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A Descriptive Qualitative Study of Religion and Spirituality's Role in Critical Illness Decision-Making Among Black and White Family Caregivers

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Abstract

BACKGROUND: Spiritual beliefs and spiritual support from clinicians can affect medical decision-making and coping during times of serious illness.

RESEARCH QUESTION: How do religion and spirituality affect the critical illness experience of Black and White family caregivers of patients who are critically ill?

STUDY DESIGN AND METHODS: Twenty-one semistructured interviews were conducted with Black and White family caregivers of patients admitted to ICUs in a southeastern United States health system between January 3, 2023, and May 11, 2023. Eligible family caregivers either reported unmet spiritual needs or a high degree of importance of spirituality in their lives. Participants were asked how spirituality affected medical decision-making and coping while their loved ones were seriously ill. Coders were masked to participant race during thematic analysis.

RESULTS: Of 21 family caregivers, 9 caregivers (42.9%) were Black and 12 caregivers (57.1%) were White. Black and White family caregivers generally were middle-aged (mean [SD]: 50.6 [13.6] years and 61.7 [10.7] years, respectively) and female (n = 7 [77.8%] and n = 9 [75.0%], respectively). We observed that clinicians showed less engagement about spirituality with Black compared with White family caregivers in this sample. Black family caregivers felt more comfortable discussing their spirituality with members of their community, such as pastors or friends. A common belief among all family caregivers in this sample was that God, rather than the medical team, was in control of their loved one's outcome. This was accompanied by a shared desire for accessible spiritual spaces in the ICU and proactive clinician engagement in their spirituality.

INTERPRETATION: Although spirituality served as an important coping mechanism for all family caregivers in this sample, racial differences in spiritual support offered to family caregivers were identified. Ensuring that multidisciplinary critical care teams are prepared to deliver culturally competent spiritual care is a priority.

Keywords

caregivers; critical illness; health equity; ICU; medical decision-making; religion; spiritual support; spirituality

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Nearly 600,000 Black Americans experience critical illness each year, and up to 20% die in ICUs.[1,2] Compared with their White counterparts, Black patients and their family caregivers are more likely to experience conflicts with clinicians about treatment decisions and to receive unsatisfactory end-of-life care.[3–5] Religious and spiritual beliefs—and clinicians' responses to these—have been implicated as potential contributors to these racial disparities.[6,7] For example, clinicians may find it difficult to incorporate hopes for miracles into clinical communication and decision-making.[7,8]

Most Black Americans endorse the importance of religion in their daily lives and show relatively higher levels of religious participation compared with individuals from other racial groups.[6,9–12] Spiritual support from clinicians builds patients' and family caregivers' trust in clinicians.[13–15] Although most ICU clinicians believe that it is important to address patients' and caregivers' spiritual needs, < 20% do so routinely.[16–21] Clinicians report feeling unprepared to address spiritual concerns, especially when their cultural or religious backgrounds differ from those of patients and caregivers.[22] This may be a particularly salient finding for Black patients and caregivers because only 5% of ICU physicians identify as Black.[23] Spiritual support is associated with resilience and improved quality of life.[10,24,25] When clinicians do not address spiritual concerns, patients or caregivers may experience lower quality of life, depressive symptoms, and spiritual distress.[26–28]

The goal of this study was to elicit Black and White family caregivers' perspectives on (1) the influence of religion and spirituality on ICU decision-making and (2) how clinicians and health systems can support their religious and spiritual needs. Further, we sought to compare Black and White caregivers' experiences of and preferences for spiritual support. We focused on caregivers, rather than patients, because many patients who are critically ill lack decisional capacity.[29] To achieve these goals, we conducted semistructured interviews with non-Hispanic Black or White caregivers of patients who are critically ill.

Study Design and Methods

This study was approved by the Duke University Institutional Review Board (Identifier: 00101745). We followed the Consolidated Criteria for Reporting Qualitative Health Research (e-Appendix 1).[30]

Parent Trial and Sample Selections

The qualitative data analyzed for this study were collected during a larger mixed-methods randomized controlled trial of a mobile application designed to elicit and address palliative care needs of ICU family caregivers.[31] Patients in the parent trial were 50 years of age or older, had been treated in an ICU for between 1 and 8 days, and met ≥ 2 criteria signifying a high likelihood of benefitting from palliative care (ie, dementia, poor functional status, or multisystem organ failure). Caregiver needs were assessed using the Needs, Existential Concerns, Symptoms, and Therapeutic Interactions (NEST) scale.[32] The NEST tool is used to determine needs during end-of-life care.[32,33] One of the 13 NEST items prompted caregivers to consider whether "the ICU doctors understand my spiritual beliefs" on a scale from 0 to 10, with 0 being "not at all" and 10 being "very much so." Among individuals screened for trial participation, 2 criteria were used to determine their eligibility for interviews: (1) NEST spirituality item response of ≤ 9 or (2) NEST spirituality item response of > 9 and a response of ≥ 50 on a second question ("How important is spirituality in your daily life?") on a scale from 0 to 100, with 0 being "not at all" and 100 being "very important." These criteria were chosen to elicit diverse perspectives from individuals with unmet needs related to spirituality, as well as those without unmet needs, but for whom spirituality was important. Additional eligibility criteria included non-Hispanic Black or White self-identified race or ethnicity, age of 18 years or older, and conversational fluency in English.

Data Collection

An interview guide was developed iteratively by D. C. A., an ICU physician and health equity investigator, and S. L. D., an ICU nurse and qualitative investigator, using the existing literature.[34] The interview guide assessed caregivers' experiences in the ICU, including how religion or spirituality, or both, influenced coping and medical decision-making (e-Appendix 2). Professional qualitative investigators conducted audio-recorded interviews lasting up to 60 minutes by telephone or video-conferencing software. Interviews were conducted between 34 to 291 days after ICU admission. Data collection continued until thematic saturation was reached. Because data collection and analysis occurred in tandem, the team evaluated in real-time whether new information (ie, new codes or new concepts within codes) was learned in interviews, and recruitment was stopped after 3 successive interviews yielded no new information.[35,36] Caregivers were compensated $25 after interviews.

Data Analysis

Interview recordings were transcribed and uploaded to NVivo 12 Pro (QSR International) for analysis. O. F. A. created an initial codebook using concepts from the background literature and interview guide itself, as well as inductive concepts identified from the transcripts (Table 1). O. F. A, D. W., and D. C. A independently coded 5 (23.8%) transcripts to ensure a consistent understanding and application of codes. Then, O. F. A. and D. W., Black or Asian health sciences graduate students, independently coded the remaining transcripts and wrote memos to summarize major concepts in all transcripts. Regular meetings including the 2 coders, S. L. D., and D. C. A. were used to resolve uncertainties in coding through group discussion until consensus was reached. Coders were masked to caregiver race until all coding was completed. Code frequencies were determined by counting the number of caregiver transcripts including each code (e-Appendix 3). The analytic team subsequently compared memos and code frequencies by caregiver race to identify preliminary themes that summarized the most salient aspects of caregivers' experiences and preferences. Themes were revised iteratively and were finalized after discussion by the analytic team.

Results

Of the 39 eligible family caregivers who were approached for consent, 27 caregivers (69.2%) consented to participate, 22 caregivers (56.4%) completed interviews, and 21 caregivers (53.8%) had complete interview recordings that could be transcribed. The final sample included 9 Black caregivers (42.9%) and 12 White caregivers (57.1%) (Table 2). For Black caregivers, 6 caregivers (66.7%) were selected on the basis of their NEST spirituality score (mean [SD], 6.7 [3.0]) and 3 caregivers (33.3%) were selected on the basis of their spirituality importance score (mean [SD], 98.3 [2.9]). For White caregivers, 9 caregivers (75%) were selected on the basis of their NEST spirituality score (mean [SD], 5.0 [2.1]) and 3 caregivers (25%) were selected on the basis of their spirituality importance score (mean [SD], 100 [0]). Black and White caregivers generally were middle-aged (mean [SD], 50.6 [13.6] years and 61.7 [10.7] years, respectively) and most were female (n = 7 [77.8%] and n = 9 [75.0%], respectively). More Black than White caregivers were the children of the patients who are critically ill (n = 7 [77.8%] and n = 2 [16.7%], respectively). Patient characteristics and additional caregiver characteristics are reported in Table 2.

We identified 2 racially distinct themes: (1) less proactive clinician engagement with Black vs White family caregivers about religion and spirituality and (2) Black family caregivers' relative discomfort with discussing spirituality outside of their community. We also identified 3 themes that were shared by both Black and White caregivers: (1) comfort in God's plan, (2) desire for easily accessible spiritual spaces in the ICU, and (3) shared desire for proactive clinician involvement in family's religion and spirituality. Representative quotes are provided below and in Table 3.

Theme 1: Less Proactive Clinician Engagement With Black vs White Family Caregivers About Religion and Spirituality

Most Black caregivers reported that the ICU team did not have discussions with them about religion and spirituality (e-Appendix 3). This lack of engagement also occasionally extended to chaplains, as in this case, in which a caregiver asked his own pastor to pray for his mother while she was dying:

> "When I met with [the doctors], I don't remember anybody mentioning [religion]. . . . The chaplain came by, but I just didn't see him. But obviously, if there is one that can come by, that would be helpful. . . . I had to call [my pastor] to pray with my mom. . . . I said, listen, they're saying she doesn't have long. . . . I had to do that kind of on my own, you know?" (Black male, 42 years of age, child of patient)

Some Black caregivers who did discuss spirituality with the medical team were met with a muted or absent response. In this case, the caregiver wondered if the clinicians had implicated her religious beliefs in her decision to continue life-sustaining care against their recommendation:

> "We didn't have a lot of conversation about spirituality after the first 2, first couple of days. . . . I don't know if they felt that our religious beliefs were the reason why we made some of the decisions [to continue life-sustaining care] that we made. . . . [When religion was discussed], there was a lot of kind of nodding on their side. . . . [The female doctor] was just like, she kind of just nodded and like she understood. The male doctor . . . he didn't engage with it. He just went ahead to a different conversation." (Black female, 44 years of age, child of patient)

In contrast, many White caregivers described clinicians proactively probing their or their critically ill loved one's religious affiliations and beliefs:

> "[The doctor] basically, was asking me, you know, if he [the patient] believes, what his faith was." (White female, 78 years of age, spouse of patient)

> "It was clear from my room, from [patient name's] room, again, we had the crucifix hung up. We had I'd taken Facebook, all the Facebook messages, I wrote them on Post-its [3M] and stuck them on the wall. . . . There were hundreds of them all over

> the wall, you know, and lots of them, you know, were prayerful, you know. OK. And so, they [medical team] would ask, are these people from your church? . . . It was absolutely acknowledged [by the team].” (White female, 57 years of age, spouse of patient)

Theme 2: Black Family Caregivers’ Relative Discomfort With Discussing Spirituality Outside of Their Community

Most Black caregivers viewed religion and spirituality as a private matter to be shared within their family and community. This was evident in 2 ways. First, some Black caregivers did not spontaneously broach religion and spirituality with the medical team if they were not asked, preferring to share spiritual concerns through prayer with their family:

> “I just didn’t bring [religion] up [with the medical team]. . . . We just prayed amongst ourselves.” (Black male, 60 years of age, spouse of patient)

Second, several Black caregivers declined to meet with the hospital chaplain, either because they were suspicious of this external resource—equating it to impending death—or they preferred to pray within their own social network:

> “My husband didn’t want to meet with the chaplain. . . . I guess he felt that, you know, if a chaplain come in the room that, you know, how some people think that it’s the end.” (Black female, 53 years of age, spouse of patient)

> “Somebody did offer to call a chaplain and ask that we need a chaplain. And I think I told them no . . . our pastor would be coming up.” (Black female, 57 years of age, child of patient)

In fact, no Black caregivers in our sample mentioned using a hospital chaplain. Other reasons for not using this service were that it was not offered by the medical team or caregivers were not present when the chaplain visited the ICU. In contrast, White caregivers more readily shared their religion and spirituality in a public manner, including with the hospital staff. This caregiver was offered and agreed to see a chaplain:

> “Yes, after she passed, they asked if we wanted a chaplain . . . and we said yes.” (White female, 66 years of age, child of patient)

Another White caregiver explicitly announced her religion through her clothing, which invited conversation and support from nurses with similar religious affiliations:

> “I wore a lot of t-shirts that boldly proclaim my faith. And they would talk to me. There were nurses that were Christians.” (White female, 61 years of age, spouse of patient)

Theme 3: Comfort in God’s Plan

Most of both Black and White caregivers believed that God, not the medical team, was in control of their loved one’s outcome and that the outcome was predetermined (e-Appendix 3). Caregivers described acceptance about God’s plan. Religion and spirituality were a major source of resiliency and positive coping for caregivers:

> "So, my faith, it really, it kind of helped me out a little bit, because I believe God says when it's our time, it's our time. And I don't think it was ready for her [the patient] to go yet. So, it wasn't her time." (Black female, 43 years of age, child of patient)

> "Well, I kept thinking. You know, like why? You know, like why God, why? . . . And then I remember my mom would always say to me, 'You may not like or understand what God does, but he knows why he's doing it, and he has his reasons for doing so.'" (White female, 55 years of age, spouse of patient)

A few caregivers believed God was working through their doctors, which engendered similar feelings of comfort.

Theme 4: Desire for Easily Accessible Spiritual Spaces in the ICU

Caregivers offered suggestions for improving spiritual support of caregivers in ICUs. Although most Black and White caregivers knew about spaces in the hospital for prayer and reflection, they endorsed difficulty accessing these spaces. They emphasized the anxiety associated with leaving their critically ill loved ones to access a distant chapel. Thus, they suggested that ICUs have adjacent chapels or spaces for caregivers to pray:

> "I guess if you're going to make it [chapel] available, make it more convenient versus having to go so far away." (Black male, 60 years of age, spouse of patient)

> "One thing that did frustrate me about the chapel is they didn't publish any service times." (White female, 57 years of age, spouse of patient)

Theme 5: Shared Desire for Proactive Clinician Involvement in Family's Religion and Spirituality

Both Black and White caregivers offered another suggestion for improving spiritual support of ICU caregivers: that clinicians engage proactively with caregivers' religious and spiritual needs and beliefs. For example, caregivers preferred to have spiritual resources offered to them, rather than having to identify resources themselves:

> "If that's offered up front, you can, the patient can make their, avail themselves of that service and not have to prompt. . . . I would say that it's easier for people that are going through a medical crisis to have things offered versus having to ask." (Black male, 60 years of age, spouse of patient)

In addition, caregivers hoped that clinicians would ask about their religious and spiritual beliefs:

> "If there was any way to encourage care teams to be more comfortable and feel safer talking about those things, I would love to see it." (Black female, 31 years of age, child of patient)

> "I don't know when in the conversation it should come up, but maybe one of those early rounding times, you know. 'Do you have any spiritual needs?' . . . Or, yeah, 'There is a chapel there, or you know, maybe even a counselor.' You know,

> something like that would probably be very helpful." (White female, 52 years of age, spouse of patient)

Discussion

In this qualitative study of caregivers with unmet spiritual needs or a high degree of spirituality, Black and White family caregivers reported finding comfort in a predetermined plan for their loved one, and they expressed desires for reflective spaces proximate to the ICU and for clinicians to engage with their spiritual beliefs and needs. In contrast, racial differences were present in caregivers' reports of engagement with clinicians about religion and spirituality.

Themes that described internal desires or sentiments (eg, comfort in God's plan) were represented consistently among both Black and White caregivers, whereas themes that described external experiences (eg, interactions with clinicians) demonstrated racial differences (Fig 1). This finding may be aligned with critical race theory, which posits that social structures and norms, rather than individual differences, are the root cause of racialized experiences.[37] In other words, our results may suggest that religion and spirituality serve similar supportive roles for Black and White caregivers dealing with serious illness; however, the way that these beliefs and needs are shared with and appraised by agents of the health care system is different for Black and White caregivers.

Our results show is a seeming contradiction: that some Black caregivers want clinicians to inquire about their spiritual beliefs and needs, yet they are reluctant to share these with members of the ICU team. We suggest that these themes may be consonant and understood by examining the process of self-disclosure.[38] Disclosing private information about oneself, such as one's spiritual needs, is a common way to build alliance and empathy in human relationships. However, self-disclosure also requires that the recipient be perceived as trustworthy, because an individual's self-image and relationship with the recipient can be threatened if the disclosure is not respected or validated.[39] This is an especially salient risk in power-imbalanced relationships, such as clinician-caregiver relationships.[39] Black caregivers who may have experienced racism in health care settings and with whom clinicians are relatively disengaged regarding matters of religion and spirituality, as corroborated in our results, may view self-disclosure as nonbeneficial or potentially even risky.[18] Instead, responding to a clinician who inquires about religion and spirituality may mitigate the risk of disclosure because it presupposes curiosity about a caregiver's needs and beliefs. Simply put, being asked may be more comfortable than telling. For this reason, many expert groups advocate that clinicians use existing spirituality assessment tools to begin conversations with patients and caregivers,[40–43] and our results support the importance of this recommendation among individuals from minority racial and ethinic groups. Although caregivers may still decline to engage in discussions about religion and spirituality, as was the case for several individuals in our sample, standardizing spiritual assessment and care may lessen the possibility of inadvertently creating disparities in these realms. Further, our results suggest that it is important to begin such conversations earlier in the course of critical illness to avoid reinforcing beliefs that discussion of spiritual support resources, such as chaplaincy, signals impending death.[6,44–47]

Most of the spiritually attuned caregivers in this study's sample believed that a higher power (eg, God) was in control of their loved one's health outcome.[48] This may be at odds with the prevalent approach to medical decision-making in the United States that prioritizes individual agency and autonomy.[49] This tension between spiritually attuned family caregivers' external locus of control and clinicians' internal locus of control requires further study, including assessing clinicians' perspectives.[50] Future research also should examine how multidisciplinary ICU team members can contribute to providing spiritual care in cases where family members desire it.[51]

Our results provide potential practice recommendations for ICUs and critical care clinicians. First, several caregivers endorsed a desire for a reflective space to process spiritual concerns without needing to travel far from their loved one's bedside. Second, Black caregivers reported a reliance on community faith leaders during their loved one's critical illness. Structural pathways to ensure inclusion of community faith leaders in medical decision-making, when desired by caregivers, should be instituted. Finally, nearly all caregivers in our sample confirmed that religion and spirituality play an important role in adaptive coping.[52,53] Given the high burden of psychological distress among ICU caregivers,[54–56] standardizing spiritual assessment and care in ICUs may improve the psychological health of caregivers.[43,57–61] Whether such care is delivered by ICU clinicians themselves or other care team members should be determined by local workflows and capacity assessments.[19,43,57]

Strengths and Limitations

The strength of this study lies in our use of a largely inductive approach to creating the codes, thereby allowing for the emergence of new and unpredicted themes. Moreover, because coders were masked from the race of the caregivers during analysis, this helped to mitigate any biases that might have arisen. One limitation is that we did not query specific religious or spiritual beliefs and denominations. Hence, the conclusions drawn from this study may not be applicable to all religious or spiritual practices, nor are our findings applicable to family caregivers who do not engage substantively with religion or spirituality. Our single-site data embedded in a trial also may limit generalizability; however, the goal of this qualitative study was to query individual experiences in depth. Future multicenter research may help to address these concerns. Finally, given that the interviews were conducted sometimes months after ICU admission, recall bias may have limited the information that caregivers shared during interviews.

Interpretation

In summary, religion and spirituality may be important coping mechanisms for Black and White caregivers experiencing the critical illness of their loved one. Although caregivers in our sample wanted clinicians to engage in discussion of religion and spirituality, this may have happened less effectively for Black than White caregivers. Instituting structural processes to provide standardized and culturally competent spiritual care to patients and caregivers for whom this is important may improve their experience of critical care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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ABBREVIATIONS:

NEST	Needs, Existential Concerns, Symptoms, and Therapeutic Interactions

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Take-Home Points

Study Question:

How do religion and spirituality affect the critical illness experience of Black and White family caregivers of patients who are critically ill?

Results:

In interviews with 9 Black family caregivers and 12 White family caregivers, we observed a shared desire for accessible spiritual spaces and proactive clinician engagement about spirituality, a common belief that God was in control of patients' outcomes, but also more comfort discussing spirituality with community members among Black family caregivers and less clinician engagement about spirituality with Black family caregivers.

Interpretation:

Although spirituality served as an important coping mechanism for all family caregivers in this sample, racial differences in spiritual support offered to family caregivers were observed.

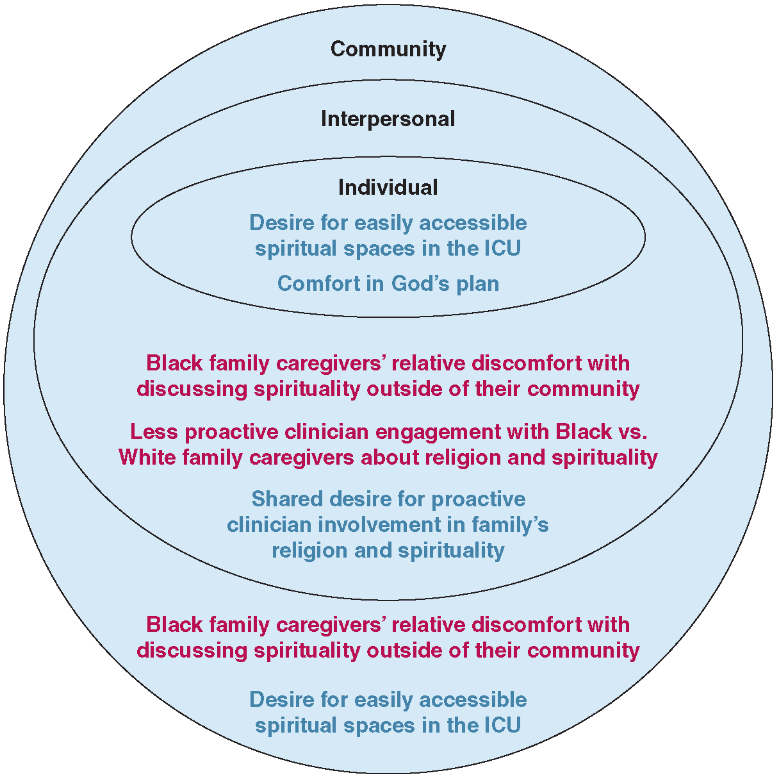

Figure 1 –.

Diagram showing a conceptual model summarizing themes relevant to religion and spirituality among Black and White family caregivers of critically ill patients. Adapted from the socioecological model. Themes that are similar between Black and White family caregivers are shown in blue, and themes that are different between Black and White family caregivers are shown in red. Disparate themes appear in the interpersonal and community level.

TABLE 1]

Analytic Codes and Their Definitions

Code	Definition
Relevance	
Irrelevant	Religion and spirituality not relevant to shared decision-making or to participant personally
Relevant	Religion and spirituality relevant
Medical	Religion and spirituality relevant to shared decision-making
Personal	Religion and spirituality relevant personally
SDM impact	Impact of religion and spirituality on shared decision-making
Hope	Hope, faith, or belief for a positive outcome
Acceptance	Acceptance of medical situation, including poor prognosis and suffering
Miracle	Discussions about miracles or defying possibility
Other	Shared decision-making impacts not captured by above child codes
Personal impact	Statements about how religion and spirituality affected the individual personally during ICU stay
Positive	Positive impacts: resiliency, coping, peace, comfort
Negative	Negative impacts: disagreement with family, bearing burden of suffering
Request/Prayer	Statements about prayers or requests to a higher figure
Locus of Control	Discussion about who the participant believes is in control of their loved one’s outcome
Religious	God is in control
Medical	The doctors are in control
Other	Mixed statements (eg, God acts through doctors) or other statements
Religious Icons	Statements about religious icons (eg, Bible, Qur’an, scripture, crucifix) relevant to ICU stay
Worship Areas	Discussions about worship areas or spiritual places relevant to ICU stay
Relationship with providers	Including communication with providers and relationship with providers (defined as any hospital personnel: doctor, nurse, chaplain, service staff)
Shared identities	How the existence (or lack of) shared identities with clinicians affect shared decision-making or relationship with clinicians
Faith discussions	Whether discussions with provider or nurse about faith happened
Suggestions	Suggestions about how clinicians or hospitals can support religion and spirituality needs
Support	
Hospital	Statements about religion and spirituality support resources from the hospital regardless of whether they were used
Community	Religion and spirituality support from community, eg, friends, church, and so on (excluding family)
Family	Religion and spirituality support from family

Code	**Definition**
Other	Other sources of support
Accessibility	Including how accessible the ICU team were and the faith-based resources (eg, time availability and distance)

TABLE 2]

Demographic Characteristics by Self-reported Race of Family Caregivers

Characteristic	Black (n = 9 [42.9%])	White (n = 12 [57.1%])
Patient characteristics		
Age, y	65.2 (9.7)	64.3 (9.2)
Race		
Black	9 (100%)	0
White	0	12 (100%)
Female sex	7 (77.8%)	5 (41.7%)
Location before hospitalization		
Home	7 (77.8%)	12 (100%)
Skilled nursing facility	2 (22.2%)	0
No. of chronic comorbidities	2.7 (1.7)	2.4 (1.2)
Code status[a]		
Full code	9 (100%)	11 (91.7%)
Do not attempt resuscitation	0	1 (8.3%)
Insurance type		
Medicare	3 (33.3%)	5 (41.7%)
Medicaid	0	2 (16.7%)
Commercial	4 (44.4%)	5 (41.7%)
No insurance	2 (22.2%)	0
Received palliative care consultation[b]	2 (25.0%)	4 (36.4%)
Died during hospitalization	3 (33.3%)	4 (33.3%)
Family caregiver characteristics		
Age, y[c]	50.6 (13.6)	61.7 (10.7)
Female sex	7 (77.8%)	9 (75.0%)
Relationship to patient		
Spouse	2 (22.2%)	9 (75.0%)
Child	7 (77.8%)	2 (16.7%)
Parent	0	1 (8.3%)
Spirituality NEST score	2.2 (2.9)	3.8 (2.9)

Characteristic	**Black (n = 9 [42.9%])**	**White (n = 12 [57.1%])**
Time between discharge from ICU and interview, d	123.8 (65.4)	90.2 (74.0)

NEST = Needs, Existential Concerns, Symptoms, and Therapeutic Interactions.

[a] Code status at the time of randomization in the parent trial.

[b] Two responses missing, 1 each from Black and White family caregivers.

[c] One response missing from a Black family caregiver.

TABLE 3]

Themes and Representative Quotations

Themes and Quotations	Family Caregiver Descriptors (Race/Sex/Age [y]/Relationship to Patient)[a]
Less proactive engagement with Black vs White family caregivers about religion and spirituality	
"No, I never really talked to them about [religion], no."	Black/male/60/spouse
"The chaplain was never even brought up, but I thought they normally do come in when they expect people not to make it."	Black/female/44/child
"Yeah, I mean, it [religion] was touched upon, you know, is there something that you would want or whatever? Do you want a chaplain? . . . That part of it was touched upon by the medical team."	White/female/56/child
"Yeah, I believe the doctor [told] us to keep praying. He’d tell the family, which was me and his mom, and his sister, and his dad."	White/female/64/spouse
Black family caregivers’ relative discomfort with discussing spirituality outside their community	
"I didn’t really get into any discussions about faith . . . other than that our pastor would be visiting. . . . So, he was able to come up and pray for mom while she was in the ICU. So, that was and I really did appreciate that because he drove 2 hours."	Black/female/57/child
"I did not [use the chaplain] only because the visitors we had would come and we would pray."	Black/male/60/spouse
"And I think she had a chaplain come in, you know, a couple of times kind of chatting with her, which I think helped because she was very depressed."	White/female/56/child
"There’s a couple of times I asked for chaplain and he came by. . . . That was good. And he came by subsequent times. . . . It was good interaction."	White/female/78/spouse
"It was clear from my room, from [patient’s] room, again, we had the crucifix hung up. We had, I’d taken all the Facebook messages, I wrote them on Post-its and stuck them on the wall. . . . It was absolutely acknowledged [by the team]."	White/female/57/spouse
Comfort in God’s plan	
"Yeah, it helped tremendously. It definitely kept me encouraged and I think it did for her as well. . . . Things haven’t always been the best, but they’ve always worked out according to his plan and I felt like you know in this moment or in that moment that he wasn’t going to take his hands off of my mom."	Black/female/31/child
"I have a God perspective on it, which allows me to go through the moments with some kind of peace, you know. Not really high emotions or, you know—try to stay focused on the situation at hand."	Black/male/60/spouse
"Well, I just had to trust [God]. . . . I can’t heal [my husband]. If God didn’t heal him, then that was it. . . . You know, a peace of mind. . . . We had to accept what was going on."	Black/female/75/spouse
"It was like, every time I turn around, there were scripture that applied. Don’t fear what they fear. Don’t be frightened. . . . It was kind of like a spiritual high. It was really kind of weird. But, [God] was there. He was bolstering me up."	White/female/61/spouse
"You know, there was no way that I was going to turn anything down because it was like he was being given a gift from God . . . by being offered any organ. And so that so I couldn’t refuse anything, then I’d be refusing, you know, a second chance at life that that, you know, God was like offering to him."	White/female/55/spouse
"[Faith was] incredibly helpful and sustained me and gave me comfort and hope that whatever happened, he’d be OK. He’d be OK. If he’s meant to stay, he’ll stay. And he’ll be OK, which he was. . . . I do hope for a miracle and I do pray for a miracle. But more than that, I pray that God’s will be done. Whatever happens is God’s. Yeah. And I know that he uses pain and illness and death as part of his plan."	White/female/57/spouse
Desire for easily accessible spiritual spaces in the ICU	
"The only thing that I see would be amazing is a meditation room like they have the cancer clinic. . . . That’s a place where they would not have to actually go so far to walk, to still be somewhere accessible."	Black/female/child[a]

Themes and Quotations	Family Caregiver Descriptors (Race/Sex/Age [y]/Relationship to Patient)[a]
"Instead of families having to go to the chapel, having a space that can be a little closer just because I do think those families are having to rely on their faith more with their family and loved ones in more critical care."	Black/female/31/child
"I mean, I don’t even know where the chapel is. . . . That hospital so darn big. Yeah, that [providing information on chapel location] would be actually not bad because I didn’t know."	White/female/78/spouse
"I walked over to the [university chapel] several times during that time. So, you know, having it [chapel] there, I mean, in the waiting area, it probably wouldn’t be a bad idea to have some like a Bible or some other, you know, form of, you know, whether it be different types of religions you can have out there in the waiting area, down there in the Interfaith Chapel. I mean, that might be helpful."	White/female/54/spouse
Shared desire for proactive clinician involvement in family’s religion and spirituality	
"Maybe offer, you know, of course, the chaplain or a place to be able to pray."	Black/female/44/child
"I guess they could have told me [about the hospital resources]. I don’t know. I wouldn’t have known."	Black/female/75/spouse
"I assumed that there was still a chaplain service. I would like to think, it might be nice, actually not thinking about it. If at some point earlier in the ICU stay, if a medical team member offered up that availability or that possibility if needed and maybe not put so much of that onus on the family member."	White/female/52/spouse

[a] Did not report age.