

# Racial Differences in Shared Decision-Making About Critical Illness

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**IMPORTANCE** Shared decision-making is the preferred method for evaluating complex tradeoffs in the care of patients with critical illness. However, it remains unknown whether critical care clinicians engage diverse patients and caregivers equitably in shared decision-making.

**OBJECTIVE** To compare critical care clinicians' approaches to shared decision-making in recorded conversations with Black and White caregivers of patients with critical illness.

**DESIGN, SETTING, AND PARTICIPANTS** This thematic analysis consisted of unstructured clinician-caregiver meetings audio-recorded during a randomized clinical trial of a decision aid about prolonged mechanical ventilation at 13 intensive care units in the US. Participants in meetings included critical care clinicians and Black or White caregivers of patients who underwent mechanical ventilation. The codebook included components of shared decision-making and known mechanisms of racial disparities in clinical communication. Analysts were blinded to caregiver race during coding. Patterns within and across racial groups were evaluated to identify themes. Data analysis was conducted between August 2021 and April 2023.

**MAIN OUTCOMES AND MEASURES** The main outcomes were themes describing clinician behaviors varying by self-reported race of the caregivers.

**RESULTS** The overall sample comprised 20 Black and 19 White caregivers for a total of 39 audio-recorded meetings with clinicians. The duration of meetings was similar for both Black and White caregivers (mean [SD], 23.9 [13.7] minutes vs 22.1 [11.2] minutes, respectively). Both Black and White caregivers were generally middle-aged (mean [SD] age, 47.6 [9.9] years vs 51.9 [8.8] years, respectively), female (15 [75.0%] vs 14 [73.7%], respectively), and possessed a high level of self-assessed health literacy, which was scored from 3 to 15 with lower scores indicating increasing health literacy (mean [SD], 5.8 [2.3] vs 5.3 [2.0], respectively). Clinicians conducting meetings with Black and White caregivers were generally young (mean [SD] age, 38.8 [6.6] years vs 37.9 [8.2] years, respectively), male (13 [72.2%] vs 12 [70.6%], respectively), and White (14 [77.8%] vs 17 [100%], respectively). Four variations in clinicians' shared decision-making behaviors by caregiver race were identified: (1) providing limited emotional support for Black caregivers, (2) failing to acknowledge trust and gratitude expressed by Black caregivers, (3) sharing limited medical information with Black caregivers, and (4) challenging Black caregivers' preferences for restorative care. These themes encompass both relational and informational aspects of shared decision-making.

**CONCLUSIONS AND RELEVANCE** The results of this thematic analysis showed that critical care clinicians missed opportunities to acknowledge emotions and value the knowledge of Black caregivers compared with White caregivers. These findings may inform future clinician-level interventions aimed at promoting equitable shared decision-making.

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Shared decision-making is a fundamental aspect of person-centered care.<sup>1</sup> This collaborative process involves clinicians, patients, and/or their surrogate decision-makers (referred to hereafter as caregivers). The primary benefit of shared decision-making is facilitating goal-concordant care for patients, with secondary advantages extending to caregivers, clinicians, and health systems, manifesting as reduced psychological or moral distress and shortened hospital length of stay.<sup>2-5</sup> This collaborative approach holds particular significance for critically ill patients, as their care often entails medically complex decisions characterized by prognostic uncertainty and value-laden judgments regarding acceptable quality of life.<sup>1</sup> Moreover, these decisions fall on caregivers when patients lack decisional capacity, adding another layer of complexity.

Critical care professional societies recognize shared decision-making as a core competency for clinicians.<sup>1</sup> Beyond information exchange, deliberation, and treatment decision-making, shared decision-making encompasses clinicians' relational skills, such as establishing trustworthiness and providing emotional support for decision-makers.<sup>1,6</sup> Despite this recognition, there has been limited evaluation of whether critical care clinicians engage in shared decision-making equitably.<sup>7,8</sup> This study's hypothesis posits that contextual factors in intensive care unit (ICU) settings, including the time-pressed nature of decisions and the absence of established relationships between clinicians and patients or caregivers, may activate racialized heuristics among clinicians, resulting in racially disparate shared decision-making.<sup>9-13</sup> As such, the objective of this thematic analysis was to compare how ICU clinicians approached shared decision-making in recorded conversations with Black and White caregivers of patients who were critically ill.

## Methods

### Parent Trial and Participant Selection

Existing data from a randomized clinical trial conducted between 2012 and 2017 in 13 medical and surgical intensive care units (ICUs) in North Carolina, Pennsylvania, and Washington were included in this thematic analysis.<sup>11</sup> Caregivers assigned to the intervention completed a decision aid about outcomes of prolonged mechanical ventilation. Subsequently, unscripted meetings were conducted by ICU clinicians with caregivers from both study groups. Written informed consent for audio recording was obtained from 146 caregivers. We transcribed all 20 meetings with Black caregivers and 20 meetings with White caregivers, purposively sampled to ensure similar distributions between groups of caregiver age, sex, relationship to the patient, and self-assessed health literacy (3-item instrument scored from 3 to 15, with lower scores corresponding to increasing health literacy),<sup>14</sup> as well as meeting length, study site, and study group. Caregivers self-reported their race. One recorded meeting with a White caregiver was excluded due to poor audio quality. Thematic saturation, signifying the point beyond which no new themes are identified, was reached

## Key Points

**Question** How do critical care clinicians approach shared decision-making with Black compared with White caregivers of critically ill patients?

**Findings** In a thematic analysis of 39 audio-recorded clinician-caregiver meetings, racial differences were most evident in the following clinician behaviors: providing emotional support to caregivers, acknowledging trust and gratitude expressed by caregivers, disclosing medical information, and validating caregivers' treatment preferences.

**Meaning** Racial disparities exist in critical care clinicians' approaches to shared decision-making, suggesting potential areas for future interventions aimed at promoting equitable shared decision-making.

during the analysis of 39 meetings; hence, additional meetings were not transcribed.<sup>15</sup> This study received approval from the Duke University Health System Institutional Review Board. This study adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) reporting guideline (Supplement 1).<sup>16</sup> Data analysis was conducted between August 2021 and April 2023.

### Analysis Team

A multidisciplinary team was assembled to enhance the analytic perspective and facilitate reflexivity.<sup>17</sup> A total of 4 investigators, including 2 White sociologists with expertise in social inequality research (W.W., D.P.), 1 East Asian ICU nurse (H.Y.), and 1 East Asian postgraduate student (K.T.), coded the data. Consequently, investigators with expertise in health equity research served as arbiters, including 1 White sociologist (J.S.) and 1 South Asian ICU physician (D.C.A.).

### Codebook Development

A codebook was iteratively developed based on the existing literature (Table 1). It included components of shared decision-making recommended by critical care professional societies (eg, discussing prognosis) and mechanisms of inequities in clinical communication (eg, biases).<sup>1,18-30</sup>

### Analysis

Transcripts were uploaded to NVivo 12 Pro (QSR International). W.W. manually conducted line-by-line coding of all transcripts, creating a summary matrix of data from all meetings.<sup>31</sup> Simultaneously, other coders (D.P., H.Y., K.T.) independently reviewed 5 to 8 transcripts each and created summary matrices to ensure coding consistency. Discrepancies were resolved by consensus during weekly meetings attended by all members of the analytic team. After being unblinded to caregiver race, the analytic team used combined matrices and code frequencies to identify clinician behavior patterns within and across racial groups, recorded as themes when group consensus was reached.<sup>32</sup> The focus on clinicians aimed to inform a future clinician-targeted intervention to promote equitable shared decision-making.

Table 1. Analytic Codes and Their Definitions

Codes	Definitions
Speaker	Clinician, caregiver
Diagnosis or prognosis <sup>1</sup>	Description of patient's condition, or prognosis for survival, physical function, cognition, or ability to return home (ie, discharge disposition)
Treatment options <sup>1</sup>	Explanation of treatment options, including risks and benefits
Goals, preferences, values <sup>1</sup>	Any mention of patient or caregiver goals, preferences, or values, including advance directives or caregiver's substituted judgment, as well as the medical team's goals for the patient
Questions and answers	Questions asked by either the caregiver or medical team to the other and answers if provided (does not include rhetorical questions)
Support <sup>18</sup>	Any mention of social or other support systems, and referrals from the medical team for support resources (eg, chaplain)
Medical history	References to preexisting conditions or past health issues that are not directly linked to current decision-making
Trust <sup>19,20</sup>	Explicit or implicit indications of trust, distrust, skepticism, trustworthiness, or confidence
Family reactions <sup>18,21,22</sup>	Caregiver emotions or descriptions of how the caregiver is coping with their loved one's illness
Empathy <sup>22,23</sup>	Statements by the medical team that acknowledge caregivers' emotions
Missed opportunities <sup>23-25</sup>	Instances where the medical team failed to respond to the caregiver's emotional statements
Communication and interpersonal skills <sup>18,26</sup>	How the medical team establishes rapport or communicates information (eg, assessing understanding); includes humor and rhetorical questions
Health literacy <sup>18,26</sup>	Caregiver demonstration of access to or understanding of health information
Past experiences <sup>18</sup>	Caregivers' prior experiences with health problems and/or health care, including employment experience
Religion/spirituality <sup>27</sup>	References to religion, spirituality, higher power, or fate
Power differentials <sup>18,21,28</sup>	Deferral to expertise or position; dismissal or condescension
Biases <sup>21,26,29</sup>	Evidence of preconceptions based on cultural stereotypes or demographic characteristics; also biases for or against treatment options
Cultural competency <sup>26</sup>	Indications of behaviors, attitudes, or policies that support or do not support cross-cultural communication

## Results

The study sample comprised 20 meetings with Black caregivers and 19 meetings with White caregivers (Table 2).<sup>14,33,34</sup> The duration of meetings was similar for both Black and White caregivers (mean [SD], 23.9 [13.7] minutes vs 22.1 [11.2] minutes, respectively). Both Black and White caregivers were generally middle-aged (mean [SD] age, 47.6 [9.9] years vs 51.9 [8.8] years, respectively), female (15 [75.0%] vs 14 [73.7%], respectively), and possessed a high level of self-assessed health literacy, which was scored from 3 to 15 with lower scores indicating increasing health literacy (mean [SD], 5.8 [2.3] vs 5.3 [2.0], respectively). Clinicians conducting meetings with Black and White caregivers were generally young (mean [SD] age, 38.8 [6.6] years vs 37.9 [8.2] years, respectively), male (13 [72.2%] vs 12 [70.6%], respectively), and White (14 [77.8%] vs 17 [100%], respectively). Table 2 provides a summary of patient, caregiver, and clinician characteristics.

A total of 4 themes characterized clinicians' shared decision-making behaviors that differed by caregiver race: (1) disparate empathy for caregivers, (2) unacknowledged trust and gratitude, (3) varying disclosure of medical information, and (4) inconsistent validation of treatment preferences (Box). Other aspects of the majority of meetings did not vary by caregiver race. Clinicians and caregivers tended to be present-focused rather than future-focused, and clinicians inconsistently explored patients' values or provided a full range of treatment options, such as cessation of life-sustaining treatments.

### Disparate Empathy for Caregivers

Racial differences were evident in how clinicians provided emotional support to caregivers, particularly in acknowledging the difficulty of coping with critical illness in a loved one or assuming the role of a surrogate decision-maker. Statements directed toward Black caregivers were short and generic, contrasting with long and personalized statements directed toward White caregivers. Opportunities for empathic responses were missed when Black caregivers expressed negative emotions, while White caregivers received acknowledgment and validation of their emotions.

#### Clinicians and Black Caregivers

The following example shows a brief empathic statement made by a clinician to a Black, male caregiver:

"I know that this is a very hard time for you."

A similarly brief and generic statement was made in a separate meeting with a clinician and a Black, female caregiver:

"It's a lot to handle."

#### Clinician and White Caregivers

In contrast, in a meeting with a White family, a clinician made the following statement:

"You two have been incredibly supportive and very courageous through it, and I very much respect how difficult this is for you."

**Table 2. Descriptive Characteristics by Race of Primary Caregivers in Family Meetings**

Variable	No. (%)	
	Black caregivers (n = 20)	White caregivers (n = 19)
<b>Meeting characteristics</b>		
Total No.	20	19
<b>Study site</b>		
1	10 (50.0)	10 (52.6)
2	5 (25.0)	5 (26.3)
3	4 (20.0)	4 (21.1)
4	1 (5.0)	0
Duration of meeting, mean (SD), min	23.9 (13.7)	22.1 (11.2)
Caregivers present, mean (SD), No.	2.5 (2.5)	2.0 (1.2)
<b>Patient characteristics</b>		
Age, mean (SD), y	47.3 (17.5)	50.9 (20.7)
<b>Sex</b>		
Female	9 (45.0)	7 (36.8)
Male	11 (55.0)	12 (63.2)
<b>Race</b>		
Black	20 (100)	0
White	0	19 (94.7)
Multiracial	0	1 (0.3)
Charlson Comorbidity Index score, <sup>33</sup> mean (SD)	3.3 (2.3)	4.0 (3.2)
APACHE II score, <sup>34</sup> mean (SD)	24.4 (8.7)	22.6 (7.0)
<b>Tracheostomy status</b>		
Placed before family meeting	6 (30.0)	5 (26.3)
Placed after family meeting	7 (35.0)	6 (31.6)
Not placed	7 (35.0)	8 (42.1)
Alive at hospital discharge	15 (75.0)	15 (78.9)
<b>Caregiver characteristics</b>		
Age, mean (SD), y	47.6 (9.9)	51.9 (8.8)
<b>Sex</b>		
Female	15 (75.0)	14 (73.7)
Male	5 (25.0)	5 (73.7)
<b>Relation to patient</b>		
Spouse or partner	6 (30.0)	7 (36.8)
Child	5 (25.0)	4 (21.2)
Parent	6 (30.0)	5 (26.3)
Sibling	3 (15.0)	3 (15.8)
Religiosity, mean (SD) <sup>a</sup>	32.0 (44.6)	18.9 (36.8)
Health literacy, mean (SD) <sup>b</sup>	5.8 (2.3)	5.3 (2.0)
Randomized to intervention	12 (60.0)	8 (42.1)

(continued)

**Table 2. Descriptive Characteristics by Race of Primary Caregivers in Family Meetings (continued)**

Variable	No. (%)	
	Black caregivers (n = 20)	White caregivers (n = 19)
<b>Clinician characteristics</b>		
Total No. <sup>c</sup>	18	17
Age, mean (SD), y <sup>d</sup>	38.8 (6.6)	37.9 (8.2)
<b>Sex</b>		
Female	7 (35.0)	7 (36.8)
Male	13 (72.2)	12 (70.6)
<b>Race and ethnicity</b>		
Asian	3 (16.7)	0
Black	0	0
White	14 (77.8)	17 (100)
Other <sup>e</sup>	1 (5.6)	0

Abbreviation: APACHE, Acute Physiology and Chronic Health Evaluation.

<sup>a</sup> The question asked, "On a scale of 0-100, (0 being not strong at all, 100 being very strong), how strong an influence do you consider your religious/spiritual beliefs to be in your life?"

<sup>b</sup> Self-evaluated 3-item instrument scored from 3 to 15, with lower scores corresponding to increasing health literacy.<sup>14</sup>

<sup>c</sup> Two clinicians conducted 2 meetings each with Black caregivers, and 2 clinicians conducted 2 meetings each with White caregivers.

<sup>d</sup> Age was missing for 1 clinician who conducted 1 meeting with a Black caregiver and for 2 clinicians who conducted 1 meeting each with White caregivers.

<sup>e</sup> The other category includes American Indian or Alaska Native, Native Hawaiian, or other Pacific Islander individuals.

**Clinician and Black Caregiver**

In some cases, caregivers explicitly expressed negative emotions, such as fear or frustration, which were ideal opportunities for clinicians to respond with empathy. However, when a Black, male caregiver shared his fear about post-ICU care, the clinician deferred discussion:

Caregiver: "I'm more scared about the nursing home than I am about how we're getting a trach."

Clinician: "So, we'll talk about it when the time comes. Now is not the time."

**Clinicians and White Caregivers**

In contrast, when a White, male caregiver expressed fear, the clinician acknowledged and validated his emotion:

Caregiver: "It was frightening when we first heard the word [tracheostomy]."

Clinician: "When you first hear the word, it is. And it's very overwhelming."

Another White, male caregiver expressed frustration about the slow pace of his loved one's recovery, and the clinician responded in a highly personalized manner:

Caregiver: "I know you and your team are doing everything you all can. But it's getting frustrating for me."

**Box. Additional Representative Quotations From Meetings With Individual Black and White Caregivers****Theme 1. Disparate Empathy for Caregivers****Conversation With a Black, Female Caregiver**

Caregiver: "But until we get that [test result], it's just kind of difficult for me, you know. All my questions have been answered regarding what we've discussed so far."

Clinician: "Good."

Caregiver: "It's just that, you know, the troubling part is that she's still not in a conscious state."

Clinician: "Right."

Caregiver: "So, you know, that's the troubling part for me."

Clinician: "Right, right."

**Conversation With a White, Female Caregiver**

Caregiver: "That [lumbar puncture] scares the hell out of me."

Clinician: "We will actually have preliminary results on things like cell counts in there I think by this evening if we get it down to the lab. You know, so we may have some preliminary stuff as early as this evening to bring back to you."

Caregiver: "That would be wonderful."

Clinician: "I know meningitis sounds scary. But a bacterial meningitis in this setting is something we can treat with antibiotics."

**Theme 2. Unacknowledged Trust and Gratitude****Conversation With a Black, Female Caregiver**

Caregiver: "Well, I got confidence in you guys 'cause you're taking good care of her and she's gonna be fine. I know it's gonna be a long road."

Clinician: "So, short-term goals are to be free of the ventilator and to pull fluid off."

**Conversation With a White, Female Caregiver**

Caregiver: "You guys are great and I'll tell you what, the nursing staff that you have working with you for the patients are amazing at keeping the families updated. I don't know how they can make every single family in here feel like they're the only one, but they honestly do."

Clinician: "That's wonderful. That's good to hear."

**Theme 3. Varying Disclosure of Medical Information****Conversation With a Black, Male Caregiver**

Clinician: "So the ventilator, it pushes air into her lungs and it says, 'Hey, your lungs are too weak because of the fluid and because of

the pneumonia, so I'm going to push air in you and I'm going to help your lung, I'm gonna help you do what you can't do."

**Conversation With a White, Male Caregiver**

Caregiver: "I just happened to be sitting out in the waiting room...and he [the physician] stopped and told me that the bronchoscopy went fine. They found a lot of thick, I call it gunk, whatever you want to call it."

Clinician: "Yep, just some mucus."

Caregiver: "You all speak a different language."

Clinician: "We do. We gotta be careful of that...So Dr [redacted] may have told you one of the things we found is that he had some significant mucous plugging up his right lung...And there's been a little bit of a spot on his chest X-ray down in that area that looks like the lung is just not completely inflated and that's probably why his airway was all plugged up, essentially...I definitely suctioned everything out...In fact, the amount of oxygen that he's needing on the ventilator...we've been able to decrease it."

**Theme 4. Inconsistent Validation of Treatment Preferences****Conversation With a Black, Male Caregiver**

Caregiver: "We work in the medical field. We've done trach care...you know, and all that. Our grandfather just passed away at 104. We had no outside help. We did it ourselves...If it means us pulling a 24-hour day and going 12 hours apiece, we're gonna do what we gotta do for my mom."

Clinician: "I appreciate that...and I'm really talking about what her quality of life would be after an ICU stay. She's pretty sick and a lot of times when people are this sick, in fact...more than half the time, people don't get better from this when they get this sick."

**Conversation With a White, Female Caregiver**

Caregiver: "Ain't nobody gonna give up on him. That's for sure."

Clinician: "No."

Caregiver: "I'll have him cussing me out again."

Clinician: "When he does, you bring him back and let us see."

Clinician: "If this was my wife, I would be frustrated too...I thank you for sharing your frustration with us. Let us work to help alleviate some of that...so we can take some of the stress and anxiety away, okay? I think you guys are doing everything right for her."

**Unacknowledged Trust and Gratitude**

Black caregivers commonly expressed trust and gratitude for the medical team, which clinicians infrequently acknowledged. In contrast, when White caregivers verbalized trust, clinicians affirmed their personal commitment to the patient.

**Clinicians and Black Caregivers**

This first example illustrates a conversation between a clinician and a Black, female caregiver:

Caregiver: "I appreciate what you all are doing. If it weren't for you all, he wouldn't be here 'cause you all making good choices...I got trust in you all."

Clinician: "Okay."

Caregiver: "You're doing a very excellent job."

Clinician: "Do you have any questions?"

Another conversation with a Black, male caregiver was similar:

Caregiver: "I mean you gave us some steps of hope, you know?...I appreciate you. They said you're a good doctor, okay? Now I can see that...Like you didn't guarantee anything, but you still gave us that sense of hope and...that means a lot to us."

Clinician: "Okay. Alright, folks."

### Clinician and White Caregiver

In contrast, when a White, male caregiver verbalized trust, the clinician affirmed their personal commitment to the patient:

Caregiver: “Cause I’m confident...you’re going to do everything you can...your very best to get him out of it. Ain’t no doubt in my mind about that.”

Clinician: “I absolutely will...I’m invested, and I’m as hopeful as you guys are, and my goal is to have conditions be as ideal as possible.”

### Varying Disclosure of Medical Information

Clinicians tended to share more medical information with caregivers demonstrating greater health literacy, but this was not consistently true for Black caregivers, even when knowledgeable about critical illness and the health care system. Black caregivers often received limited medical information, while clinicians engaged with White caregivers’ questions and acknowledged their expertise.

### Clinicians and Black Caregivers

In this first example, a Black, female caregiver who was not familiar with post-ICU care options was dissuaded from thinking about her husband’s medium-term prognosis despite undergoing mechanical ventilation for more than 10 days:

Clinician: “Once he gets the tube out...he’ll probably end up needing some kind of long-term care facility for a little bit of time.”

Caregiver: “Don’t they have that here at the hospital?...When you said a long-term care facility, you don’t mean a nursing home, do you?”

Clinician: “Just take it a day at a time ’cause it’s overwhelming to think of it in 2 months [from now]. We have to tell you what to expect, but you don’t know what it’s really gonna be. And so, there’s no point worrying how sick he may be or what he may need right now.”

In another case, despite a Black, female caregiver’s understanding of complex treatments like extracorporeal membrane oxygenation, the ICU clinician used simplistic language when speaking with her:

Clinician: “Her kidneys are unhappy, her lungs are unhappy, and...her brain is unhappy.”

Moreover, when a Black female nurse and her family asked questions about their loved one with a rapidly progressive lung disease who was expected to die, the clinician sounded increasingly frustrated and repeatedly interrupted them:

Caregiver: “Yeah, but you wouldn’t have ever stopped antibiotics completely in an ICU for someone who—”

Clinician: “Oh, yes we would.”

Caregiver: “Who is on a trach and—”

Clinician: “Oh, yes, we would.”

Caregiver: “Someone who’s immunosuppressed? You would stop antibiotics?”

Clinician: “Oh, yes, we would. Yes.”

Caregiver: “With rituximab, you would stop antibiotics?”

Clinician: “Yes.”

### Clinicians and White Caregivers

In contrast, clinicians engaged with White caregivers’ questions and acknowledged their expertise. For example, in a meeting with a White, female caregiver who was an ICU nurse, the clinician asked many open-ended questions to allow the caregiver to speak for much of the meeting, shared lengthy descriptions of ventilator liberation and post-ICU care, and frequently alluded to the caregiver’s professional expertise:

Clinician: “As you know, this [ventilator liberation] is a long process...We hope that, now with the trach, we’ll be able to come off the sedation...Was she responding to you when you were in there? Do you think she was having pain?”

Even when a White, female caregiver questioned the medical team’s recommendations, she still received both empathy and detailed medical information about her husband’s treatment options:

Caregiver: “I called our personal physician today...He told me pretty much the same thing that’s been told here, but I just needed to hear it from him...So I just have to learn to trust you guys...We don’t know any of you from Adam. I’ve been a nurse for 45 years...so none of this is new to me.”

Clinician: “It’s still different though when it’s your loved one.”

Caregiver: “Yes, it is.”

Clinician: “And the only thing I guess I maybe didn’t mention...is if you choose to proceed with the trach...we would also like to proceed with a PEG [percutaneous endoscopic gastrostomy] tube placement...If you have the trach, you’re not quite able to eat...The PEG tube would give him his nutrition...And so we’re not putting his nasal sinuses at risk for infection, and also I don’t think having tubes down your nose is particularly comforting.”

### Inconsistent Validation of Treatment Preferences

Many White caregivers preferred a palliative or time-limited approach based on prior advance care planning conversations, while no Black caregivers explicitly favored this approach. Clinicians more readily supported palliative treatment preferences for all patients, resulting in less validation for Black caregivers’ medical decisions. However, even when compared with White caregivers who preferred restorative care, Black caregivers faced more resistance from clinicians regarding their treatment preferences.

### Clinicians and Black Caregivers

In one meeting, when a Black, male caregiver described decisional conflict, the clinician suggested that the choice to continue restorative care was uninformed:

Caregiver: "I understand the situation. My mother passed away 5 years ago. I took care of her...I understand that we all gonna go. I think my only crossroad that I'm having now, that when he was well, is that he wanted me to do everything...Because of what he's told me, I can't make the call because then I feel like I'm going against what he asked me to do."

Clinician: "...I don't think people really understand what 'do everything' means...If I wasn't in health care, I would think 'do everything' means give me every kind of pill you can and do everything, but didn't realize that means cutting holes in me."

In another conversation with a Black, female caregiver, the clinician alluded to medical futility:

Caregiver: "You know, I don't like what I see now...but I do it because I think that she has a chance to come out of this. She is a fighter."

Clinician: "...How much longer do we try, you know?...We're being as aggressive as we can be, but we may be getting to a point where we have to go okay, can we do anything else?"

Despite the clinicians' concerns, both patients from these conversations survived their hospitalizations.

#### Clinician and White Caregiver

In contrast, when speaking with a White, female caregiver who preferred restorative care, the clinician affirmed his commitment to the patient and caregiver:

Caregiver: "When he was first intubated...he made me promise not to let anybody turn anything off."

Clinician: "I understand your promise to him...We won't leave any stone unturned."

#### Thematic Summary

In the recorded interviews, clinicians exhibited differential shared decision-making behaviors based on caregiver race, with disparities noted in empathy, acknowledgment of trust and gratitude, disclosure of medical information, and validation of treatment preferences.

## Discussion

In this thematic analysis of 39 meetings with Black or White caregivers of patients who were critically ill, we identified clinician-caregiver shared decision-making behaviors, which were found to differ by caregiver race. These included disparate empathy for caregivers, unacknowledged trust and gratitude, varying disclosure of medical information, and inconsistent validation of treatment preferences. Such differences may be a mechanism for known racial disparities in clinician-caregiver relational outcomes (eg, Black caregivers report greater conflict with clinicians about treatment decisions) and patient outcomes (eg, greater use of life-sustaining treatments during terminal ICU admissions among Black patients).<sup>4,35</sup> The focus of this study on clinicians also affirms

that the responsibility for eliminating inequities must not fall to those who are experiencing them.

Our finding of racial disparities in clinicians' relational skills corroborates evidence from other clinical settings.<sup>36,37</sup> This phenomenon, when related to empathic communication, is known as the racialized empathy gap and has its roots in the process of out-group social categorization.<sup>38-40</sup> In other words, empathy is elicited most strongly by those who are familiar. Training programs that teach clinicians the language of empathy may be a solution.<sup>41,42</sup> However, given that the detection of emotion in others and empathic reactions are racialized, it is necessary to confirm whether the benefits of such training programs are experienced by all patients and caregivers.<sup>43-45</sup> Further, communication training typically only focuses on managing negative emotions, which may be preferentially responsive to one specific sociocultural norm of communication. We found that many Black caregivers instead shared positive sentiments, such as trust or gratitude, and these were not acknowledged by clinicians.<sup>46-48</sup> Future research should investigate patients' and caregivers' desired responses to such statements, followed by modification of communication training programs. In addition, verification of these results in larger samples that support quantitative inferences is needed, as well as research that measures the effects of empathic communication on health outcomes and patient-reported or family-reported outcomes.

We also found that clinicians shared limited medical information with Black caregivers and provided little validation for the restorative treatment preferences that were endorsed by all Black caregivers in this study's sample.<sup>49,50</sup> Together, these findings represent forms of epistemic injustice, which occur when one's knowledge or fitness to be a knower is challenged.<sup>51</sup> We observed White caregivers successfully wielding cultural health capital, a resource comprising health knowledge and fluency in norms of self-presentation in clinical encounters, to obtain more medical information.<sup>52,53</sup> When used by Black caregivers, the same resource appeared to be less credible or frankly threatening to the clinician's expertise, which resulted in less sharing of medical information and even conflict.<sup>54,55</sup> We also observed clinicians disproportionately challenging Black caregivers' decisions for their loved ones.<sup>29,53</sup> These data substantiate testimonies of Black patients with serious illness and report that silencing and dismissal are the most commonly experienced forms of interpersonal racism, which then contribute to their perceptions of clinician and health system untrustworthiness.<sup>56</sup> In a time when trustworthiness is increasingly recognized as critical to the success of public health campaigns, clinical trials, and many other aspects of health,<sup>57,58</sup> these data offer a potential target for intervention.

#### Strengths and Limitations

Strengths of this study include a multicenter sample and a multidisciplinary analytic team with representation of nursing and sociology perspectives. There are also several limitations. First, we could not measure nonverbal communication. Second, this study's data were cross-sectional while shared decision-

making can be longitudinal. However, these data were collected at a critical decision point (ie, whether to pursue tracheostomy), and this study's objective was to compare how clinicians approached shared decision-making with Black and White caregivers, even at one point in time. Third, clinicians may have altered their communication because they were being observed. However, such a change would be expected to bias this study's results toward the null as clinicians communicated more proficiently and perhaps with greater attention to equity, although race was not a focus of the parent trial. Fourth, clinician demographics, such as race and sex, were not considered as factors that may be associated with shared decision-making, in part because of the limited racial diversity of the clinician sample and to preserve the anonymity of

participants.<sup>59</sup> Fifth, this study's analysis team did not include any individuals who identified as Black.

## Conclusions

In this thematic analysis, the most notable racial differences in critical care clinicians' approaches to shared decision-making involved relational and epistemic aspects of communication. These may represent targets for future clinician-level interventions. Preparing clinicians to provide emotional support and value caregivers' knowledge and expertise, within the framework of antiracism, may be necessary for promoting equitable shared decision-making and health outcomes.<sup>60,61</sup>

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