

Racial and Ethnic Disparities in Health: A View from the South Bronx

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Abstract: This study seeks to understand the perspective of Black and Hispanic/Latino residents of the South Bronx, New York, on the causes of persistent racial and ethnic disparities in health outcomes. In particular, it focuses on how people who live in this community perceive and interact with the health care system. Findings from 9 focus groups with 110 participants revealed a deep and pervasive distrust of the health care system and a sense of being disrespected, exacerbated by difficulties that patients experience in communicating with their providers. The paper suggests how health care institutions might respond to these perceptions.

Key words: Health disparities, trust, community-based participatory research, qualitative research.

Research has documented significant racial and ethnic disparities in health status, access to health care and health outcomes.^{1,2} People of color have shorter life spans,³ lower rates of insurance coverage,^{2,4} and are less likely to have a usual source of care than non-Hispanic Whites.^{2,4} Moreover, compared with non-Hispanic Whites, African Americans and Hispanics have higher incidence of morbidity and mortality for many diseases.⁵ For example, in the predominantly minority community in which we have been working in the South Bronx, New York,* the mortality rate for diabetes

*This community is made up of four contiguous ZIP codes (10452, 10453, 10456, and 10457), and includes the neighborhoods of Highbridge, Morrisania, West Tremont, and Morris Heights. The population is approximately 270,000, more than 95% of whom are Black or Hispanic. The Black population includes African Americans, Caribbean Americans, and recent immigrants from Africa. The Hispanic population is largely Dominican and Puerto Rican, although there are also many new immigrants from Central and South America.

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for women ages 18 to 64 years is twenty times higher than in the predominantly White Upper East Side of Manhattan, a ten-minute subway ride away.⁶ Although these disparities have been recognized for many years, we know little about how the affected communities understand, interpret, and explain them.

As part of its REACH 2010 Initiative (Racial and Ethnic Approaches to Community Health), the Centers for Disease Control and Prevention funded an effort in the South Bronx, New York, led by the Institute for Urban Family Health, to reduce morbidity and mortality resulting from diabetes and cardiovascular disease.⁷ The coalition that formed to carry out this initiative, Bronx Health REACH, is currently implementing a far-reaching program focused most broadly on eliminating disparities in access to high quality health care and, more specifically, on primary and secondary prevention of diabetes and related cardiovascular disease. As a component of our formative research to help the Bronx Health REACH Coalition design its intervention, we held a series of focus groups with community residents. Our purpose was to solicit the views of the people living and using the health care system in the South Bronx: what do they believe causes these disparities in health status, and what steps might be taken to close the gap?

Methods

These focus groups were part of the coalition's larger research and evaluation portfolio, which has included a community-based, door-to-door survey;⁸ an implementation evaluation that has focused primarily on coalition development and the implementation of a faith-based initiative; analysis of hospital discharge and other administrative data; and periodic surveys of program participants. As with the coalition's other research and evaluation activities, the focus group component used a community-based participatory approach,⁹ emphasizing a collaborative and reciprocal learning relationship between community members and trained researchers,¹⁰ and the subsequent use of the findings by the coalition to help shape its agenda and improve its work.^{11,12} The coalition's research team, which included community leaders as well as trained researchers, collaborated in the development of the focus group questions, reviewed and discussed the data, and together presented the findings at several coalition meetings, where action plans were developed and refined.*

Over a three-month period, we held 9 focus groups (2 of which were in Spanish) with a total of 110 people. Seventy-eight of the participants were Black; 31 of the participants were Hispanic. One of the participants was non-Hispanic White. The majority (90 out of 110) were women. Institutional review board approval was obtained from New York University and all participants signed informed consent forms, which included permission for video and audiotaping.

In order to ensure a varied group of participants, we used a broad spectrum of community institutions (churches, social service agencies, housing development

* Our use of a community-based participatory research approach to the focus groups, which were the coalition's first research and planning activity, created a shared experience and common base of knowledge that, five years into the coalition's work, still provides a touchstone and reference point for the coalition's work.

groups) to recruit focus group members. By recruiting and holding the focus groups at venues other than health care institutions, we hoped to avoid bias or any sense of intimidation that might make the participants reluctant to share their views as consumers of health care services. The focus groups were held at the community-based organizations, often immediately following or as part of a previously scheduled meeting, class, or church service. The English language focus group sessions were conducted by two leaders, one a Caucasian professor and the other an African American consultant who grew up in and remains an active member of the Bronx community, where she previously headed several community-based organizations. A bilingual consultant who was experienced in facilitating focus groups among diverse low-income populations conducted the Spanish language sessions. The focus groups lasted one and one-half to two hours. We paid participants \$20 as compensation for their time.

Following introductions and a review of ground rules, the focus group leaders presented data about racial and ethnic health disparities among African Americans, Hispanics, and Whites, and asked the participants for their views about why these disparities exist.¹³ These data included differences in life expectancy, as well as differences in morbidity and mortality for several diseases, including diabetes and cardiovascular disease. For example, the focus group leader would say, "On average, White men live 8 years longer than Black men and White women live 6 years longer than Black women. Why do you think this is true?" The focus group leader then probed in detail each explanation that was offered in order to understand how that factor might affect people's well being, and to explore the speaker's own experience, as well as the views and experiences of the other members of the focus group. For example, if a participant suggested that poor eating habits cause disparities in cardiovascular disease, the leader would probe further to understand perceptions about why people eat poorly, whether participants have tried to change their eating habits and what barriers they have encountered, where participants get their information about healthy eating, and what might be done to help people in the community improve their eating habits.

With the consent of the participants, all of the focus groups were video and audio taped. Each tape was reviewed and extensive verbatim notes were taken by at least two researchers, who independently coded the materials to facilitate analysis. In addition, every tape was reviewed and themes were identified by two community leaders who served both as partners in the coalition and as members of the research team. Using a reviewing guide, for each tape the reviewers identified between five and ten major themes or observations with supporting examples, and made suggestions for additional areas to be probed in the future. The research team also viewed and discussed portions of the tapes at three meetings.

Participants identified three categories of issues that they believe contribute to racial and ethnic disparities in morbidity and mortality: (1) stress, resulting from low socioeconomic status, racism, poverty, crime; (2) unhealthy behavior, resulting from lack of information, resignation, lack of available or affordable resources, competing priorities; and (3) an inadequate and unresponsive health care system. All of the focus group findings have played a part in shaping the coalition's ambitious

agenda, which includes a nutrition and fitness program, a faith-based outreach initiative, a training program for community health advocates, and a public education campaign. Reflecting the coalition's needs and priorities, we focus here primarily on the third issue: how people perceive and interact with the health care system. The focus group findings related to this theme were particularly useful to the coalition's development of its nascent programs and policy agenda for increasing health care access and improving the quality of care in the community. (Programs designed to address health behaviors and to provide support for disease management were already underway.) Moreover, the members of the research team felt that the findings about interactions with the health care system offered a new and personal perspective that warranted attention and analysis.

Results

Trust. A growing body of research has begun to explore the dimensions and predictors of trust in the patient-doctor relationship, and its impact on the use of preventive services, treatment adherence, continuity of care, and other patient behaviors and attitudes.^{14, 15, 16} Although findings concerning the impact of race and ethnicity on trust have been inconsistent, several studies have documented distrust of the health care system among African Americans,¹⁷ which has been explored in greatest depth in the context of the legacy of the Tuskegee Syphilis Study and the reluctance of minority populations to participate in clinical research trials.¹⁸ In addition, several surveys have found that a significant percentage of African Americans and Hispanics believe that they receive lower quality health care than White patients, and are treated with less respect by their physicians.¹⁹

In our focus groups, distrust and fear of the health care system were pervasive and strongly voiced themes. Many people felt that their complaints were not taken seriously; others did not trust the diagnosis they received. For example, one man described how he went to an emergency department after being hit by a car. Although he was x-rayed, he was incredulous that they found nothing wrong with him: "I'm not made of steel. There's gotta be something wrong... Never got a cast or a splint; they told me nothing's torn, nothing's fractured. I didn't get proper care... I was neglected by those I trusted."

Several people suspected that their doctors were incompetent, and that the qualified doctors leave the South Bronx for more lucrative parts of the City once they are trained. One woman noted that her doctor "looks at the books on my time... You were supposed to do that in school... Let me get somebody who knows what they are doing! If you can't do your job, get out of the field."

Many felt that because of their race or ethnicity they were given second-class care. One woman expressed her experience this way: "Going to the doctor is traumatic. I don't trust any of them... They don't care; they really don't care... You're a person of color... your existence is unimportant." Another observed that when a Black man and a White man have the same symptoms, "They send the Black man home and put the White guy in the hospital for observation." Discussing access to prescription medicine, one man commented, "Not trying to say nothing about the White race, they try to take care of themselves the best way, give them the best things... Hispanics and Blacks get mistreated wrong because Whites get the best and we don't get the best."

In several of the focus groups, people expressed the fear that they were being experimented on, often describing themselves as “guinea pigs.” This fear was a manifestation of a deep and broad distrust that extended well beyond the health care delivery system. The participants observed within their community an array of social, political, and economic structures that they believed contribute, both directly and indirectly, to poor health outcomes.^{20,21} For example, several participants were suspicious of consumer products and foods marketed in poor, minority neighborhoods that could not be found elsewhere. One man speculated that “all these experimental things that are put into our neighborhoods...[cause] kids in our neighborhoods grow up at eight or nine years old—girls with breasts and pubic hairs and boys with masculine voice and facial hair.” Many believed that their health and the health of their children was in jeopardy at least in part because of malevolent forces beyond their control.

Communication. The lack of trust of the health care system was exacerbated by poor communication between patient and physician. Many of the focus group participants felt that their doctors did not have time to answer questions or made no effort to communicate. One woman explained, “I didn’t feel I was being told anything. I don’t think any doctor should just give you some pills and not explain why you are taking them, or what they’re supposed to do or what you are supposed to do.” Another woman described going to the doctor for a physical examination: “They don’t tell you what tests they are doing, so you don’t know what they are testing or if you have something.”

Many participants commented that they found it difficult to understand their doctors. One woman, concerned about a family history of diabetes, described herself as confused. “I’ve been to several doctors and asked about diabetes and they all give me different answers or give answers I don’t understand. I don’t have a Ph.D.! I don’t get no straight answers...They talk these big ‘ol words to me and I’ll be like – what does that mean?!” A man agreed, “You end up more confused than when you went in.” Several participants blamed their lack of understanding on their own low educational levels. For some, this was a source of shame. For example, when the focus group leaders probed about what educational techniques might work, one African American man responded, “Did you ever hear the expression, ‘If you don’t want a Black man to know something, put it in a book?’”

Those who trusted the care they received often emphasized the importance of communication, having things explained clearly and in detail and being listened to. One man explained, “I trust my doctor one hundred percent. I really have a lot of faith in this guy. Whatever he recommends, I am with it...He takes the time to explain every little thing...My doctor kind of motivated me by giving me the information I needed and getting on my case, which made me a little more active and concerned about taking care.” One woman, who had been with the same doctor for five years, said, “When I talk to my doctor, she listens. Some doctors – you tell them and they’re quick to write a prescription. Don’t get the full effect... ‘Well how you feeling?’ ‘Let me see what’s aching you.’”

Participants in every group worried about their lack of knowledge of their own conditions or of family risk factors. Although the vast majority of participants had relatives with chronic diseases (particularly prevalent were diabetes and

cardiovascular disease) and were themselves therefore at risk, many felt uninformed about prevention, recognition of symptoms, and disease management. On several occasions, what people said they knew was incorrect. For example, several participants expressed the conviction, explained this way by one, “Diabetes skips a generation... If your mom has it then your child will get it... It’s a proven fact.”

For many, truly communicating meant understanding the role of traditional medicine and incorporating religious beliefs into their care. One woman suggested, “Doctors should talk to their patients so they can understand how to take care of themselves – not always through medicine... They should combine with traditional herbs and roots and incorporate herbal healing—roots, molasses, red onion, sassafras.” Another woman explained that her culture values the information and advice handed down by grandparents and she suggested, “My Jewish doctor needs to know that his grandmother gave him stuff that he believes in too!”

Respect. In every group, participants described feeling undervalued and disrespected by the health care system. Many recounted stories of humiliating encounters, which they attributed to racial, economic, or other prejudices or stereotypes. One woman began to weep when she recounted how because she was “Black and on Medicaid,” she wasn’t given a gurney to go to the operating room. She said she felt like she was going to “the gallows.” One young man described going to the emergency department when he got stabbed: “They looked at me as a stereotype... All they saw was a Black gang member... I needed stitches, but they didn’t stitch me up. All they did was put the gauze on and tell me I could leave. They didn’t call anyone for me; they just needed the bed.” Several participants felt that they were treated with disrespect because they were young, minority women. As one woman explained, “If you’re Mrs. So-and-so, it makes a difference.” Many felt stigmatized or mistreated because they were uninsured or on Medicaid, or because people assumed that they were: “If you are Black, they assume you have no insurance.”

In every group, people emphasized the importance of staff attitude and demeanor. One woman, who was very pleased with the clinic she attended, explained, “When I go to the doctor, I feel like a little pussycat. I get treated with care... The girl at the front desk, she treats you nice; she always has a smiling face... They play with my baby so nicely.” But, more commonly, participants complained about the disrespect with which they were treated by administrative and clerical staff: administrators “hidden behind high desks who refuse to look up,” “workers just chatting with each other,” being left “like I was nothing” and “attitude.”

Race, ethnicity, and class status played important and complex roles in patients’ interaction with staff. In all of the focus groups, people identified multiple and overlapping fault lines between themselves and clinic or hospital staff: Spanish-speaking/English-speaking; Black/White; Caribbean American/U.S.-born African American; Puerto Rican/Central American. Many Spanish-speakers felt that they were treated with disrespect by English-speaking clerical staff. One woman recounted being told by a receptionist, “You’re in America. We don’t speak Spanish here.” Several African American participants spoke of feeling excluded or disrespected by Spanish-speaking employees: “Spanish people make you feel like you are nobody. They take Spanish people first.”

Many found it particularly painful to be mistreated by people of their own race or ethnicity. As one man explained, “You expect to be treated differently – you expect to be treated better by your own.” One African American man commented, “Lots of times when I go to the hospital, I don’t like to deal with my own race because they be the main ones with the attitude.” Some attributed this to an arrogance that comes with economic advancement: “You can take a person and give them a little economic opportunity, give them a job and they can take care of themselves now...and they step on the person that is under them now.” As a result, one person explained, they have no respect for Black patients: “They assume when they see your Black face that you are on something that won’t pay their salary.”

Others attributed this disrespectful behavior to the stress that the workers themselves are under: “They’re already all stressed out, most often especially the minorities...When they come to the job...they get mistreated by other workers...So that when the customers, the patients come in, they like ‘Who is that? None of you is paying me nothing!’”

Participants universally complained about the stress and sense of disrespect they felt from long waiting times and the “clinic-type atmosphere” with “one hundred people that have gone in front of you and one hundred people waiting behind you,” “all of us cramped in one place.” One participant characterized this as “ghetto care.” Another described it as “take a number.” One woman said, “It enlarges the heart” to sit there so angry. Another woman, who said she had waited four hours for her appointment, described feeling like an “abandoned dog.” Many said that long waiting times were a strong disincentive to seeking care. In one focus group, many participants agreed with a woman who recounted why her husband refused to go to the hospital: “He will not wait four hours to be seen, even if he is dying!”

For many, disrespect was evident in the short amount of time that doctors spent with them and their sense of being rushed through the encounter. Indeed, in one focus group when several people praised the care they had received in Manhattan, no one talked about the physical plant or amenities. As in other studies, these patients viewed amenities as quite distinct from quality of care.²² Instead, they referred to shorter waiting times and not feeling rushed by the doctor. One woman gave a typical example of using a “Park Avenue dentist” when she had private insurance. “The service was so lovely,” she said. She wasn’t rushed and the doctor expressed concern with how she was feeling.

Self-advocacy. Many of the participants, almost all of whom were women, emphasized the importance of advocacy to assure that they or their family members were receiving high quality care and attention, and that their rights were not being infringed upon. Those most satisfied with their care were often the strongest proponents of this view and, not surprisingly, were the most vocal participants in the discussion. Many described the strategies they used. One woman with eight children described her active involvement in their care: “If you are going to look in my daughter’s mouth, I’m gonna look too. If I see something you don’t see, I’m gonna ask you how come you don’t see that white growth over there? That’s how I am.” Another described how she tested the system.¹⁵ She did not mention her daughter’s “sleepy eye” to the doctor, but waited to see if he noticed it: “This is how I tell that

you're really looking at my baby." One woman said bluntly, "I make it my business to be noticed; I make it my business to be a pain in the ass [at my clinic]." When she brings in a sick child, she makes it clear that she expects to be seen right away: "They know if they don't take care of her now, I'm gonna pull the roof off."

Those who espoused the importance of self-advocacy admonished others in the group in very strong terms. One woman said of mistreatment or inadequate care, "As individuals, you don't have to stand for that. That's why you have rights. You don't have to settle." She challenged the others: "You deserve better...People only do what you let them do." Later she said, "Whites are in control, but not as much as they were years ago. How you let people treat you is what you get treated." Another woman advised, "You've got to make noise...There is a chain of command and if you don't know it, they will treat you any way they want. You'd better find out."

But many others did not feel comfortable advocating for themselves. Some were simply resigned to the inequities and inadequacies of the system. As one man put it, "If you ain't got money, you just got to have patience because places is overcrowded... You've got to have money. That's the bottom line. You got to brace yourself to that." Others felt that by asserting their rights, they were playing into the stereotype of minorities as troublemakers: "By making a bad impression, people react badly. That's why we get treated the way we get treated...People want to see Black people act like fools."

With few exceptions, the men in the groups were more reluctant than the women to complain or to intervene to assure that their care was adequate. Many felt awkward, incompetent, and exposed in these encounters. Several described their sense of pent up frustration and anger, and worried that this rage, once unleashed, would cause them to "go off," confirming the view that "Black people look crazy and act crazy." One young man went further, describing the effort that goes into making it through the day: "It applies to hospitals; it applies to everyday living. All these pressures that we have build up... Everybody ain't seen all the hard steps, all the bullet wounds, all the hard stuff people got to get through just to show their face proper to meet the level they expect you to be at... So when you fall a little bit short of that level, you get knocked down and you be scared to speak up half the time because if you do, you might take it too far...and then you get in trouble."

Many of these participants described taking a more backdoor approach to making sure their needs were met. Often this entailed "inappropriate" utilization of the health care system. One woman described how when she goes to the emergency department, "I tell them I have chest pains. I lie so that I can get seen quicker." Another woman said that she avoided waiting "all day" in the hospital by going to the emergency department "in the wee morning when nobody is there."

Discussion

Underlying the focus group participants' perceptions of and interaction with the health care system was a pervasive feeling of being devalued. This sense, what one young man described as the "raw deal" of racism, extended well beyond their attempts to access the health care system to many parts of their lives: poor housing, unemployment, lack of community resources, the poor quality of food available in

the neighborhood, crime, tensions with the police. The people with whom we spoke intuitively knew what the research shows:²³ that the resulting stress, fear, anger, and sense of defeat directly affect health (e.g., leading to cardiovascular disease), health behaviors (e.g., smoking, drinking, substance abuse, overeating), and how one perceives and utilizes the health care system.

While these views ought not to be surprising, the participants expressed sentiments, some of them chilling, that are not often captured in response to survey questionnaires. Surveys have found fairly high levels of satisfaction and trust of health care providers among Black and Hispanic patients, although these levels are generally lower than that of White patients.^{14, 18, 24, 25, 26, 27} Similarly, in our own door-to-door survey, which was undertaken by community residents trained as surveyors, only 7% of the respondents said that they had “felt uncomfortable or had been treated badly in their experiences getting health care in the past year.”⁸

Why then did the focus group participants express such a pervasive and high degree of mistrust and such a strong sense of being devalued? As one member of the coalition put it, why was “the volume was turned up much higher than any of us expected”?

We do not believe that our findings can be explained by a bias in the focus group sample. Participants were recruited in community-based settings, often as part of or following a class or gathering that was unrelated to health, community organizing, or advocacy. Although it is possible that this recruitment strategy may have resulted in a group of participants who were more likely to be connected to community organizations and less socially isolated than other residents, they were no more likely to be particularly sensitive about or to be disgruntled by the health care system.

As other researchers have pointed out, reconciling different results from different research methodologies is a challenge for many community-based research efforts, which often collect data using multiple methodologies, thereby increasing the likelihood that findings will differ.²⁸ As our community surveyors noted, there is a great deal of wariness in the South Bronx about surveys or forms of any kind. Several commented that people would be reticent about expressing their concerns or dissatisfaction, particularly about an issue potentially touching on race, unless they were in a setting in which they felt free to do so.⁸ The focus groups, in which people learned about and were asked directly to discuss racial and ethnic disparities in health outcomes, provided such a setting. This framing of the topic opened the door to a critique of the health care system, and may have changed the definition of what constituted a socially acceptable answer.²⁹ Thus, although our findings are not generalizable, because of our community-based sampling and the richness of the data we collected, we believe that these insights are relevant across a broad spectrum of circumstances and settings. What then is the obligation of the health care system to respond to this highly complex and sensitive societal problem?

First, those of us who work in the health care industry, whether as managers, providers, support staff, or researchers, must reflect on its history and current practices. Certainly, the shameful history of racism in health care has been well documented. We saw many instances of how that history has cast its shadow over the views of the residents of the South Bronx, heightening their suspicions and

sensitivity. A physician consulting a book in his Park Avenue office might be seen as scholarly. In the South Bronx, the same action was seen as a sign of incompetence and a confirmation that the care was second-class.

But, to some extent, these suspicions of differences in care are grounded in reality. Researchers have documented racial differences in diagnosis, rates of surgical procedures, and medical management of many conditions.^{1, 29, 30, 31, 32, 33} Moreover, it is hard to imagine that patients will begin to trust the health care system until the system begins to address some of the structural issues that undermine trust, such as the existence of separate systems of care depending upon insurance status, which in many urban areas correlates with race and ethnicity. In the view of our focus group participants, disparities in health status are sustained and amplified by inequalities that persist in the health care delivery system.

Second, we must recognize that respect is an important aspect of health care quality, and one that patients hold paramount.²² Fostering patient trust requires attention to many relationships, both interpersonal and institutional: to the relationship and quality of communication between the physician and the patient, to the patient's interactions with non-clinical staff, and to the unspoken message sent by how care is structured (for example, waiting times, the atmosphere in the waiting room, time with the doctor). Part of the Bronx Health REACH Coalition's work is aimed at getting community groups and health care providers to agree upon and monitor a set of standards for respectful and responsive care. What we heard from focus group participants is that an important component of this effort is training administrative and clerical staff to understand their importance in this equation, and training physicians in communication skills. Such efforts must be supported, documented and, when successful, replicated.

To create a truly responsive health care system will require us to rethink some of its fundamentals, for example, to broaden our definition of care to include the receptionist's greeting of a patient and a workshop for patients on self-advocacy skills. Standards of care must extend beyond accessibility, clinical quality, and convenience to deal directly with issues of trust and dignity. Until we begin to recognize the extent of these problems and tackle them honestly and head on, we will not begin to live up to the standard articulated by one focus group participant:

Treat us as human beings; treat us with love... Whether you're a doctor or whether you are a lawyer, or whether you are an ordinary person—that person next to you is you. The man sitting on the street is your father; it's your brother. It's you!... You have to teach children so that the person filling out the application in the hospital sees you as her family. This is where it begins; then it goes to the nurses and doctors. In health care, we have to start looking at each other as human beings.

Acknowledgments

This study was funded by the Centers for Disease Control and Prevention as part of the REACH 2010 initiative. The authors would like to thank Kelly Ann Burke, Spring Gombe, Eugenia Acuna, Shaun Belle, Lloyd Dawkins, Doxene Roberts, and Michael Yedidia for their invaluable contributions to this work. We also thank the

focus group participants for sharing their insights, and the members of the Bronx Health REACH Coalition for turning those insights into a plan of action to make health equality a reality.

Notes

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