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Diverse patient perspectives on respect in healthcare: A qualitative study

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Abstract

Background.—The dominant view of respect in western bioethics focuses almost exclusively on respect for autonomy (or ‘self-rule’) as conceptualized primarily from the perspective of philosophers. We designed this study to understand, from the perspective of patients from different racial/ethnic groups, what it means for patients to be treated with respect in healthcare settings.

Methods.—We conducted focus groups with African American, Latino, and white patients in the Northwestern U.S. Focus groups were community-based and stratified by race and gender. We asked participants to describe respectful and disrespectful physician behaviors. We reviewed transcripts and coded for: 1) definitions of respect and 2) specific behaviors that convey respect or disrespect.

Results.—We conducted 26 focus groups, 5 each with African American men and women, 4 each with Latino men and women, and 4 each with white men and women. We identified two primary definitions of respect described by all three racial/ethnic groups. These were: 1) being treated like a person (“*like you’re a person not just a statistic, or another patient*”), and 2) being treated as an equal (“*treat me as an equal, like I matter*”). When exploring specific behaviors that convey respect or disrespect, there were largely similar themes identified by all or most racial/ethnic groups. These were being known as a particular individual, avoidance of stereotyping, being treated politely, honest explanations of medical issues, and how lateness is handled. There were also some differences across racial/ethnic groups. The most prominent demonstration of respect mentioned among African American participants were for physicians to hear vs. dismiss what patients say and trusting the patient’s knowledge of him/herself. The most prominent demonstration of respect discussed in the Latino focus groups was having the provider show concern by asking the questions about the patient’s clinical condition.

Conclusions: Our study found that patients have insights not included in common definitions of respect, and that deliberate inclusion of diverse participants increased the number of themes that

emerged. Understanding what makes patients from different backgrounds feel respected and disrespected, from the perspectives of patients themselves, is vital to delivering care that is truly patient-centered.

Respect is fundamental to all human interactions and especially important in healthcare, where its presence allows for some level of patient dependency without fear of mistreatment or abuse. In Western bioethics, the long-held, dominant view of respect focuses almost exclusively on respect for patient autonomy, or ‘self-rule,’ which provides the basis for informed consent and involving patients in treatment decisions.¹ More recent literature criticizes this narrow notion of respect as being too ‘American’ or individualistic, and outlines a broader ‘European’ view of respect that is focused on respect for autonomy, dignity, integrity, and vulnerability.² These differing concepts of respect are conceptualized primarily from the perspective of academics, who draw their observations about morality from different experiences than those of many patients. In medical education, teaching of communication skills offers a more practical and less esoteric operationalization of respect, yet it remains somewhat divorced from the underlying and guiding philosophical framework.

There is little empirical data on how the public (patients) might view respect in healthcare.^{3, 4} In particular, common conceptualizations of respect often do not explicitly include the perspectives of minority groups whose cultural construction of respect may differ from that of the majority. Further, members of minority groups in society are more likely to experience disrespect, and therefore may have more insight into the construct. We conducted this study to understand, from the perspective of patients from different racial/ethnic groups, what it means to be treated with respect in healthcare settings. The overarching goal of this line of research is achieving a healthcare system founded on the values of the people it serves. To reach this goal, we must understand basic moral frameworks from diverse perspectives.

Methods

Study Design, Setting, and Sample

We conducted focus groups with African American, Latino, and white patients with diabetes and/or hypertension in urban and rural communities in the Northwestern United States. The intent of including participants with either diabetes or hypertension (of any type or severity) was to ensure representation from those who are likely to have more experience with healthcare as a result of their chronic condition. Focus groups were community-based, stratified by race and gender, and facilitated by race/gender concordant moderators from the communities of the focus group participants. Focus groups with Latino patients were conducted in Spanish, and transcripts were translated into English by a bilingual, Mexican-American research assistant. The focus groups were designed to elicit patients’ perspectives on their relationships and interactions with physicians and included questions asking participants to describe physician behaviors that made them feel respected or disrespected. All study procedures were reviewed and approved by the Oregon Health & Science University Institutional Review Board, and all participants gave informed consent.

Analysis

One member of our research team (EB) first reviewed all transcripts and applied codes using NVivo software to each distinct segment of text addressing the concept of respect. Another investigator (MCB) then reviewed this preliminary set of codes and discussed them with the research team. At this stage, we refined (expanded and/or collapsed) codes and developed a final set of themes, and all three authors reviewed the themes with associated segments of text. Themes were divided into those representing ways of defining respect (describing a more general orientation or manner towards the person), and those representing specific behaviors that convey respect. Quotes were selected based on their centrality within the illustrated theme, with attention paid to representing the voices of a broad array of participants. Finally, themes that emerged were compared across groups and divided into those that were similar or different across all racial/ethnic groups. Those that were similar were mentioned with the approximate same frequency or intensity in focus groups across race/ethnicity. Those that were different were divided into (a) prominent differences, in which the theme only appeared in one of the racial/ethnic groups and/or was strikingly more prominent in one of the groups, and (b) minor differences, which arose in focus groups with one or two but not all of the racial/ethnic groups and did not represent a disproportional dominance in expression by one over the other group.

Results

Study Sample

We conducted 26 focus groups, 5 each with African American men and women, 4 each with Latino men and women, and 4 each with white men and women. Each focus group included 6 to 10 participants, with ages ranging from 21 to 90.

Overarching Definitions of Respect

We identified two primary definitions of respect described by all three racial/ethnic groups. These were 1) being treated like a person and 2) being treated as an equal. Being treated like a person was described by our study participants in many different ways. For example, one Latino participant said, *"I think that some doctors ..., they see a lot of patients, but... they just grab your chart. They don't look at people through their human side; they just see them as numbers. They say, 'Oh, this patient arrived, this patient's chart number,' and I mean, they don't really take the time to look at people."* One white participant urged doctors *"to see you as a person, not their ten-thirty."* Another white participant wanted to be treated *"like you're a person, not just a statistic or another patient,"* and another said *"Yeah, a number, a test subject, you know. Like what they do with animals; they rush them in, rush them out, and I want to be, I want to be a person."*

In terms of being treated like an equal, one Latino participant complimented a healthcare group: *"I think that, what I notice is that they treat you very educated."* A white participant urged his doctor to *"Treat me like an equal,"* and another was more critical: *"I felt as though they thought that they had knew it all and you knew nothing."* An African American participant said *"Don't talk to me like you think I'm stupid or ... talk down to me."* Another

summarized the discussion as follows: “*Basically, everybody’s saying, we just want to be treated like we matter.*”

Prominent Differences in Behaviors that Convey Respect across Racial/Ethnic Groups

There were some striking differences across racial/ethnic groups in descriptions of how physicians demonstrate respect. The two most prominent demonstrations of respect mentioned among African American participants were for physicians to hear (rather than dismiss) what patients say, and trusting the patient’s knowledge of him/herself. Representative quotes from participants are described in the Table.

Listening to what patients say was occasionally mentioned by others but far less frequently than with African American participants. For example, one African American participant said, “*I would feel better if they let me tell them what’s wrong that particular day.*” and another said “*wait and let me explain the reason why I’m there and what’s bothering me first... otherwise, you might end up giving me some stuff that I don’t need, you know, and let me tell you what’s bothering me.*” One African American participant noted, “*Even though this doctor was always kind and considerate, I just, I couldn’t get him to listen to my, um, my symptoms that I was having. And that went on for several years. And that was disrespectful.*”

A closely related theme of trusting patient’s self-knowledge did not come up in any of the focus groups with Latino or white patients but was strongly and consistently expressed by African American participants in our sample. One said, “*You know your body. When you come in, in a position of being in control, and know yourself,*” and another said, “*You can NOT tell me wasn’t nothing wrong ... I mean, I feel like that’s disrespect, you know, it’s like, you know what’s wrong with you.*”

The most prominent demonstration of respect discussed in the Latino focus groups, which did not arise in any of the white or African American focus groups, was having the provider show concern by asking questions about the patient’s clinical condition. One Latino participant said, “*Well, first of all... ask concrete questions about your problem. And basically, that’s it,*” and another said they could tell that a doctor had respect for them by “*the questions that they ask. If they ask in a serious manner, to the point about the illness that one has.*” In another focus group, a Latino participant urged doctors to, “*Ask about the medications that one’s taking, and the results about what, what you’re taking.*”

Minor Differences in Behaviors that Convey Respect across Racial/Ethnic Groups

There were three themes that arose in focus groups with one or two but not all of the racial/ethnic groups and represented what we considered to be minor differences. These were (1) honest explanations of medical issues, (2) avoidance of stereotyping, and (3) allowing patient input. Representative quotes from participants are described in the Table.

Honesty was explicitly mentioned as valuable by participants in the white and Latino focus groups. One white participant said, “*And you know, a lot of times when you’re getting the information, they’ll um, well, like we’ve all said, they’re not going to give you enough of it.*” One of the Latino patients complimented their healthcare team, “*they take time to*

explain and ... they help us to understand our problems,” and another asked that doctors “tell us the truth of what, what’s going on.”

Stereotyping in healthcare was a theme mentioned by participants in the white and African American focus groups. One African American participant said, “Well, I did, I felt like he was saying that because, I feel like a lot of...well, I won’t say a lot of, but some doctors feel like, because you’re black, you’re on drugs.” Another said, “I mean, we weren’t that type of people. We’re not all the same, you know? We don’t beat up on our kids.”

Finally, allowing patient input into the treatment choices was a theme mentioned only by the participants in the white focus groups. One said, “So, try this for three weeks, monitor your sugars. If it don’t work, insulin it is. And I respect her for the fact that she’s giving me the choices.”

Similarities in Behaviors that Convey Respect across All Racial/Ethnic Groups

There were several themes identified by all racial/ethnic groups. These were: 1) being known as a particular individual, 2) being treated politely vs. rudely, and 3) how lateness is handled. Representative quotes from participants are described in the Table. Being known as an individual was explicitly mentioned in the form of remembering the patient, calling the patient by name, and individualizing care. For example, one white participant said, “*You can also tell when a doctor’s reciting the same thing that he just said to the previous customer, too.*” An African American participant said that the doctor shows respect by “*when you walk in there, that doctor knows your name...my first name and where you work and... everything, everything about you.*”

Being treated politely vs. rudely took many specific forms in participant comments. One white participant said, “*Basically it’s the tone they use when they talk to you. It’s like, you can tell when somebody’s talking down to you instead of with you.*” An African American participant recounted the following story: “*There was, uh, a lady at the clinic, and she was, like, really... she was really big, and she just seen the doctor, and apparently she had a odor, or whatever, but it was.. her doctor and the other doctor, I heard them giggling and laughing at her.*”

Two prominent sub-themes of politeness were making eye contact and greeting/welcoming the patient. One Latino participant said, “*Above all is the gestures that when the doctor is ready to see the patient, for him to smile to see what is happening. At that time one feels very comfortable with the doctor.*” One white participant said, “*Like this one doctor that never looked at me ...I think that was a lack of respect.*” An African American participant said, “*That’s where you need to look.. Don’t be looking way up here when I’m talking to you.*”

The final theme, handling lateness, could be thought of as part of politeness but was mentioned so consistently and specifically that we have pulled it out as its own theme deserving of attention. This theme includes a sense of one’s time not being valued and a sense of being rushed. One white participant praised his doctor as follows: “*You feel like it, it gives you the idea that you’re the only patient he has.*” Another complained, “*The doctor*

that didn't spend a lot of time with me, either. Just in – out. I think that's disrespectful.” One African American participant said, *“I expect it means just, when you guys put me back in that room, just stick your head in to tell me it's going to be a minute, or something like that,”* and another said, *“it get to the point where, you know, I get so upset, I mean, that can hurt you too... because it seem like they ain't caring...about my time anymore.”* A white participant said, *“Show me a little bit of personal respect and be on time. I mean, we got to take – if we're working, we got to take off work to come see you. I mean. That kind of thing.”* And a Latino participant said, *“Get there on time. When they say you have an appointment at a certain hour, to not put you in the cubicle, and then leave you there, that really, really irritates me.”*

Discussion

We found that the American general public endorse as important several aspects of respect that go beyond the dominant ‘American’ bioethical conception of respect for autonomy. Some of these patient-endorsed features of respect are more consistent with the European bioethical consensus statement that includes respect for not only *autonomy* but also *dignity*, *integrity*, and *vulnerability*. Below we use this broader conceptualization of respect to frame our findings and map the themes derived from our focus groups to these 4 theoretical domains. This mapping is intended to be preliminary but is important to explore as a means to developing a robust theoretical underpinning for the most basic moral principle in healthcare.

Specific moral duties that fall under the construct of respect for patient *autonomy* are clearly expressed by participants in the themes of wanting honest and clear explanations, and in wanting input into treatment plans. Yet it is also worth noting that these themes did not represent the majority of what was said, nor were they mentioned in any of the comments from our African American participants. This is not to conclude that these themes are not important to African Americans, only that other issues took precedence in conversations with African American participants. Moreover, participants from all racial/ethnic groups brought up substantive themes beyond autonomy.

Respect for *dignity* is defined as acknowledgement of the intrinsic worth and equality of all human beings.⁵ Our participants endorsed the importance of dignity in the overarching definition of respect, treating people equally. The specific behaviors supportive of dignity are more elusive and require some abstraction. For example, the prominent theme among Latino patients, asking questions about medical conditions, might be interpreted as a sense of caring or investment in the value of the patient as person through concern about medical issues. But the most theoretically aligned expression of dignity from our participants was the call to treat us “like we matter.”

Integrity is defined broadly as “coherence of life in time and space”² and can also be understood as “wholeness” or “coherence” as an individual, and can be understood as narrative coherence in a person’s life.⁵ The moral requirement to respect integrity, therefore, takes the form of listening to the patient’s narrative, knowing the patient as a unique person, and for many, the avoidance of stereotyping. These themes were prominent among the racial

groups in our sample, and represent a large bulk of the specific behaviors associated with the construct of respect.

The theme of trusting patients' self-knowledge is of particular interest because of its prominence among African American participants, and because it perhaps pushes the conceptualization of respect into new territory. For example, Fricker describes 'testimonial injustice' that occurs when prejudice causes a hearer to give a deflated level of credibility to a speaker's word.⁶ The speaker is wrongfully undermined in his or her capacity as a knower, and when this 'credibility deficit' occurs as the result of identity prejudice, it is termed an 'identity-prejudicial credibility deficit.'⁶ Identity-prejudicial credibility deficits are often connected with other forms of injustice that the subject is likely to suffer throughout different dimensions of social activity – economic, educational, professional, and legal - as part of a broader pattern of social injustice.⁶ When it is persistent and systematic, it is not trivial for its subject: testimonial injustice strips people of social power. Under these circumstances, it is not surprising that African American participants emphasize the importance of health professionals respecting their own knowledge.

Vulnerability is defined as the fundamental fragility of the human condition.⁵ All persons, by this broad definition, are vulnerable and yet few want to think of themselves as such. Rendtorff argues that vulnerability has been largely misunderstood in modern society, which aims to eliminate it. Perhaps it is not surprising, then, that respect for vulnerability was not explicitly mentioned by any participants. Yet vulnerability emerges as present when viewing the corpus of participant comments as a whole – in particular, vulnerability to mistreatment. If a well-off, healthy person were asked what it means to be respected in healthcare, it is doubtful that they would start talking spontaneously about not being looked down on, categorized as a drug dealer, or treated as if they were stupid. The most privileged members of society do not often experience these forms of denigration. Importantly, however, although some people may be more or less vulnerable, respecting vulnerability involves recognizing the universality of vulnerability and not focusing specifically on 'vulnerable populations.' We are all vulnerable to something, and we are all fragile as human beings.

The question of whether there are regional, ethnic, or cultural differences in what the obligation to respect another person means, or whether such an obligation is universal, is complicated and worth specifically addressing. On the one hand, we found that deliberate inclusion of participants from three different racial/ethnic groups increased the number of themes that emerged. It should be emphasized that, although we deliberately sought racial/ethnic diversity, our study took place in a single geographical region of the United States and focused on people with a chronic condition who may have different experiences than others. A full account of respect from all possible informants from every single cultural and experiential background is beyond the scope of any single study. Yet the point here is that increasing diversity of perspectives did expand and enrich our view of respect.

On the other hand, we found that the overarching definitions of respect – treating patients like persons and treated them equally - were the same in all three racial/ethnic groups. This finding is echoed in a series of studies that looked at patient perspectives on good communication across four countries in Europe, finding that patients tend to appreciate a

core set of similar behaviors (albeit with slight differences).^{7–9} The variations we found in specific behaviors may not represent different underlying constructs, but merely differences in priorities or different takes on universal themes based on different experiences. Further, the fact that our American informants endorsed behaviors that map onto the views put forth in the European Consensus Statement suggests that the construct of respect may indeed be part of a common morality.

Finally, it is worth noting that so much of what the public reports as evidence of respect in healthcare settings is not what is explicitly thought of as important or taught in bioethics, but what is studied and taught by communication experts. Listening carefully and letting the patient know that they are heard and understood, recognizing each patient as an individual, asking questions to convey interest in the patient's medical condition, explaining things in a way that can be understood, allowing the patient input into the medical plan, greeting patients and apologizing for being late – are all behaviors that have traditionally fallen in the domain of communication skills training. These behaviors should be more explicitly grounded in the language and theoretical framework used by bioethicists in describing the concept of respect for patients as persons.

Understanding what makes patients from different backgrounds feel respected and disrespected, from the perspectives of patients themselves, is vital to delivering care that is truly patient-centered. The bioethical community should reconsider the moral obligation to respect patients in light of what the patients themselves have to say, and health communication scholars would do well to embrace the moral constructs that underlie the research and training that is done to develop the communication skills of health professionals.

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Table.

Themes representing Respectful Behaviors^a

Domain	African American	Hispanic/Latino	White
Listening/Attention vs. Dismissing	"You're listening to what I'm saying to you, not just hearing, there's a big difference between listening and hearing somebody. You can hear a noise and not pay attention to it. But if you listen to it, you can figure out what it is. So, that's what I want them to do, listen to what I'm saying."	"Be attentive. Just listen to all your complaints, and all the information, they really pay attention."	"I appreciate my doctor because he focuses on the problems that I present with."
Trusting Self-Knowledge	"We know, like I said, we know what's wrong with us, we know what's hurting, whether they want to believe it or not."		
Asking Questions		"Well, for me, respect means that when I arrive, he asks me, 'How are you? How have you felt?' ... Explain to me your problem."	
Stereotyping	"I mean, we weren't that type people. We're not all the same, you know? We don't beat up on our kids."		"I would think that for me – not being categorized. Because they come in homeless. Maybe I haven't been able to shave for a couple of days. Maybe my jeans are dirty. Don't think that I'm less than a human being, less than intelligent. I mean, I've got a bachelor's degree already. I'm not stupid. You know, don't talk to me like I'm stupid. Don't categorize me."
Honest Explanations		"Explain. Tell me, 'I'm gonna change the date, I'm gonna change it and it's for this reason.'"	"I want the information. I want all the information I need to have to help myself get better."
Allowing Patient Input			"So, try this for three weeks, monitor your sugars. If it don't work, Insulin it is. And I respect her for the fact that she's giving me the choices."
Being Known as Individual	"When they come in, they know... who I am and, you know, what was going on, you know, they remember the last visit that we had."	"I say that respect comes from the doctor ... getting to know the patient."	"That's, that tells you right there that ... at least he read your chart and knows who you are."
Treated Rudely vs. Politely (Including subthemes of greetings and eye contact)	"If you're talking to them and they can't make eye contact with you, something's wrong."	"Well, they never laugh about my problems, or they never say bad words."	"The other thing, like at over at [hospital name], when you come into my room as a doctor, you got fifteen guys behind you and they're all students. Ask me if I mind I got fifteen other mother fuckers looking at me. Sometimes I do. You know? Seriously."
Handling Lateness	"It get to the point where, you know, I get so upset, I mean, that can hurt you too...because it seem like they ain't caring...about my time anymore"	"Get there on time."	"Show me a little bit of personal respect and be on time. I mean, we got to take – if we're working, we got to take off work to come see you. I mean. That kind of thing."

^a dark outlines represent prominent themes specific to one particular racial/ethnic group