Navigating the Health Care System: A View from the Urban Medically Underserved

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ABSTRACT

Objective: The purpose of this project was to discover areas identified by minority and underserved patients that lead to dissatisfaction with the health care system and specific areas identified as barriers to health.

Methods: Six focus groups (n=25) were conducted, with participants including mostly poor African-American adults with and without a primary care home, in addition to 1 group of community dwelling mentally ill patients, and 1 group of case managers for community dwelling mentally ill patients who navigate the health care system for their clients. Qualitative analysis by 3 authors identified themes emerging from the focus groups.

Results: The following themes were identified: (1) difficulty with insurance, including coverage, accessibility, stability, and choices; (2) socioeconomic, more than racial, barriers to care; (3) a misunderstanding or lack of information about the health care system and a lack of health literacy; and (4) lack of personal accountability for health and health care.

Discussion: Patients with access to a primary care home seemed more satisfied with the health care system. An increase in health literacy education and simplification of insurance policies and procedures could increase satisfaction and possibly improve outcomes for underserved patients. Providing preventive care and improving patient accountability for personal health may also improve satisfaction and outcomes.

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INTRODUCTION

In recent years, health care disparities of minority patients have been well documented. The 2002 Institute of Medicine report on health care disparities reviewed over 100 studies of health outcomes focusing on quality of health care for various minority populations.[1] This report concluded that not only decreased access to care affects health outcomes, but also—even when controlling for variables such as income, access, and socioeconomic status—people of color have less interventions and overall poorer health outcomes than white Americans.[1] It is not easy, however, to differentiate the multiple factors that likely contribute to the differences in health outcomes for minority patients, including genetic factors, access to care, socioeconomic factors, and physician bias and prejudice (conscious or unconscious). Specifically in Milwaukee, there are multiple markers of disparities, including a significant difference in AIDS incidence by race.[2] Only by finding the causes of disparities can Wisconsin achieve its goal of ending health disparities by 2010.[3]

Academic health centers have traditionally had a large population of underserved patients, providing a unique opportunity to assess needs and address disparities when they are found. Yet much of the available research to date has focused on proving that disparities exist; limited research asks the important question of *why* they exist.[4] To address the reasons health care disparities exist, and therefore try to find solutions for these disparities, it is important to ask the people most affected by them. Focus groups are a useful tool for evaluating perceptions of health care disparities and patients' experiences in the health care system.[5-6] Focus groups may be especially well suited for minority populations since they provide a non-judgmental outlet for people to voice opinions and frustrations in a peer-group setting.[5]

For this study, focus groups mainly consisted of patients from a primary care clinic in urban Milwaukee, Wis, but also included members of the surrounding

community, and case workers for the mentally ill. The goal was to explore the perceptions and experiences within a specific group of medically underserved individuals. Specific objectives included exploring perceptions about personal health, experiences within the health care system including feelings of being treated unfairly, comfort levels with physicians, and barriers to appropriate health care.

The Family Care Center (FCC), located in urban Milwaukee, serves a primarily African American population (80%). The majority of patients are women (61%). The clinic serves a medically underserved population with 47% possessing Title 19 insurance, 12.9% Medicare, and 21.3% commercial insurance. In 1999, the ZIP code that includes the FCC had a median household income of $13,140 compared to $45,901 in the metro area, with 47% of residents below poverty level and only 67.8% of those graduated high school (versus 84.5% in the metro area).[7] Moreover, according to the US Census Bureau, the area qualifies as a Health Professional Shortage Area (HPSA).[8]

METHODS

Six focus groups were conducted in the fall of 2007, with 4 groups consisting of patients from the FCC. Demographics from the focus group can be found in Table 1. Patients belonging to an ethnic minority group who had public health insurance and were over the age of 18 were eligible. The patient's physician invited the patient to participate during a regular clinic visit. Recruitment took place for a period of 3 months. If a patient was interested, he or she provided a name and phone number and was called later by a member of the research team to set up an appropriate meeting time. Additional participants were recruited from a local church and the neighborhood outside the clinic. One focus group consisted only of community dwelling mentally ill patients who were also patients at FCC. These participants were recommended by their physician and/or case manager and were personally invited. The final group consisted of case managers who navigate the health care system for mentally ill clients. The focus groups were asked the same questions (Table 2), but the questions were modified slightly for the case managers so the responses given were about the participants' experiences with their clients instead of their personal experiences in the health care system.

Approval for the focus groups was obtained from the Aurora Health Care Institutional Review Board. Each participant completed a concise demographic survey and was assigned a pseudonym to mask his or her identity during the discussion. Demographic data was collected on the 25 participants who were community dwelling and/or patients; however, demographic data was not collected from case managers since their clients were the subjects being assessed. Participants received an incentive of $25 for their participation. An African American moderator facilitated all but 1 of the focus group discussions, while 2 interviewers who were white and Asian Indian observed participants and recorded notes. One group was facilitated by a white moderator. All interviewers have a background in qualitative research, and none are employees of the FCC.

The focus groups were audio taped and transcribed. Three researchers independently read, searched, and compared themes to reach a consensus. An expert consultant then coded the transcripts with the identified themes using Ethnograph v5.0 software.

RESULTS

Of the 25 non-case worker participants, 96% were African American, 52% had a chronic illness, and 78% were unemployed.

The following themes were identified from the transcripts: (1) difficulty with insurance, including coverage, accessibility, stability, and choices; (2) socioeconomic and racial factors; (3) misunderstanding of the health care system and a lack of health literacy; (4) lack of personal accountability for health and health care. A summary of supporting comments from the questions is found below, and supporting quotes are in Table 3.

Present State of Health

Participants noted that jobs, insurance, "the system," stress, and unhealthy lifestyle (including exercise and diet) affected their present state of health. The most frequently noted factor was family history. Even when probed by the moderator during 1 discussion whether unhealthy lifestyle contributed to their present state of health, participants said that family history was still the key contributor to overall health. In contrast, the group of case managers noted that affordable and safe housing, stress, income, personal habits, and the environment were the main contributors to personal health.

Treatment by the Health Care System

Participants were asked whether they or a friend have ever been treated unfairly by the health care system. When asked specifically whether they thought their race affected the way they were treated by the health care system, participants noted that "it's got nothing to do with race," and, "there is no racism at all unless you don't have that insurance."

Table 1. Self-reported Demographics Compiled from Focus Group Participants

Participant Characteristic	Focus Group
Age	
18-25	17.4%
26-35	13%
36-45	21.7%
46-55	21.7%
56-65	17.4%
>65	4.3%
Gender	
Male	30.4%
Female	69.5%
Race	
African American	95.6%
Latino/Hispanic	4.3%
Employed	
Yes	21.7%
No	78.2%
Household Income	
<$10,000	60%
$10,001-25,000	30%
$25,001-40,000	5%
$40,001-55,000	5%
Chronic Illness	
Yes	56.5%
No	43.5%

Participants expressed their frustrations with insurance coverage and the lack of choices when it comes to which doctors they can see. Participants also noted long wait times and "bad attitudes" by the clinic staff and insurance companies.

The case managers noted that their clients "definitely receive different care" than they do. They noted they have shorter wait times and receive better care and attitudes from the health care professionals than their mentally ill clients receive. The case managers, however, acknowledged it was difficult to pinpoint whether the differences were because of health insurance, mental illness, or race.

Comfort with Doctors
When subjects were asked how comfortable they felt asking questions of their doctors, most participants answered that they were very comfortable. Females and those with a regular doctor appeared to be more comfortable asking questions. Moreover, many female participants pointed out that overall they were more comfortable with a female professional.

Participants without a regular doctor were not comfortable asking their doctors questions. In fact, 1 person

currently without a medical home pointed out that he was afraid to ask questions in case it looked like he didn't trust the doctor enough.

Participants noted that they didn't have the freedom to change doctors if they weren't comfortable with the one they had due to insurance limitations. Even participants without a current physician spoke of the "old time doctors" that would take care of you even if you didn't have insurance. Many participants stated that having 1 doctor who was available when needed to answer questions and who knew them well was what determined how comfortable they were with the care they were receiving.

Barriers to Care
When asked about what barriers stand in the way of getting the best care, the overwhelming answers were money and insurance. Community action, not coming together to make changes and demand care, was also mentioned. The group of case managers pointed out that stigma about mental illness and a lack of understanding on the part of many health care professionals were often barriers specific to their clients; they also recognized the lack of money to get affordable, safe housing and to pay for quality food and healthy lifestyle choices as a barrier to health. One group mentioned customer service on the part of the medical and insurance communities as a barrier. Another group acknowledged race and socioeconomic status as a barrier, as well as the difficulty obtaining insurance and how complicated it was to try to use it. One participant even pointed out that his solution to avoid bills for needed medical care was to give a false name and address so the billing department couldn't track him.

When asked what participants would change about our health care system, the most noted answer was insurance coverage including providing coverage for everyone, covering more of the costs like transportation and medications, and being allowed to choose your own physician no matter the insurance coverage. One group pointed out that the government is spending money in other countries before taking care of its own citizens' health care. One participant thought it would be a good idea for insurance companies and government to not interfere with physicians' decisions; eg, stop telling doctors what they could and could not provide for their patients.

DISCUSSION

There is no easy answer to the problem of health disparities. Asking questions of people who are at higher risk for adverse health outcomes is 1 way of determining areas to focus on in an attempt to eliminate disparities. Many important lessons were learned from these

Table 2. Focus Group Questions

1. Think about your present state of health. What do you think affects this most? For instance: family history or health habits (like eating and exercise), your surroundings (like your home and neighborhood), or the health care system (insurance, doctors, etc).

2. Have you or a friend ever felt you were treated unfairly by the health care system (the term health care system includes hospitals, clinics, insurance companies, etc) or a provider of health care? If so, how?

3. Think about all the times you've been to a hospital or seen a doctor. Have you or anyone you know ever felt like they didn't get the same care or as good of care as someone else by any doctor or hospital? Why do you think so? Do you think it has to do with your race?

4. Now think about your current doctor. How well do you think your current doctor responds to your needs? Do you feel like you have the option to change doctors if you don't feel your needs are being met?

6. How comfortable are you asking questions of health care people when it pertains to your own health?

7. What do you think are the biggest barriers or things that stand in your way for you and members of your community to get the best health care?

8. Today we've talked a lot about your health care and the health care system. If you could change 1 thing about your health care (the doctors, nurses, insurance, hospitals, etc.) what would it be?

9. Is there anything else you'd like to share that we didn't discuss yet?

focus groups as outlined in the identified themes. The first 2 themes identified are certainly related, however the authors of this study felt there was enough concern about insurance issues to warrant separating them.

Difficulty with Insurance Coverage, Accessibility, Stability, and Choices

An overwhelming number of participants who had a current doctor felt very comfortable asking questions and felt they had the ability to change doctors if needed. In fact, it seemed that it was more difficult for patients to stay with a single doctor they knew and trusted than it was to switch providers. The measure of quality of a doctor in this study seemed to be availability. Most participants desired to keep a relationship with their physician and were frustrated with the fact that insurance companies seemed to have control over who they were able to see. It was mentioned by the group of case managers that there is a very limited number of physicians who will accept their clients, and this becomes a big challenge in providing quality care. There was a striking difference between the groups that had a medical home and those without access; patients without access spoke of a lack of trust and frustration with the health care system. Many of them were uncomfortable asking questions of physicians.

Participants who had no current insurance or regular doctor also noted how hard it was to obtain insurance if you had no dependents. Without insurance there is very limited meaningful access to care; many participants were relying on free clinics or even deception to try to obtain care. Some very troubling findings were the ways people had to "beat the system." When care is needed, participants talked about using fake names or going to different hospitals to avoid being stuck with a bill since they didn't have insurance. Another participant stated that even now that she has insurance she is afraid to go to the doctor because of a previous bill she received after obtaining emergency services years ago. These results are of concern because they impact the quality of care patients are able to receive since without accurate contact information, hospital staff lose the ability to do follow up or provide ongoing services.

There were also insightful comments into the community impact of this dilemma, including the increased stress that can lead to crime within the community and the lack of commitment to change because people are unwilling to risk losing what little they have. Increasing accessibility to insurance and simplifying the process of obtaining and utilizing it might relieve some patient frustration; unfortunately, there is no easy answer to increasing coverage.

Socioeconomic and Racial Factors

One of the more interesting results was the focus on quality of service and access to care when participants were asked about unfair treatment. Most discussions focused around wait times or attitudes of health care professionals. The majority of groups were asked directly if they felt their race changed the treatment they received; very rarely was the answer yes. There have been studies that still show a racial bias in health outcomes after controlling for socioeconomic status and insurance, but that wasn't sensed by the majority of participants in our groups. There was no observed difference between people who reported having a chronic illness and those who did not, although this was hard to track due to difficulties with the recording methodology. No direct measures of

Table 3. Pertinent Quotes from Focus Group Participants, Divided by Topic and Theme

Present State of Health

Theme 3: Misunderstanding of the health care system and a lack of health literacy
"Family history and the system… They don't, to me they don't check everything they should. They check you through changes, they try different medications, but instead of looking to see what is really … the problem just besides your family history, you know."

Theme 4: Lack of personal accountability for health and health care
"My family history has a lot of like sicknesses and diabetes, high blood pressure, hypertension, stuff like that. It's in my genes."

Unfair Treatment by the Health Care System

Theme 1: Difficulty with insurance coverage, accessibility, stability, and choices
"…some people will take time to make sure that they hit every area of a medical experience to find out if this is what your diagnosis is, but some people, they just push you right along … as soon as you say you got no insurance, that's it."

Comfort with Doctors

Theme 1: Difficulty with insurance coverage, accessibility, stability, and choices
"I be scared to ask them cause I figure they know their job. And I be scared to think they think I'm telling them how to do their job. ...if you're an auto mechanic, how would you feel if I'm telling you how to fix this car?"

"I feel my doctor is real good. I like her, and I feel I can change [doctors] quick, too."

Barriers to Care

"I think the biggest barrier would be that on the part of the concern of the people that are waiting on you is, um, if they don't care about the health care that you get, then you wouldn't get any good health care. So that to me would be your biggest barrier is how the people that you're going to treat you. It doesn't have anything to do with you. I mean, you're going for service. If the service is lousy, it has to do with the people that are giving the service, so the biggest barrier is finding good service and staying with that…"

Theme 1: Difficulty with insurance coverage, accessibility, stability, and choices
"I give 'em fake names…Everytime I ever been to [a certain hospital] for anything I give 'em a bogus name, a bogus social security number…"

Theme 2: Socioeconomic and racial factors
"Money, money, money."

Theme 3: Misunderstanding of the health care system and a lack of health literacy
"…I don't know where to pinpoint it, either on the doctor itself or my insurance company, you know, 'cause if the doctor can't cover it through my insurance then I never get it. You know, so either/or, one of them."

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health status were used in this study, only self-reports of frequency of doctor visits.

Although there were isolated events that were identified as racially motivated, participants generally did not feel race was a factor in their treatment in the health care system. One participant pointed out he couldn't tell if there was a difference without knowing how others were treated. Even the group of case managers discussed the difference between treatment of their clients and themselves by referring to the type of insurance or mental illness, not to race or ethnicity. Although many studies have shown there are racial health care disparities that are independent of insurance or socioeconomic status, this type of perception would lead one to believe these inequalities are buried beneath the surface of day-to-day interactions within the health care system.

Misunderstanding of the Health Care System and a Lack of Health Literacy

The lack of health literacy and understanding of the insurance and health care system was striking, even by those who had regular access to it. Participants were often uncertain who to blame for the problems they were having with obtaining care. Doctor's offices seemed to have little respect or understanding of the challenges facing patients in regard to arriving on time for appointments without reliable transportation. Physicians seemed to have little insight into the realistic role that a case manager plays in the life of a patient, or what could be expected in terms of compliance with time-consuming or confusing recommendation for a patient with a mental illness. Participants, including the case managers, noted that insurance companies are, at best, challenging to get ahold of, and provide little explanation or warning as to how they work or why things change as they often do.

Lack of Personal Accountability for Health and Health Care

Participants seemed to feel a sense of helplessness when it came to personal health. There was a distinct sense of a lack of opportunity to affect one's own health. Reasons given included family history of health problems, a lack of access to insurance, and an inability to afford medications even with insurance. In fact, participants often cited family history as the key contributor to overall health. Very few people mentioned what they could do to affect their own health in a positive way. Whether this was due to lack of knowledge when it

comes to personal health habits like diet and exercise or whether our questions didn't allow the opportunity to discuss the issue is uncertain.

Limitations

There were some limitations worth mentioning in this study. First, 1 group was not recorded due to equipment malfunction; in this case we relied on notes only for our summaries and were not able to use direct quotations from that group. Second, although our facilitator was African American, our observers were not. This may have affected the comfort level of some patients to speak openly about race. In addition, 1 group was facilitated by 1 of the observers due to a scheduling conflict. No significant difference in themes or answers was noted in that group when compared to the others.

In the first focus group, participants were not specifically asked if race was a factor in their treatment by the health care system. This question was modified in the second group and all subsequent groups to include a specific question about race as this was felt to be more appropriate. Due to poor recordings and a lack of strict use of pseudonyms prior to speaking, we were unable to link demographic data to people's direct quotes. For future projects, it would be interesting to see if there would be a difference in themes based on experiences within the health care system, socioeconomic status, or overall health status.

As with most qualitative research, we also had a sample bias. The majority of participants were patients at a single clinic, which somewhat limits the ability to generalize findings. However, the 1 group of non-clinic patients and the group of case managers did not show any significant differences in themes identified.

CONCLUSION

The lessons learned from our focus group participants provide interesting perspectives on health care in Milwaukee. Surprisingly, there was very little mention of racial biases, although many people did have isolated stories. The overwhelming theme, however, was focused on the complexity of our current system and the difficulties with obtaining and maintaining access to care and to a physician who is trusted. Even possessing insurance does not guarantee coverage, as many of our participants pointed out. It is interesting to note that people found a way to bypass the system while still obtaining care by using fake names. This is disturbing to many of us in medicine not only as a symptom of a real problem within our system but in terms of direct patient care: there is no way to provide follow-up information to someone if you don't have any real contact information.

These findings are similar to the results of the Institute of Medicine 2002 report on racial and ethnic health care disparities. The report notes 1 factor that contributes to disparities is the operation of health care systems and the legal and regulatory climate in which they exist.[1] When a system is so complex that even the people working within it find it challenging and confusing, it is logical that the people trying to use the services will find difficulties, and hence, find shortcuts to obtain needed services.

In the future, it would be interesting to expand the groups to include populations that may have different experiences within the system; specifically, do direct comparisons of satisfaction with overall health between groups that have access to care via insurance and groups that don't, as there was a difference within our groups between people with access and people without. It would also be interesting to do listening or learning sessions about patient advocacy. Finding ways to help improve a patient's understanding of general health and lifestyle choices may also be a cost-effective and useful tool to help increase a patient's sense of control and possibly improve some health outcomes. This would require a direct measure of general health.

Many more avenues of inquiry exist, but the most important thing is to continue to ask questions, to wonder why, and to examine ourselves within the medical community to protect vulnerable populations and improve measures of health.

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