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## Research Information

## Diverse patient perspectives on respect in healthcare: A qualitative study

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## ARTICLE INFO

## 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.

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## 1. Introduction

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.

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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.

## 2. Methods

### 2.1. 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.

### 2.2. 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.

## 3. Results

### 3.1. 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.

### 3.2. 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."*

### 3.3. 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 Table 1.

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."*

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