Ayanian 2006; Hausmann et al. 2010). Research showing a relationship between perceived discrimination and health find that perceptions of unfair treatment in health care shape patient–provider trust (Adegmembo, Tomar, and Logan 2006; Hausmann et al. 2013), satisfaction with care (LaVeist, Nickerson, and Bowie 2000; Benkert et al. 2006), adherence to medical advice (Casagrande et al. 2007; Penner et al. 2009), how quickly one seeks care (Van Houtven et al. 2005; Casagrande et al. 2007), the likelihood one will utilize care (Wamala et al. 2007; Lee, Ayers, and Kronenfeld 2009), and stress, and mental and physical health status (Krieger and Sidney 1996; Ren, Amick, and Williams 1999; Bird, Bogart, and Delahanty 2004; Williams and Mohammed 2009). Rogers et al. (2015) using a longitudinal design find an association between perceived racism at Time 1 and (worsened and new) disability after two to five years of follow-up. Hausmann et al. (2010) results show that the association between perceived discrimination and health may also depend on the measure of unfair treatment employed.

Taken together, results suggest value to exploring the medical consequence of subjective experiences in health care. We, however, do not fully understand how patients

come to conclusions about perceived discrimination within the health care setting, nor how these perceptions are then reported in pre-determined categories on questionnaires. Here, we explore respondents' explanations of responses to a single-item survey question about discrimination within the health care context. Our objective is to focus specifically on the role of potentially unique aspects of the context of health care and health care settings, and how respondents frame reports of perceived discrimination in survey responses.

Methods

Data collection

Findings for this paper are from a larger mixed-methods study on sexual behavior, alcohol, sexually transmitted infections, and racial/ethnic identity and discrimination. The original purpose of the larger study was to test sensitive questions that were proposed for the NHANES. The NHANES is a national survey that examines the health of the US population. A small sample was used to test a specific subset of proposed questions for the 2009 NHANES. The survey responses for this study were collected through Audio-Computer Assisted Self-Interviewing (A-CASI) software. When using A-CASI, questions are shown on a screen and are read aloud to the respondent through headphones. Respondents indicate their response by pressing keys on the keyboard. The benefit of using A-CASI is its potential to improve the likelihood of attaining sensitive information and to enable people with low literacy to answer survey questions (Office of Applied Studies 2001). Face-to face semi-structured cognitive interviews followed the A-CASI survey. These semi-structured interviews were conducted in 2008 in the Questionnaire Design Research Laboratory (QDRL) at the National Center for Health Statistics (NCHS). Respondents completed the surveys on the computer; interviewers for the semi-structured interviews were White. All interviewers had experience interviewing racial and ethnic minorities. All interviewers had advanced degrees (M.A. and/or Ph.D.). They were all trained in cognitive interviewing and formally in qualitative methods, as the main job of the researchers at the QDRL is to conduct qualitative and cognitive interviews in order to test and develop survey questions for the federal government. Interviews lasted an hour, were audio-recorded, and then transcribed verbatim.

The goal of the qualitative interview was two-fold: to discover the aspects of care respondents perceived as discriminatory and to uncover patterns of interpretation that respondents use to answer survey questions, with the latter being a goal of cognitive interviewing (Ridolfo and Schoua-Glusberg 2009). As a qualitative method, cognitive interviewing provides detailed insight into the potential for response error in the administration of survey questions through the use of probes. All respondents were first asked whether they remembered how they answered the question in A-CASI. Respondents were then asked to talk about what they were thinking when they answered each question and then why they ultimately decided on the response they chose. Specific probes were, 'How did you come up with that answer,' 'What were you thinking about?' 'Why did you say same as, Was this in the past 12 months,' and 'When did this happen?' With this understanding, it is possible to determine if survey questions are actually

eliciting the type of information that is desired. For example, did respondents answer the survey questions keeping in mind the 12-month specification, did they tie their experience to their race or ethnicity, and did they compare their treatment to the treatment of those of other races. Because cognitive interviewing parallels traditional semi-structured interviews, interviewers also obtained data on the experiences and frameworks that respondents considered and what they deemed as discriminatory treatment.

Sample

Respondents were adults residing in Washington, DC, Maryland, and Virginia. Eligible respondents were recruited through a free local commuter newspaper, the *Washington Express*, and through recruitment of participants from prior QDRL projects. Respondents were given \$40 remuneration. Screening was conducted to ensure gender, education, race/ethnicity, and income variability. All participants provided verbal informed consent, signed an informed consent form, and received an informed consent reference sheet. Conduct of the study was approved by the Human Subjects Committees of the NCHS.

The sampling strategy used was purposeful; this sampling strategy resulted in a useful set of respondents for exploratory work as it is comprised largely of Blacks, Hispanics, and those who have low socioeconomic status, all of whom are usually underrepresented in survey samples. The original sample size was 59. However, our analyses are limited to the 29 respondents whose interviews were conducted in English, who sought health care within the past year, and whose interviews were made available for analysis (see

Table 1. Demographic profile of respondents.

	N = 29	Total (%) ³
<i>Gender</i>		
Female	17	59
Male	12	41
<i>Race</i>		
Black	15	52
White	10	34
Asian	1	3
AI/AN	1	3
Multi-racial	2	7
<i>Ethnicity</i>		
Hispanic	5	17
Non-hispanic	23	80
<i>Age</i>		
19–29	9	31
30–39	6	21
40–49	10	34
50–58	4	14
<i>Education</i>		
Less than HS	5	17
HS/GED	8	28
Some College	9	31
4-year degree or more	7	24
<i>Household income</i>		
Under \$20,000	12	41
\$20,000 or more	15	52
Missing	2	7

³Some categories may not sum to 100% due to rounding.

Table 1). Interviews from respondents who chose Spanish as the language for their interview were not made available to the researchers; however, Hispanics who chose to interview in English were available and are included in the results. The majority of the sample is female (59%), half is Black (52%) and 17% of the sample is Hispanic. About a third of the sample is between 40 and 49 years of age, and about 2 out of every 5 have a high school diploma or less.

Measures

This study utilizes only one close-ended measure based on responses to one of the proposed survey questions for the 2009 NHANES survey (albeit the same survey question that has been used on the BRFSS). To capture respondents' *survey-reported perceptions of discrimination in health care*, they were asked one of the aforementioned common questions in the health care literature on discrimination: 'Within the past 12 months, when seeking health care do you feel your experiences were worse than, the same as, or better than people of other races?' We treated these responses as a categorical variable consisting of worse than, same as, better than, and do not know (representing ambiguity).

Through qualitative coding of interviews, we created a measure of *interview-reported discrimination in health care* with the following categories: worse than, same as, better than, and do not know. In his/her interview response, a respondent might convey that he/she does not truly know how to answer the question, and in this case the answer would be coded as 'uncertain.' Portions of individual responses were also eligible to be coded as multiple categories. For example, in the qualitative response the respondent might provide an example of receiving the same treatment while accessing care and another example in which he/she received worse treatment within the past 12 months. Such a respondent's qualitative coding would thus be 'same as' and 'worse than' resulting in multiple counts for the same individual.

Analysis

Our quantitative analysis is purely descriptive. We simply describe responses from differing data collection sources (survey and interview) to provide background for our main, qualitative analysis. Our primary interest is in processes and frameworks used to make decisions about responses, so most of our emphasis is on the qualitative analysis. First, qualitative categories were identified through systematic open coding. Second, through a process of memoing, these codes were content-analyzed to capture patterns that emerged. These codes were broken down into themes and subthemes. The quotes presented are representative of the data in each theme or subtheme. Q-notes, a qualitative software program developed by the QDRL that allows for the coding and analysis of qualitative data, were used for initial coding. The strength of Q-notes is that the actual visual and/or audio recording of the qualitative interview is embedded and preserved alongside the survey responses within the application so findings are instantly traced to the original source. The coding was created and agreed upon by members of the research team at the QDRL (Ridolfo and Schoua-Glusberg 2009). The first author verified these codes and broke them down into themes and subthemes.

Findings

Interview responses indicate underreporting of both discrimination and uncertainty on surveys

Table 2 provides a description of respondent's reports of discrimination. Reports of 'worse treatment' are much higher in the interview data (41%) compared to the survey data (15%). In other words, based on survey data, less than one in five respondents perceive recent discrimination in health care, however, in interviews, more than one out of every three of these same respondents report experiencing discrimination. Furthermore, uncertainty is much more prevalent in the interview data than in the survey data. Only 4% of survey responses choose 'don't know', whereas 37% of the interview responses express uncertainty.

Observable behaviors influence perceptions of discrimination in health care

While many people do not know how others are treated when accessing care, some respondents try to rely on observable comparisons to identify discrimination. By observable behaviors, we mean contexts or interactions in which patients believe they are able to see or hear how their treatment compares to others. The qualitative data reveal details that are important and specific to the health care realm, namely, waiting rooms and patient-provider relationships. These aspects of health care are places in which patients make observations that then shape their perceptions of discrimination.

Waiting room

Our data indicate that many respondents focus on dynamics occurring in the waiting room when they consider and evaluate experiences of discrimination. The waiting room is arguably the most open and accessible space for patients to evaluate and compare their experience of any kind to that of others. Some respondents assess how long they wait compared to how long individuals of another race may have to wait before being seen by the doctor:

R: I put 'the same as' [for my survey answer]. When I observed and looked in the office to see, you know, because sometimes when you go to a doctor's office and I always look to see whose

Table 2. Comparison of reported perceived discrimination in the health care setting^a, survey versus Interview ($n = 29$).

Categories	Survey Data		Interview data	
	Response		Response	Codes
Same as other races	74% (21)		70% (19)	Same treatment
Better than other races	4% (1)		7% (2)	Better treatment
Worse than other races	15% (4)		41% (11)	Worse treatment
Do not Know	4% (1)		37% (10)	Ambivalent/uncertain
Refusal	4% (1)		0% (0)	Refusal
Missing	4% (1)		0% (0)	Missing

^aThe question posed was, 'Within the past 12 months, when seeking health care do you feel your experiences were worse than, the same as, or better than people of other races?'

Notes: The numbers in the column 'Response' for the 'Interview Data' do not equal 29. In the interview, respondents may have recalled instances in which they received better and worse treatment (for example). We coded by example, not by case. Each case (respondent) could provide more than one example, so the total count does not equal 29.

name is after mine and I'll pay attention if they take that person before or after me. Because sometimes that has happened to me and I say, look I was here at 9:00 and she's here at 10:30 and you took her before me. I address that to them. So I observe. They do that by the book. They take this person next and this person next. (White female)

This respondent says that her treatment is the same as other races because people are not called in to see the doctor-based on race. Instead they do it 'by the book' or in other words, based on arrival time. Using the waiting room as an example, another respondent explains why she thinks her treatment is the same as other races. She says, 'I just went to the doctor last Monday and everybody sits and waits. That's basically it. All kinds of races were there. I didn't see any preferential treatment. We were all sitting, all waiting, twiddling our thumbs' (Black female). In another example, a respondent references the waiting area in the emergency room. He believes his treatment is the same as other people because patients are in the waiting room for the same type of health issues. He says, 'I spend a lot of time in the ER so a lot of people are there for the same reason. I hear them talking. Yeah they're pretty loud' (Black male).

Patient-provider relationship

Interviews indicate that patients also assess the quality of the interpersonal relationship they have with their provider to determine whether they are a recipient of discrimination. The following respondent, whose survey response is 'worse than' other races, complains that some health providers neglect to give Black patients a basic level of respect:

R: They look at you like you got Medicaid anyway so [they think,] come in here, lay on the table and get out. Instead of saying, 'How do you feel today, what are you experiencing?' Things like that, [rather] they just bump, bump, bump. (Black male)

The respondent conveys an experience in which the provider simply wishes to get the patient out the door, demonstrated in his expression, 'bump, bump, bump.' Communication also appears to be lacking; the respondent indicates that the provider does not ask about his symptoms or health needs. Similarly, another respondent who rates his experience as 'worse than' references the quality of communication between himself and the provider:

R: You know that doctors are supposed to be caring, they are supposed to tell you that everything is alright, but it was very early in the morning, he came and he sat down, you know, toward the end of the bed and that's when he was asking me questions and then he wasn't patient about, you know, you know, not answering the questions. I saw this snappy person instead ... (Black male)

This respondent also notes the impatience of the communication in the doctor-patient relationship and how the doctor fails to answer his questions and live up to his expectations of how a doctor should behave. Like the previous response, this respondent focuses on the quality of doctor-patient interaction to inform his survey response. Overall, the analysis indicates that when respondents encounter verbally domineering, unresponsive, or abrupt providers they consider this negative treatment as unequal treatment. In the absence of a comparison to other patients, some patients seem to assume that poor interaction between themselves and the provider means they are receiving worse care than others.

Respondents seem to have a hard time disentangling insurance issues from the topic of racial discrimination in health care

Insurance-based discrimination is defined as unfair treatment patients receive based on insurance status or the specific type of insurance they have (e.g. Medicaid, Medicare, managed care) (Lillie-Blanton 2005; Thorburn and De Marco 2010; Weech-Maldonado et al. 2012). Our respondents seem to take ownership and type of health insurance (private or public) into account when forming their perceptions about their own experience of differences in health care based on their own race. Many believe that insurance status is a driving determinant of equality or inequality in treatment, and even display a somewhat nuanced understanding of varying degrees of influence.

Several of our respondents who rated their treatment as the ‘same as’ other races note how having insurance guarantees that one will receive equal treatment, regardless of race. For example, one respondent who marked his survey response as ‘same as’ explains, ‘I will probably feel, probably the same. Same, my same doctor, how does he treat others? I don’t really know. But if they got insurance, I guess he will treat them good’ (White Hispanic male). This respondent assumes that health insurance is an equalizer, basing the presence of discrimination in health care on insurance status. A woman who received care at a Veterans Administration hospital notes that she received the same treatment because of ‘the insurance’ (along with the fact that her damaged cornea, which was the reason for her medical visit, was ‘fixed’) (Black female).

Other respondents believe that insurance influences treatment, and also paint a more comprehensive (as opposed to the binary of insured versus uninsured) picture of the influence of insurance. The following response is typical: ‘The better insurance you have, the better you get treated. If you have low or you don’t have the insurance coverage then you just sit there’ (White female). Later this respondent identifies three groups of people: those with ‘better insurance’ (i.e. people who have private insurance), ‘low insurance’ or Medicaid, and those with no insurance. Another respondent questions how specific insurance plans like Kaiser (a Health Maintenance Organization) might facilitate disparity:

R: Sometimes I feel like if I do have a problem and call in and make an appointment they say, we can get you in in two months. I don’t really think that’s race. It’s health care system. Or calling and saying I know I need to see this type of doctor, but my insurance [Kaiser plan] says I first need to see my primary doctor. If I have to make an appointment for my primary doctor it may take a month to get that appointment and then two or three weeks to see the specialist. (Black female)

While not demonstrating a well-developed understanding of how different types of insurance plans contribute to quality and quantity of care, this respondent does question its influence. Our respondents seem to be aware of insurance-based structural discrimination and take it into account when asked about racial discrimination in health care.

Uncertainty does not deter respondents from choosing one of the ‘valid’ close-ended categories

Our closed-ended discrimination question provided respondents with the option to choose ‘don’t know,’ but previous research indicates that survey respondents do not

view this option as a valid survey response (Schaeffer and Presser 2003). In our data, a large portion of respondents select a 'valid' survey response (i.e. same as, better than, worse than), yet voice uncertainty or express that they do not really know how others are treated in their interview narratives. Among those who expressed ambiguity in their qualitative interview, none answered 'better than' in their survey, 7% (2) refused to answer the question or marked 'don't know,' 7% (2) marked 'worse than' in their survey response, and 21% (6) marked 'same as.' Thus, these data suggest an over-reporting of equality.

A Black woman initially reports in her survey response that her treatment is worse than that of other races. In the interview, however, she vacillates between assuming her treatment is the same as other races and being unsure of how her treatment compares with other races:

R: This is a weird one for me too. I think it's insurance. I don't think the folks treated me bad because of race. I think that some problems I've had have been because of insurance but I don't know although I said 'yes.' I said 'worse than' but I would say 'same as'. But then, I don't want to make it complicated but how do you know how someone else is treated? (laughs) I would say 'same as'. Somewhere between same as and worse. ... So I actually say insurance but see, I don't know what other people are dealing with. I don't know what happens with you [indicating the interviewer] being non-Black going to the health care. I don't know what happens with you. (Black female)

When comparing this respondent's survey response (which was marked as worse than) to her qualitative narrative we see that she finds it difficult to determine if her experience is worse, the same, or not able to be determined. Her thoughts are further complicated because she struggles with trying to separate race and insurance coverage from one another.

More often in our data, respondents do not seem to know how others are treated and thus assume their treatment is equal. Though people do not know how others are treated they see the response option 'same as' as a default response. A respondent who answers 'same as other races' for the survey question says,

To be honest with you 'no' [I don't remember a time when I was treated differently] because I've never witnessed another race get treated a certain way except on TV and that's strictly entertainment so you can't go by that if you expect to live in the real world. (Black male)

Similarly, the following quote is from a White male who does not seem to know how others are treated in his qualitative response though his survey response is 'same as.' He responds:

I just figured. I just went to a normal doctor. If a Black guy or Hispanic guy went to the same doctor he'd probably get the same treatment. Maybe there are other doctor's offices where different races get preferential treatment. I'm sure there are but it didn't seem that way at the doctor's office I went to. (White male)

The phrases and words 'I figured,' 'probably,' and 'it didn't seem' suggest that the respondent is not sure his viewpoint is reflective of others' lived experiences, but it does not stop him from selecting 'same as' in his survey response. It appears that in the midst of not having witnessed how others are treated, many respondents assume equality because – as was quoted in a data excerpt – 'doctors are suppose to be caring' and receive some

level of authority and respect as professionals. A woman who response falls in the ‘don’t know’ category states, ‘I think they [doctors] try to treat their patients as equal. They would try to, I think’ (Asian female).

Discussion

This exploratory study attempts to shed light on the meaning behind a single-item survey question probing about discrimination in health care. Our findings reveal that, first, respondents’ evaluations of discrimination in health care are largely informed by directly observable items. As such, the waiting room is one area where respondents make conclusions about whether they believe they have experienced discrimination. The importance of knowing that the waiting room becomes a tool by which people evaluate their quality of care is valuable. Previous scholarship on discrimination in health care has not highlighted the waiting room as a worthy place of assessment; however, it is likely that perceptions of treatment in health care begin and are heavily influenced by staff behavior during the time preceding entry to the examining room. At this juncture patients are able to actually see others, and to make comparisons between themselves and others.

In the absence of this information, interview findings demonstrate that respondents experience a good deal of uncertainty and ambiguity when determining their perceptions about discrimination in health care. The constraints of quantitative survey research – and the desirability of a ‘valid’ answer – make it extremely difficult for patients to report uncertainty. Our findings indicate that this specific type of survey-based question (single-item) may underestimate the prevalence of discrimination, particularly when compared to other research methods such as self-reports through qualitative interviews. As a result, at the very least, rich information is lost; at most, we have an inaccurate interpretation of what respondents’ survey responses really mean and what is an accurate percentage of people who perceive discrimination in health care. Our respondents specifically over-report equity. Future research should explore this issue further, and perhaps consider adding a ‘don’t know’ option or changing ‘don’t know’ to ‘unsure,’ or ‘not certain’ as a survey response option.

Prior research raises concerns that standard survey measures of unfair treatment underestimate experiences of discrimination because surveys typically provide narrow options of discriminatory encounters (Schnittker and McLeod 2005). Our data supports these concerns, and suggests that to combat the possibility of underreporting discrimination in health care, the specific items that assess the unique ways in which unfair treatment is manifested in health care should be expanded. Some prior work has been done in this regard (e.g. you feel a doctor or nurse is not listening to what you were saying, the doctor or nurse acts as if he is she thinks you are not smart). However, multi-item questions regarding discrimination in health care might also expand to ask about perceived differential treatment in: wait times to see the doctor/nurse, treatment by staff members, time spent with the doctor, thoroughness of the examination, and medical advice or treatment, which were voiced by our respondents as ways in which they determine if they have received equal or inferior treatment.

Most importantly, at the crux of our argument is that even beyond the limitations of a single-item indicator, ambiguity in general (not knowing whether one has received inferior or unfair treatment) might be an issue for respondents regardless of whether

the measure focuses on personally mediated or group-level discrimination, uses a one-or two-stage approach, whether attribution comes early or later, and no matter the time-frame of the discriminatory encounter. The problem of ambiguity in general may extend to most measures of health care discrimination because of the very nature of health care settings. Patients' opportunities to directly compare their experience to others are largely limited within the health care realm. Mandated privacy, relatively short interactions, and a lack of publicly visible hierarchies (e.g. pay grades, awards, assignments, etc.) that exist in other social contexts (such as the work place) limit patients' available information within the context of health care. People do not seek health care in a 'public' way given that they usually go alone, interact with providers behind closed doors, and rarely have sustained interactions with other patients in the same facility. Inherent in most survey questions, regardless of whether a comparative statement is explicit such as 'how does your treatment compare to other races,' is the need to evaluate one's own experience in relationship to another's. It is this difference in experience and treatment between one's self (or racial group) in comparison to others that largely determine whether one has received unfair treatment. The systematic review by Shavers et al. (2012) note that a weakness of survey studies on health care discrimination is that 'self reports depend on respondent awareness of being discriminated against' (23). This study provides empirical data that suggest that awareness, but additionally an inability to know whether one has experienced discrimination might be influencing discrepancy in prevalence rates of perceived discrimination in survey versus observation data. The oftentimes subtle and ambiguous nature of discrimination *coupled with* the privacy in health care might lead to not only minimization bias (occurs when people perceive less discrimination than actually exists) (Kaiser and Major 2006), but also ambiguity bias which we believe is the inability to or extreme difficulty in perceiving discrimination beyond personal perception issues. Future research should explore this issue further by evaluating whether ambiguity in general exists when multi-items and one-stage approaches are used.

Our respondents also indicate that they consider the confounding issue of insurance when thinking about their own experience with discrimination. Accordingly, previous literature demonstrates high perceptions of insurance discrimination (e.g. Ngo-Metzger, Legedza and Phillips 2004; Friedman et al. 2005; Lillie-Blanton et al. 2005; Thorburn and De Marco 2010; Weech-Maldonado 2012; Han et al. 2015). Trivedi and Ayanian (2006) find that respondents report discrimination due to type of insurance (28%) more than due to race/ethnicity (14%), though there were differences in this percentage by racial group. The literature provides evidence that those covered through Health maintenance organization's experience greater barriers to access than those insured through other forms of insurance, such as fee-for-service (Ware et al. 1996). A review of the literature on the influence of insurance on racial disparities in health finds that uninsured and insured racial minorities have poorer access to care than Whites, though this gap in access is much larger for those who are uninsured. Additionally, minorities have lower rates of health insurance than Whites (Lillie-Blanton and Hoffman 2005). An audit study also indicates that children on public insurance are six times more likely to be denied urgent care appointments than those with private insurance (Bisgaier and Rhodes 2011). A study assessing insurance-based discrimination since the passage of the Affordable Care Act finds those who

are uninsured report higher insurance-based discrimination (25%) followed by those who have public insurance (21%) with few of those privately insured perceiving unfair treatment (3%) (Han et al. 2015). Insurance-based discrimination is suspected to have a similar influence as race-based discrimination on health care seeking behaviors and quality of care. This study suggests that race- and insurance-based discrimination in health care may be difficult to tease apart partially because of the intersectionality of multiple devalued status (i.e. race, ethnicity, and/or insurance status).

According to our data, patients may not be aware of these studies, but they seem to be aware of these issues and – based on including them in their answers – seem to recognize their conflation with racial differentials in health care. This difficulty in attributing discrimination to race/ethnicity or insurance highlights another issue in discrimination and health care research: ignoring the interplay of multiple devalued social statuses and how they together shape one's experience (Lewis, Cogburn, Williams 2015). The way in which intersectionality plays out in terms of health care encounters is difficult to measure though there has been some headway in trying to measure intersectionality quantitatively (Cole 2009; Seng et al. 2012). Lillie-Blanton and Hoffman (2005) write, 'The issue is whether and to what extent does racial/ethnic background interact with health insurance to affect a person's access to care' (405).

Limitations

There are limitations to this study, and all of these findings should be taken as exploratory. First, findings are not generalizable in two ways. First, the sample only includes respondents from the US Mid-Atlantic and is a small purposeful sample; nonetheless, many of the respondents make up an often hard to reach segment of the population (low-income and a heterogeneous group of racial minorities). Second, the small sample only provides preliminary evidence of how patients build their perceptions of discrimination when answering one type of survey question; thus, results cannot necessarily be generalized to other survey measures. Nonetheless, little is known about this particular topic, and these preliminary findings illustrate the value of understanding patients' perceptions in a future, larger sample and using different types of survey questions. These are among the only data available to delve into survey participants' responses to close-ended survey questions about discrimination in health care (for an exception see Williams et al. (2012) paper where respondents were asked to provide open-ended responses to explain what the term 'unfair' means to them). Second, all interviewers were White; thus, racial minority respondents were not race-matched. Because these questions are about racial discrimination, minorities may have downplayed such experiences. As a result, there may be underestimation of perceived discriminatory experiences because of race discordance between the interviewer and the respondent (Krysan and Couper 2003); however, we are unable to assess this influence. Last, findings from this study are restricted to respondents who interviewed in English. Presumably, non-English speakers had less access to recent care and this group may be more likely to experience discrimination frequently and in different ways. Future work should examine the frameworks and references immigrants and non-English speakers use to identify discrimination when accessing care.

Conclusion

Despite the limitations, this research offers several contributions. First, the results reinforce existing literature indicating that single-item comparison questions should not be used as indicators of discrimination, but rather as indicators of perceived discrimination. It may be improved as a measure of perception if respondents feel more comfortable with a category indicating uncertainty. As was discussed in the introduction, perceived discrimination is worthy of research in its own right, as it shapes individual's health directly (through stress mechanisms) and indirectly (through health behaviors and care seeking behaviors). Second, knowing the potential importance of waiting rooms and the likelihood to default to the provider-patient relationship may guide researchers and interventionists to devote more attention to these areas when addressing *perceptions* of discrimination. The responses from these analyses suggest that, in addition to addressing bias through cultural competency, relatively easy and observable adjustments can be made to change people's perceptions for the better. Taking patients in strict order of arrival may enhance perceptions of equal care. Promotion of positive interactions between health providers and patients should continue. Future studies should continue to investigate whether health insurance for all and perceived equality in quality of insurance may be associated with decreased perceptions of discrimination. These findings reinforce the idea that the existence of discrimination is distinct from perceived discrimination, and we should continue to develop better tools to investigate perceived discrimination as a distinct phenomenon.

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