

OPEN

Differences in Family Involvement in the Bedside Care of Patients in the ICU Based on Self-Identified Race

OBJECTIVES: Being a caregiver for a patient in the ICU can place emotional burden on families and engaging families in caregiving can reduce psychological distress. Our goal was to observe support methods used by families in the ICU and identify differences between race/ethnicity.

DESIGN: A secondary analysis of a multicenter before-and-after clinical trial.

SETTING: Three hospitals in Chicago, Providence, and Florence, Italy.

PARTICIPANTS: Family members of patients admitted to the ICU.

INTERVENTIONS: In the primary study, an intervention was designed to engage families in seven domains that were based on the five physical senses (taste, touch, sight, smell, and sound), personal care, and spiritual care of the patient. During the control phase, nursing staff observed and recorded if they witnessed families participating in support methods unprompted.

MEASUREMENTS AND MAIN RESULTS: We compared the use of support methods among families from different races, categorized by race as either White, Black, or other using generalized estimating equation population-averaged logistic regression analysis. A total of 133 patients and 226 family members were enrolled in the control arm of the primary study, with patients being 71.2% White, 17% Black, and 11.8% other. Compared with Whites, families who identified their race Black or other may be more likely to participate in support methods that included personal care, touch, or spiritual care. Families who identified as Black may also be more likely to incorporate audio or sound. There were no differences in the categories of sight, smell, or taste.

CONCLUSIONS: Our study identifies racial differences in the use of bedside support methods in the ICU. Guiding families in a culturally congruent and open-minded manner may have the potential to decrease family distress and improve the experience for families in the ICU.

KEY WORDS: family engagement; intensive care unit caregiving; racial differences

Eduardo R. Nunez, MD¹

Gianluca Villa, MD²

Rory McFadden, RN³

Amy Palmisciano, RN, BSN⁴

Iacopo Lanini, BS²

Sean O'Mahony, MD³

J. Randall Curtis, MD, MPH⁵

Mitchell M. Levy, MD⁶

Timothy Amass, MD, ScM^{7,8}

To the Editor:

Being a caregiver for a patient in the ICU can place emotional burden on family members and has been associated with adverse mental health effects including symptoms of post-traumatic stress disorder, anxiety, depression, and complicated grief (1, 2). Causes of stress may be related to the challenges of decision-making, prognostic uncertainty, and witnessed suffering

Copyright © 2021 The Authors. Published by Wolters Kluwer Health, Inc. on behalf of the Society of Critical Care Medicine. This is an open-access article distributed under the terms of the Creative Commons Attribution-Non Commercial-No Derivatives License 4.0 (CCBY-NC-ND), where it is permissible to download and share the work provided it is properly cited. The work cannot be changed in any way or used commercially without permission from the journal.

DOI: 10.1097/CCE.0000000000000365

leading to feelings of helplessness (3). Prior work has shown that engaging family members in the care of loved ones in the ICU can counteract feelings of helplessness and improve adverse mental health effects associated with taking care of a loved one in the ICU (4, 5).

Race and ethnicity are important predictors of preferences for ICU care and care received (6, 7). However, little is known about what bedside practices are employed by families in the ICU to support their loved ones and become more engaged in caregiving. Our goal was to describe support methods employed by families across different racial and ethnic backgrounds to help identify opportunities for supporting those patients and family members.

MATERIALS AND METHODS

Study Design, Participants, and Setting

This was a secondary analysis of a prospective multicenter, multinational before-and-after clinical trial studying the impact of an intervention designed to engage family members of patients at high risk of dying while in the ICU (5). Using an iterative process based on literature review of family involvement in end-of-life care, the research team developed seven domains in which family participation could be beneficial, including the five physical senses (taste, touch, sight, smell, and sound), personal care, and spiritual care of the patient; forming a set of family care rituals. During the control phase of the clinical trial, nursing staff observed and recorded if family participated in any of the rituals without having introduced them to the family. For this analysis, we studied only the preintervention phase to focus on family engagement without prompting or introduction of support methods. The full clinical trial protocol is discussed elsewhere (5).

Eligible participants included family members of ICU patients with a predicted ICU mortality higher than 30% as determined by the admitting ICU attending within the first 24 hours of admission. Exclusion criteria included an anticipated ICU length of stay less than 24 hours, admission to the ICU for comfort care, age less than 18 years, pregnancy, or incarceration.

Participants were recruited from three ICUs, including: Rhode Island Hospital in Providence, Rhode Island; Rush Medical Center in Chicago, Illinois; and Azienda Ospedaliero Universitaria Careggi in Florence, Italy, between September 2015 and September 2016.

Human subject's approval was obtained from the institutional review boards (IRBs) of each site (Rhode Island Lifespan IRB Number 4089-15). All subjects enrolled provided informed consent.

Data Collection

Nurses in the ICUs were asked to record throughout each shift if they observed families participating in the listed support methods. Observations could be recorded at any time during the shift so as not to impact the clinical care of the patient. During each 12-hour shift, the nurse would record the presence, but not the frequency, of each specific support method and data were later entered into Research Electronic Data Capture.

At enrollment, basic demographic information was collected for patients and family members, as well as reason for ICU admission. Acute Physiology and Chronic Health Evaluation II and Sequential Organ Failure Assessment scores were calculated for the first 24 hours of ICU admission.

Primary Outcome

We compared the use of rituals among families from different races, categorized by the race of the patient as reported by family members, as either White, Black, or other. Rituals were compared within larger category as well as by individual activity.

Statistical Analyses

We performed logistic regression models using individual generalized estimating equation population-averaged with exchangeable correlation structure to compare presence of rituals by race. This approach was chosen as observations are nested within families and facilities. A two-tailed *t* test statistic was used to determine statistical significance with White race as the reference. An omnibus test was used to determine differences for race as a whole, and then, post hoc analyses were completed comparing White to Black race and White to other race (non-White, non-Black).

Sensitivity Analysis

To explore the possibility that participants from Florence, Italy, who identify as White may be culturally different than participants who identify as White in the United States, we performed a sensitivity analysis

excluding participants recruited at the Florence facility from our logistic regression models.

RESULTS

A total of 133 patients and 226 family members were enrolled in the control arm of the primary study, having a mean age 65 and 52 years, respectively (**Table 1**). Overall, 44% of patients were female and 71.2% identified as White, 16.9% as Black, and 7.4% as other. Among family members, 67% self-reported as female, 75.2% as White, 13.7% as Black, and 11.1% as other. Families self-reported country of birth were 67% United States, 20% Italy, 5% Latin America, 5% Europe, and 1% Asia. Of those who identified their race as other, 70% of patients and 73.3% of families had their country of birth in Latin America.

Families who self-identified their race Black or other were more likely to participate in support methods that included personal care, touch, or spiritual care compared with Whites (**Table 2**). Blacks were also more likely than Whites to use support methods that incorporated audio or sound. There were no differences in the categories of sight, smell, or taste. There were also several differences between races for specific support methods. Family members who self-identified as Black were more likely than those who self-identified as White to bring in a blanket or audio of the patient's favorite music, hold the patient's hand, apply oral suctioning, and read to the patient from a favorite book or spiritual reading (**eTable 1**, <http://links.lww.com/CCX/A548>).

Those who identified their race as other were more likely than those who identified as White to use massage, apply lotion, freshen patient's pillow, hold patient's hand, apply oral glycerin swab to patient's lips, assist with the turning of a patient, place a wet wash cloth on patient's forehead, read to the patient from a favorite book, poem or religious passage, or bring pictures, audio, videos, or favorite food from home (**eTable 1**, <http://links.lww.com/CCX/A548>).

In the sensitivity analysis that excluded participants recruited in Florence, Italy, only the ritual of spiritual care was more likely to occur in those who identified their race as other compared with White (**eTable 2**, <http://links.lww.com/CCX/A549>).

DISCUSSION

There are several different ways in which family members support their loved ones who are critically

TABLE 1.
Participant Characteristics

Variable	Patients (n = 136)	Family (n = 226)
Female, n (%)	61 (44.9)	151 (66.8)
Surrogate relationship, n (%)		
Spouse/partner		48 (21.2)
Child/step-child		97 (42.9)
Sibling		24 (10.6)
Parent		20 (8.8)
Other relative		25 (11.1)
Friend		10 (4.4)
Other		2 (0.9)
Mean age (range), yr	64.7 (19.0–91.3)	52.8 (18.5–89.9) ^a
Race, n (%)		
White	97 (71.2)	170 (75.2)
Black or African American	23 (16.9)	31 (13.7)
Asian	3 (2.2)	5 (2.2)
Native American or American Indian	1 (0.7)	1 (0.4)
Other	10 (7.4)	15 (6.6)
ICU admission		
Acute Physiology and Chronic Health Evaluation II score ^a (range)	24.9 (6–51)	
Country of birth (%)		
United States	85 (62.5)	151 (67.1)
Italy	28 (20.6)	46 (20.4)
Central or South America	10 (7.4)	12 (5.3)
Europe (not Italy)	10 (7.4)	13 (5.8)
Asia	2 (1.5)	3 (1.3)
Level of education (%)		
Primary/elementary	13 (9.6)	4 (1.8)
Secondary/junior high	16 (11.7)	22 (9.7)
High school	63 (46.3)	91 (40.3)
College/university	24 (17.6)	82 (36.3)
Advanced degree	11 (8.0)	27 (11.9)

^aPatient Acute Physiology and Chronic Health Evaluation II score within first 24 hr in the ICU (9.6% missing).

Variables with missing data: Family member age (0.9%), family member country of birth (0.4%), and patient level of education (6.6%).

TABLE 2.
Use of Bedside Support Methods by Race Based on Generalized Estimating Equation Logistic Regression Models

Support Method	Race	%	95% CI	<i>p</i> ^a	Omnibus Test <i>p</i> ^b
Personal care	White	13.7	10.1–17.4		0.02
	Black	22.6	13.7–31.5	0.046	
	Other	25.6	14.6–36.6	0.02	
Sight	White	5.2	3.1–7.4		0.35
	Black	8.3	3.0–13.6	0.23	
	Other	8.4	2.1–14.7	0.29	
Smell	White	4.3	2.5–6.2		0.25
	Black	8.2	3.1–13.2	0.10	
	Other	5.8	0.7–10.8	0.59	
Sound	White	3.1	1.3–4.8		0.09
	Black	7.9	2.3–13.5	0.04	
	Other	6.8	0.7–13.0	0.15	
Spiritual care	White	3.0	1.4–4.7		≤ 0.001
	Black	9.9	4.1–15.8	< 0.01	
	Other	13.6	5.7–21.50	< 0.001	
Taste	White	12.6	7.9–17.4		0.60
	Black	11.5	2.3–20.7	0.84	
	Other	18.8	5.4–32.2	0.35	
Touch	White	29.7	24.4–35.1		0.02
	Black	43.5	31.9–55.1	0.03	
	Other	44.6	30.8–58.4	0.04	

^aThe *p* values within support method category are comparing to racially White as the reference group.

^bOmnibus test *p* is comparing overall differences within a category.

ill in the ICU. Our study is novel in that it analyzes support methods employed by families without intervention. Our goal was not to stereotype people by race/ethnicity but rather to help identify opportunities for cultural humility and personalizing care. Higher use of these support methods may suggest that family members differ in the extent to which these methods are found helpful, which should be confirmed in future studies. However, the use of support methods does not equate to preference for these

methods, as there may be unmeasured factors that mediate the use of support methods (e.g., may want to bring objects from home, but infeasible due to transportation constraints).

We found that family members of patients that identified as Black may be more likely to use support methods that involved patient care, touch, sound, and spiritual care at the bedside. Prior work has highlighted the importance of spirituality and family in African-American culture as playing a role in end-of-life

decision-making (6). Of note, in our study, 21.3% and 25% of our cohort had palliative care and spiritual care consults, respectively, which could have an effect on support methods employed by family (e.g., chaplain may facilitate readings from a spiritual passage) (5). Our study suggests that similar engagement in spiritual care may also be more common during caregiving at the bedside with future qualitative analysis needed to identify acts of spirituality unable to be measured by an observer (e.g., prayer, mindfulness, or spiritual care occurring outside the hospital).

Our study also potentially identified differences in support methods among Hispanic race/ethnicity as those which family identified their race as other primarily had a country of birth in Latin America, with our study not including a separate ethnic identification for Hispanics. The small number who identified their race as other were more likely to use support methods that involved patient care, touch, and spiritual care. Prior work with focus groups has shown that Hispanics also emphasize faith and family involvement in their end-of-life communication (8).

Our study has several important limitations. First, because of the three specific locations of this study, our finding may not generalize to other regions. Second, the relatively small sample size makes it infeasible to compare support methods across different races other than White, Black, and other. Third, our study also includes a site from Italy where patients were mostly identified as White, but this site is culturally different from the sites in the United States. In the sensitivity analysis excluding the Italy site, most of the differences observed between races were no longer statistically significant. However, this may be because the sample size is too small to detect differences without the Italian participants. Additionally, we did not collect demographic information on the nurses recording these support methods, and it is possible that factors such as gender, race, and ethnicity of the observer could introduce bias in the measurement of observations.

Overall, our study highlights differences in caregiving and family engagement among different races and ethnicities. Encouraging and guiding families in a culturally congruent and open-minded manner may have the potential to decrease family distress and improve the experience for families in the ICU. Further work, including qualitative exploration and studies

with larger sample sizes, is needed to help better understand family engagement preferences in the ICU.

ACKNOWLEDGMENTS

We thank Gary Philips, MAS, for statistical analysis and the bedside nursing for participating in data collection while simultaneously caring for their patients. Study data were collected and managed using Research Electronic Data Capture (REDCap) tools hosted at Brown University. REDCap is a secure, web-based application designed to support data capture for research studies.

- 1 *The Pulmonary Center, Boston University School of Medicine, Boston, MA*
- 2 *Department of Health Sciences, Section of Anesthesiology, Intensive Care and Pain Medicine, University of Florence, Florence, Italy*
- 3 *Department of Internal Medicine, Palliative Medicine Section, Rush University Medical Center, Chicago, IL*
- 4 *Rhode Island Hospital, Research Division of Pulmonary, Critical Care & Sleep, Providence, RI*
- 5 *Division of Pulmonary, Critical Care, and Sleep Medicine, University of Washington, Seattle, WA*
- 6 *Department of Medicine, Division of Pulmonary, Critical Care & Sleep, Brown University, Providence, RI*
- 7 *Department of Medicine, Division of Pulmonary Sciences & Critical Care, University of Colorado Denver, Denver, CO*
- 8 *Department of Veterans Affairs, Eastern Colorado Health Care System, Denver, CO*

Supplemental digital content is available for this article. Direct URL citations appear in the printed text and are provided in the HTML and PDF versions of this article on the journal's website (<http://journals.lww.com/ccejournal>).

Dr. Amass's institution received funding from the National Heart, Lung, and Blood Institute (grant T32 HL134625). The remaining authors have disclosed that they do not have any potential conflicts of interest.

For information regarding this article, E-mail: Eduardo.Nunez@bmc.org

REFERENCES

1. Anderson WG, Arnold RM, Angus DC, et al: Posttraumatic stress and complicated grief in family members of patients in the intensive care unit. *J Gen Intern Med* 2008; 23:1871–1876
2. Azoulay E, Pochard F, Kentish-Barnes N, et al; FAMIREA Study Group: Risk of post-traumatic stress symptoms in family members of intensive care unit patients. *Am J Respir Crit Care Med* 2005; 171:987–994

3. Nunez ER, Schenker Y, Joel ID, et al: Acutely bereaved surrogates' stories about the decision to limit life support in the ICU. *Crit Care Med* 2015; 43:2387–2393
4. Davidson JE, Aslakson RA, Long AC, et al: Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. *Crit Care Med* 2017; 45:103–128
5. Amass TH, Villa G, OMahony S, et al: Family care rituals in the ICU to reduce symptoms of post-traumatic stress disorder in family members—a multicenter, multinational, before-and-after intervention trial. *Crit Care Med* 2020; 48:176–184
6. Shrank WH, Kutner JS, Richardson T, et al: Focus group findings about the influence of culture on communication preferences in end-of-life care. *J Gen Intern Med* 2005; 20:703–709
7. Muni S, Engelberg RA, Treece PD, et al: The influence of race/ethnicity and socioeconomic status on end-of-life care in the ICU. *Chest* 2011; 139:1025–1033
8. Braun UK, Beyth RJ, Ford ME, et al: Voices of African American, Caucasian, and Hispanic surrogates on the burdens of end-of-life decision making. *J Gen Intern Med* 2008; 23:267–274