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Racial Minority Families' Preferences for Communication in Pediatric Intensive Care Often Overlooked

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Abstract

Objective: To compare the communication experiences and preferences of racial/ethnic minority and non-Hispanic white (NHW) families in the pediatric intensive care unit (PICU), including their interactions with bedside nurses.

Methods: Retrospective cohort study performed at a quaternary university-affiliated children's hospital with 70 pediatric intensive care beds. From October 2013 to December 2014, English speaking family members of children admitted to the PICU were asked about their experiences communicating with PICU caregivers using a survey tool.

Results: 107 participants were included for analysis, of which 60 self-identified as a racial minority and 47 as NHW. Overall, 11% of families chose family meetings as their preferred setting for receiving information, as compared to family-centered rounds or unplanned bedside meetings. Only 50% of those with a family meeting felt they learned new information during the meeting. Chi-square statistics or Fisher's exact tests showed that minority families were less likely to report their bedside nurses spent enough time speaking with them (minority 67%, NHW 85%; $p = 0.03$) and less likely to receive communication from the medical team in their preferred setting (minority 63%, NHW 85%; $p = 0.01$). Logistic regression, controlling for covariates including education, insurance, and risk of mortality, showed that the relationship between minority status and concordance of preferred setting persisted (OR=0.32, 95% C.I.: 0.11, 0.91).

Conclusion: In general, families of PICU patients prefer meeting with the medical team during rounds or unplanned bedside meetings as opposed to formal family meetings. Despite this preference, minority families are less likely to receive communication from the medical team in

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Conflicts of Interest:

The authors declare no conflicts of interest.

their preferred settings. Meeting all families' communication setting needs may improve their communication experiences in the PICU.

Keywords

Pediatric Intensive Care Units; Pediatric Nursing; Patient Satisfaction; Minority Health; Health Communication; Culturally Competent Care

1. INTRODUCTION

Effective communication with families of children admitted to the pediatric intensive care unit (PICU) is an integral aspect of building trust with the medical team, minimizing conflict, decreasing family stress, and increasing family satisfaction with care.¹⁻⁴ The three primary modes of communication in the PICU are family meetings, family-centered rounds, and unplanned bedside meetings. Family meetings and family-centered rounds have been the most frequently studied communication settings⁵⁻¹²; however, bedside meetings have rarely been studied.⁵ It is yet to be determined which, if any, of these communication settings are most ideal or preferred by families of children admitted to the PICU, and how families' race/ethnicity might impact their preferences.

Outside of the PICU, racial/ethnic minority families are more likely to report feeling unheard and report instances of discrimination compared to non-Hispanic white (NHW) parents.¹³ While culturally-competent care is endorsed by both the American Board of Pediatrics and the Society of Critical Care Medicine as an important aspect of family-centered care,^{14,15} few studies have evaluated the experiences of racial/ethnic minority families of children cared for in the PICU. Studies have shown the important impact of using professional medical interpreters for limited-English proficient families.^{16,17} However, providing culturally-competent care requires more than simply speaking the same language,^{14,15} and few studies have assessed the impact of minority status on communication experiences in the PICU, independent of language proficiency.

Delivering culturally sensitive care has been cited by the American Board of Pediatrics as an important skill for pediatricians.¹⁸ Culturally sensitive care requires consideration of not only language and race/ethnicity, but also religion, sexual orientation, socioeconomic status and other individual characteristics that can place a person into a social outgroup. However, these other factors can be difficult to measure or account for and have thus far been understudied. Racial/ethnic minority children have been shown to suffer from significant health disparities.¹⁹ Although a 2011 study of a large PICU database showed no difference in mortality in racial/ethnic minority children compared to NHW children,²⁰ there is evidence of higher mortality rates in racial/ethnic minority children in PICU subpopulations, such as children intubated for severe asthma or children with congenital heart disease.^{21,22} Additionally, a recent study of very low birth weight children in the neonatal intensive care unit indicated that while mortality may not differ, significant variation exists among babies of different races/ethnicities in regards to the quality of the care they receive.²³ Failing to acknowledge differing cultural expectations can interfere with effective patient care.¹ Ensuring culturally equal care requires assessing all interactions families have with the

medical team – including not only physicians, but also nurses and other healthcare providers – as well as evaluating the impact of different settings for communication with families and how these might impact their communication experiences. In this study, we aimed to compare the communication experiences of racial/ethnic minority and NHW families in the PICU.

2. MATERIALS AND METHODS

2.1 Design/Setting/Participants

This study is a retrospective cohort study that is a secondary analysis of previously published data which evaluated communication patterns among providers and limited English proficient families in the PICU.²⁴ In this current study, we excluded our non-English-speaking families because those findings showing poorer communication experiences for non-English-speaking families compared to English-speaking families have previously been published.²⁴ Data from this study represent English-speaking families of children admitted to the PICU in a single center, urban, quaternary medical center between October 1, 2013 and December 2014 for a period between 24 hours and 7 days. Throughout this paper, PICU refers to both the general medical-surgical pediatric intensive care unit and the pediatric cardiac intensive care unit. Cohorts were defined as NHW if families self-identified as Caucasian or NHW, or Minority if they self-identified as any other ethnicity or race.

Our primary outcome measure was family-rated communication experiences with physicians and nurses in the PICU. The three main opportunities for communication with families include family-centered rounds, formal scheduled family meetings, and informal unplanned bedside meetings.^{5,25} In our institution, family-centered rounds are conducted at the bedside twice daily. Families are invited by the bedside nurse to participate and receive a flyer explaining the purpose of rounds when their child is admitted to the PICU. Families are also encouraged to view a video available on our intranet explaining the purpose and process of family-centered rounds.²⁶ Family meetings are scheduled by our social worker and convened at the discretion of the PICU attending physician or by request from the family. These meetings are conducted in a separate conference room, usually with the attendance of social workers, nursing staff, and subspecialists, as necessary. Bedside meetings occur unpredictably in the patient's room and at the discretion of the treating provider.

Families were approached for enrollment Tuesdays through Fridays to allow time to experience morning and evening rounds and have opportunities for interactions with providers in all three settings. Mondays were excluded because family meetings were rarely scheduled due to a new team of physicians beginning clinical service. Prior work in our group also revealed family meetings occurred infrequently on weekends due to the lack of availability of supportive staff, such as social workers, consultants, and case managers.⁵ All eligible patients with family members available at the bedside were approached. Up to two family members per patient were invited to participate; however, individuals could only participate in the survey once per hospitalization, and families were not approached on subsequent hospitalizations. Written consent was obtained from family members prior to survey administration. The study was approved by our institutional review board.

2.2 Data Collection

We developed and validated a survey to explore communication experiences between PICU providers and families described in our prior study.²⁴ In brief, the survey was pre-tested and reviewed for language, tone, length, content, and consistency by study team members. The survey was then reviewed with focus groups of ten families, resulting in language revisions and order of survey items. This iterative process was repeated until no new edits emerged.

The complete survey is available as supplemental material in the online edition of *Journal of the National Medical Association*. Self-reported family demographic data was collected, including age, relation to patient, marital status, ethnic/racial background, preferred language, country of birth, level of education, and English proficiency. The survey included items asking families where they most commonly received communication from the medical team and where they would most prefer to receive communication, as well as their presence and participation in rounds, family meetings, and other communication settings, including at the bedside. A 5-point Likert-scale (from Strongly Disagree to Strongly Agree) was used to explore families' satisfaction with communication during rounds, family meetings, and bedside meetings. For example, "Please indicate how much you agree with the following statement: 'After rounds were completed, I understood the plan of care.'" Patient data included child diagnosis, PICU length of stay, and the Paediatric Index of Mortality (PIM2)²⁷ score gathered from Virtual PICU Systems, LLC.²⁸ The PIM2 is a validated and commonly used score that estimates pediatric mortality risk using data readily available at the time of PICU admission, including systolic blood pressure, pupillary reaction to light, laboratory values, need for mechanical ventilation, admitting diagnosis, and other patient demographic features.²⁷ Study data were collected and managed using Research Electronic Data Capture (REDCap).²⁹

2.3 Statistical Analyses

Descriptive statistics were used to summarize demographic and clinical characteristics of the sample. The primary outcome measures were (1) families' preferred settings for communication (family-centered rounds, family meetings, and bedside meetings) compared to the actual settings chosen by the health care team; and (2) satisfaction with the amount of time spent communicating with the physician and nursing teams. For statistical analysis, the 5-point Likert scale variables were recoded as dichotomous measures using the "Strongly Agree" category as the cutoff point because of a skewed distribution of the measures. First, Pearson chisquare statistics, Fisher's exact tests or median two-sample tests were used as appropriate to test the association between the outcome measures and race/ethnicity of the family. Logistic regression models, in which covariates (e.g., education, insurance, and risk of mortality (PIM2) score) were controlled, were then used to assess racial differences in regard to odds of (1) concordance between preferred communication setting and most frequent communication setting; and (2) satisfaction with the amount of time spent communicating with the physician and nursing teams. Analyses were conducted using SAS v9.4 (SAS Institute, Cary, NC).

3. RESULTS AND DISCUSSION

3.1 Results

We approached 124 English-speaking families and received 109 (88% response rate) surveys. Parents reported “not available at this time” or “not interested” as reasons for nonparticipation. Of the 109 participants, two families did not identify English as their preferred language; therefore, they were excluded from this analysis. Of the 107 participants, 60 self-identified as minority and 47 as NHW. Demographic features (Table 1) of the patients revealed no differences between minority and NHW patients, with the exception that minority patients were more likely to have Medicaid insurance and have been admitted for primary respiratory diagnoses. Characteristics of the family members are presented in Table 2. NHW family members were more likely to be married and to have been born in the United States as compared to minority families.

Most families reported having been present during family-centered rounds, with no significant differences between minority and NHW families having been invited to participate on rounds or understanding the plan after rounds (Table 3). Overall, almost all family members report having been present at the bedside when their child was being evaluated (105/107, 98%). There were no differences between minorities and NHW in preferred setting for communication with the medical team; however, only a small number of families (minority 13%, NHW 9%) appeared to prefer formal family meetings as compared to family centered rounds or unplanned bedside meetings (Table 4). In our cohort, there was no significant difference in the frequency families reported having had family meetings, with most of these families feeling that they understood the plan after the meeting (minority 71%, NHW 73%; $p = 0.9$), but only about half expressed they had learned new information during the meeting.

Similarly, there was no significant difference between minorities and NHW in the setting they reported most often receiving communication from the medical team. However, when assessing concordance between preferred communication setting and most frequent communication setting, minority family members were significantly less likely to receive communication in their preferred setting ($p = 0.01$). After controlling for educational attainment, insurance status, and PIM2 score in the logistic regression model (Table 5), the effect of minority status on concordance persisted (OR=0.32, 95% C.I.: 0.11, 0.91). That is, controlling for covariates in the logistic regression model, the odds of minority families receiving communication from the medical team in their preferred setting was only about 32% of the odds for NHW families.

There were no significant differences between minority and NHW families with regards to their experiences interacting with the physician team (Table 3). However, minority families were significantly less likely to feel their bedside nurses spent enough time speaking with them (67% minorities, 85% NHW; $p = 0.03$). After controlling for educational attainment, insurance status, and PIM2 score in the logistic regression model (Table 5), the effect of minority status on satisfaction with time dedicated by nursing staff did not persist (OR=0.40, 95% C.I.: 0.14, 1.15).

3.2 Discussion

Family meetings have been among the most studied methods of communication with families in the PICU. In our study, regardless of race, few families reported a preference for receiving communication from the medical team during family meetings as compared to other settings such as rounds or unplanned bedside meetings. Family meetings are often chosen as the preferred setting to communicate with families of the most complex or critically ill children, regardless of race or language,⁶ and PICU physicians have indicated a preference to discuss redirection of care in meeting rooms compared to at the bedside.⁵ Prior studies indicate medical providers believe family meetings play an important role in communication; however, there is a lack of data suggesting families share similar feelings.⁷ Our results further call into question the over-reliance on family meetings as the main form of communication with families.

In our population, only about half of the families that reported having a family meeting felt they had learned new information during the meeting. Family meetings are more likely to have multidisciplinary and consultant attendance compared to bedside meetings,⁵ thus they may be most ideal for families of complex patients to hear input from the multiple members of their care team at once and ensure they are making decisions with multidisciplinary input.⁶ Although family meetings may be one method for communicating with families, they may not be ideal for partnership building. Given the intimate setting, bedside meetings may allow for more personalized discussion that can allow providers to build rapport and trust with their families. There is value in communicating with families in all three settings; taking into consideration and acknowledging family preferences allows PICU providers to truly practice family-centered care. Overreliance on only one communication setting may lead to missed opportunities to personalize care and optimize communication.

Multiple studies in other settings indicate that differences exist in how medical providers communicate with minorities that go beyond simply speaking the same language, and which may be improved in situations of race concordance or with increased cultural competency.^{30–34} Decreased levels of trust and poorer communication experiences have been described for minority families in pediatric critical care medicine.¹³ Our results further indicate minority families in the PICU are less likely to receive communication in their preferred settings, which may be having a direct impact on how these families experience their child's care. Providers may be doing a disservice to minority families by not specifically considering how their communication needs and preferences may differ, as well as recognizing that providers' own communication styles may differ when approaching a family of a different racial/ethnic background. Future studies should also focus on assessing the impact of other types of minority status, including religious affiliation, sexual orientation, and socioeconomic status.

3.3 Limitations

Given the large and growing racial/ethnic minority population in the United States, this study provides insight into a very important group of patients and their families. It is possible that other diversity categories, including ability/disability, gender and gender identity, sexual orientation, and religious beliefs, may impact families' communication

experiences; however, this study was only able to assess the experiences of racial/ethnic minorities. Since our sample was recruited from a single medical center in an urban setting, it is difficult to assess generalizability of the results to all families. While our primary survey tool had not been previously validated, it was rigorously evaluated with focus groups of medical providers and families to mitigate threats to validity. Since we surveyed families about their communication experiences in aggregate, we were unable to account for differences between individual communication experiences, including the number of staff members they had interacted with or if the parent being surveyed had been the primary one available for communication. We were similarly unable to control for communication differences between different nurses or physicians. While we assessed patient length of stay, we were unable to control for parental time at bedside or if the surveyed parental had been the one most available for communication with the physician or nursing staff. Finally, we were unable to collect information about why families did not prefer family meetings compared to other communication settings.

4. IMPLICATIONS

Compared to NHW, minority families are less likely to receive communication in their preferred settings. This may contribute to decreased satisfaction in minority families, as well as to health disparities. Regardless of race or ethnicity, families prefer to communicate with PICU providers during rounds or unplanned bedside meetings rather than formal family meetings. While there is a continued role for formal family meetings, PICU providers should be selective about which patients or families may most benefit from a family meeting and focus on ensuring optimal communication during rounds and informal bedside meetings.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations:

PICU	Pediatric Intensive Care Unit
NHW	Non-Hispanic White
PIM2	Pediatric Index of Mortality Score

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Table 1.**Patient Characteristics**

Patient Characteristics	Minority N=60 N (%)	Non-Hispanic White (N=47) N (%)	p Value
Gender, female	24 (40)	17 (36)	0.69
Age, years: mean (SD)	6.4 (9.4)	5.9 (6.8)	0.76
Unit			
Pediatric ICU	46 (77)	32 (68)	0.32
Cardiac ICU	14 (23)	15 (32)	0.32
Primary Diagnosis			0.008
Respiratory	33 (55)	14 (30)	
Cardiac	11 (18)	16 (34)	
Trauma/Surgery	7 (12)	4 (9)	
Hematology/Oncology	4 (7)	1 (2)	
Neurologic	2 (3)	3 (6)	
Sepsis/Shock	1 (2)	8 (17)	
Other	2 (3)	1 (2)	
Chronic Condition Present	46 (77)	37 (78.7)	0.8
Medicaid	35 (58)	11 (23)	<0.001
Prior Hospitalization			
2 Prior Hospitalizations	36 (60)	29 (62)	0.86
Prior ICU Admission	52 (87)	40 (85)	0.82
Current Hospitalization			
ICU Length of Stay, days: median (IQR)	4.9 (2.4, 8.4)	5.8 (2.4, 12)	0.5
PIM2 Risk of Mortality: mean (SD)	2.1 (3.9)	3.1 (4.4)	0.22

SD, standard deviation

IQR, interquartile range

Table 2.

Family Characteristics

Family Characteristics	Minority (N=60) N (%)	Non-Hispanic White (N=47) N (%)	<i>p</i> Value
Relationship			0.53
Mother	42 (70)	28 (60)	
Father	14 (23)	15 (32)	
Other Family	4 (7)	4 (9)	
Age, years: mean (SD)	34.8 (10.8)	37.5 (10.8)	0.16
Race			
White	n/a	47 (100)	
Black	38 (63)	n/a	
Latino	17 (28)	n/a	
Other	5 (8)	n/a	
Married	27 (45)	38 (81)	< 0.001
Born in the United States	52 (87)	47 (100)	< 0.001
High School Degree or Higher	55 (92)	47 (100)	0.07

SD, standard deviation

Table 3.

Experiences with Communication in Different Settings

Family Centered Rounds	Minority (N=60) N (%)	Non-Hispanic White (N=47) N (%)	p Value
Present during rounds	54 (90)	46 (98)	0.13
Invited to participate on rounds	47 (78)	41 (87)	0.23
Understood plan after rounds completed	30 (50)	30 (64)	0.18
Formal Family Meetings	Minority (N=17) N (%)	Non-Hispanic White (N=11) N (%)	p Value
Understood plan after completion of meeting	12 (71)	8 (73)	0.9
Learned new information during meeting	9 (53)	5 (45)	0.7
Bedside Meetings	Minority (N= 60) N (%)	Non-Hispanic White (N=47) N (%)	p Value
Medical team spends enough time communicating with family	32 (53)	32 (68)	0.12
Updates given outside rounds or meetings	26 (43)	18 (38)	0.6
Not addressed while medical team members evaluate child	38 (63)	25 (53)	0.29
Nurses spend enough time speaking to family	40 (67)	40 (85)	0.03
Rely on nurses to explain key aspects of care	37 (62)	30 (64)	0.82

Table 4.

Preferred vs. Actual Communication Settings in Minority vs. Non-Hispanic White Families

Communication Settings with Medical Team	Minority (N=60) N (%) ^a	Non-Hispanic White (N=47) N (%) ^a	p Value
Preferred Setting for Communication			
Family Centered Rounds	25 (42)	25 (53)	0.24
Formal Family Meetings	8 (13)	4 (9)	0.54
Bedside Meetings	39 (65)	22 (47)	0.06
Most Frequent Setting for Communication			
Family Centered Rounds	33 (55)	34 (72)	0.07
Formal Family Meetings	5 (8)	1 (2)	0.23
Bedside Meetings	26 (43)	25 (53)	0.31
Concordance Between Preferred and Most Frequent Communication Settings	38 (63)	40 (85)	0.01

^a Participants able to choose more than one response for Preferred and Most Frequent Settings

Table 5.

Logistic regression model comparing communication experiences of minority families with Non-Hispanic White (NHW) families

Variable	Concordance between preferred and most frequent communication setting		Satisfaction with amount of time dedicated by nursing staff	
	OR	95% CI	OR	95% CI
Race/Ethnicity				
NHW	-	-	-	-
Minority	0.32	0.11, 0.91	0.40	0.14, 1.15
Education				
<High School	-	-	-	-
High School	0.31	0.03, 3.5	<0.01	<0.01, >999
College	2.7	0.83, 8.7	0.56	0.17, 1.87
Medicaid				
No	-	-	-	-
Yes	1.5	0.51, 4.5	0.34	0.11, 0.98
PIM2 Risk of Mortality Score	1.04	0.9, 1.21	0.99	0.89, 1.12
Hosmer and Lemeshow Goodness of Fit Test (P-value)		0.56		0.5

PIM2: Paediatric Index of Mortality score