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Racial Differences in Parental Satisfaction with Neonatal Intensive Care Unit Nursing Care

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Abstract

Objective—Nurses provide parental support and education in the neonatal intensive care unit (NICU), but it is unknown if satisfaction and expectations about nursing care differ between racial groups.

Study Design—A prospective cohort was constructed of families with a premature infant presenting to primary care between 1/1/10-1/1/13 (N = 249, 52% white, 42% Black). Responses to questions about satisfaction with the NICU were analyzed in ATLAS.ti using standard qualitative methodology.

Results—120 (48%) parents commented on nursing. 57% of the comments were positive, with black parents more negative (58%) than white parents (33%). Black parents were most dissatisfied with how nurses supported them, wanting compassionate and respectful communication. White parents were most dissatisfied with inconsistent nursing care and lack of education about their child.

Conclusions—Racial differences were found in satisfaction and expectations with neonatal nursing care. Accounting for these differences will improve parental engagement during the NICU stay.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

INTRODUCTION

A premature birth can be a difficult experience for parents. Expectations of a healthy full-term pregnancy are abruptly changed and parents find themselves immersed in an unfamiliar environment. As the caregiver most frequently interacting with parents,[1] the nurse plays an important role in supporting families through the neonatal intensive care unit (NICU) experience.

Parents have identified the nurse/parent relationship as the most important factor affecting parental satisfaction with NICU care.[2, 3] Behaviors identified as positively impacting satisfaction with nursing care cluster into three areas: communicating information in a respectful manner, leading to the development of rapport with the parents;[2, 4, 5, 6, 7, 8, 9, 10, 11, 12] continuity and consistency of nursing care;[2, 4] and providing emotional support and respecting the participation of parents in the care of their infant.[5, 7, 8, 11, 13, 14, 15, 16] Behaviors negatively impacting satisfaction include controlling behaviors such as coldness, lecturing, or ordering;[17] a lack of empathy;[10] multiple caregivers and inconsistency in care;[4, 10] inadequate nurse-patient ratios;[4] and power struggles between nurses and parents with poor communication.[4, 10, 18]

Black patients receive worse quality of care, having poorer access to care, and less timely care compared to white patients.[19, 20] Black patients are less likely to report satisfaction with health care,[21, 22] possibly stemming from differences in provider communication styles, clinician's attitudes, medical mistrust, and perceived racism.[3, 22, 23, 24, 25] Provider uncertainty, biases, and stereotyping may also contribute to unequal treatment.[20]

While nurses play a pivotal role in parental support, literature searches and reviews reveal that studies specifically examining racial differences in satisfaction with NICU nursing care are absent. The purpose of our study is to examine parental expectations and satisfaction with NICU nursing care, and how these expectations may differ between black and white families.

METHODS

Study Subjects

Our sample included self-reported non-Hispanic black and non-Hispanic white participants of a larger prospective cohort study examining various underlying explanations for differences in outcomes of premature infants in the first 2 years after discharge from the NICU. Eligible families in this study included those with an infant born at a gestational age ≤35 weeks or birth weight <2000 grams, presenting within 2 months after NICU discharge to any 1 of 30 Children's Hospital of Philadelphia (CHOP) primary care centers between 1/1/10 and 1/1/13. In this sample, birth dates ranged from 11/10/09 – 09/04/12. Infants were cared for in 35 U.S. East Coast NICU's. Gestational age, birth weight, and maternal race were ascertained during an initial telephone interview or at the first office visit.

Data Collection

The study coordinator contacted and enrolled eligible families. Abt Associates, Inc. administered surveys via telephone within eight weeks of discharge, typically to the mother. The survey contained questions about trust, communication style, expectations of the health care system, and questions on parental satisfaction with their physician and the NICU course. Collected parental data included sex, age, employment, education, home ownership, ethnicity, race, marital status, household resident information, and income. As part of initial data collection, we asked open-ended survey questions about the family's experience with NICU care.

Survey responses were recorded verbatim by Abt Associates, Inc., and encrypted. Analysis was performed by the lead author. The IRB at CHOP approved the study and all participants were consented prior to the onset of any data collection.

Analysis

Survey question responses were imported into ATLAS.ti, version 6.2, a qualitative data analysis software package used for managing, organizing, coding, and displaying output in a variety of methods. We analyzed the data via several stages derived from grounded theory:[26]

1) analytical memo formation to capture thoughts regarding theory;

2) open coding to identify themes and concepts;

3) prolonged engagement and peer debriefing to interpret data and establish validity;

4) thick description with impartial peers to assign context and meaning to the data; and

5) selective coding to solidify core concepts and form factor categories.

After several initial readings of the data, an unprompted nursing care theme emerged. Participants were not directly questioned about nurses or nursing care yet it was a common thread among responses. Several analytical memos were logged and a project codebook was developed for this theme. Data were examined using open coding[26,27] leading to initial categories of factors within the nursing theme. Peer debriefing and thick description maintained coding consistency and established validity of the factor categories. Selective coding refined the initial factor categories discovered during open coding for the entire study cohort and for white and black parents separately.[26, 27]

After selective coding was performed, output for the study included several code reports with textual quotations organized by factor and by race. Query tool reports and network views determined the specific quotes used in the paper. The quality and trustworthiness of the analyses were assessed through four criteria described in previous research: prolonged engagement with the data, credibility, transferability, and confirmability.[28] The factors presented were not chosen *a priori* but were developed from responses. With the exception of some minor edits to improve clarity, all quotes are provided verbatim.

RESULTS

Of the 249 interviews completed overall, 135 parents spontaneously commented on nursing. Of those 135 parents, only parents who made strictly positive or strictly negative comments (N=120, 48% of the overall group) were included in the analysis and reported on in this study. Parent comments were from a total of 27 of the 35 NICU's included in the initial cohort. Of those who commented, 69 (57%) commented positively and 51 (43%) negatively.

Although more commenting parents were white (62%) than black (38%), black parent comments were more negative (58% negative vs. 42% positive) compared to white parent comments (33% negative vs. 67% positive) (Table 1). White parents were more likely to have a higher educational level and income, be married, own their home and be older than black parents (Table 2). Compared to white infants, black infants had higher gestational age and birth weight, yet longer hospitalizations and a complication of preterm birth (Table 3).

Factors Impacting Parent Satisfaction

Several factors impacting parent satisfaction emerged from the data. When parents of both races identified similar factors, there were racial differences regarding the relative importance of the factor.

Common Positive Factors—The following factors contributed to a positive NICU experience and parent/nurse relationship for all respondents: (1) candid interactions with effective communication (frequent and informative exchanges, use of understandable terminology, willingness to answer questions) (64% of respondents); (2) knowledgeable nurses who educate families (19%); and (3) emotional support (positivity, patience, respect, friendliness) (17%). The first factor was mentioned by both races, but with different nuances accompanying its definition: white parents placed special emphasis on informative exchanges and active involvement in the caregiving process, while black parents emphasized attentiveness, compassionate exchanges, and consideration of concerns. Both black and white parents mentioned the concept of a family-centered approach to care. Parents who commented positively on nursing described nurses who "took the time even in the middle of the night" to keep parents informed and were satisfied when nurses were "extremely attentive to the babies." Parents also felt reassured when nurses gave a "good outlook on the situation" and "acted like a family."

Common Negative Factors—Common factors negatively impacting satisfaction included: (1) nurses who did not effectively communicate the care plan, did not involve parents in the care process, or consider parent concerns and wishes (37% of respondents); (2) inconsistent care given by multiple caregivers in an understaffed NICU (35%); and (3) nurses who were disrespectful or displayed undesirable behaviors such as coldness or superiority (28%).

Parents who commented negatively on nursing described a chaotic, cold NICU environment with a high rate of nursing staff turnover. They related having "a different nurse every day," making it difficult to develop relationships and build trust. Many parents felt there were "too many babies for the staff" and that nurses were unable to "involve parents in the care"

process. Parents reported a lack of connection and patience on the part of the nurses and an inability to relate to the parents. For example, “they [nurses] should relate to parents better and not act like our questions are annoying or a waste of time.” Another parent added that “some of the nurses were a little arrogant” and “did not have a warm and welcome attitude.”

Factors Positively Impacting Parent Satisfaction by Race

Black Parents—Factors most important to black parents were: (1) candid interactions and effective communication with an emphasis on attentiveness and compassionate exchanges (63% of respondents); (2) emotionally supportive nurses (21%); and (3) knowledgeable nurses who educate families (16%).

Black mothers commented on the concept of “family” and their desire for a holistic experience where nurses treated both mom and infant as patients. One commented that her nurse “not only took care of him, but took care of me.” Black parents were satisfied with nurses that displayed “compassion” and “warm and loving” attitudes. Respondents appreciated nurses who were “genuine”, “attentive to the babies” and “willing to teach.” Nurses that “went well out of their way to inform and respect” patients were viewed positively, particularly those that “answered all questions,” “explained what was being done,” and kept mothers “updated.” Likewise, nurses that explained concepts and techniques clearly and showed mothers “what to do with a newborn” received positive reviews from parents.

White Parents—Factors most important to white parents were: (1) candid interactions and effective communication with an emphasis on informative exchanges and involvement in the care process (64% of respondents); (2) knowledgeable nurses who educate families (20%); and (3) emotionally supportive nurses (16%).

White parents were satisfied with nurses who kept them informed, describing the nursing staff as being “key” and “nurses are what make it” all come together. One stated that the “nurses were better than the doctors…they gave us a lot of information about how the baby was doing, even at 3:00 am they talked to us each time I called.” Another mother contributed that her anxiety was lessened because the nurses “always knew what was going on.”

Involving parents in their child’s care was important for white parents with many expressing a desire for nurses to consciously “involve parents in the care” process and to be “very patient” especially with new parents. White parents also expressed satisfaction with nurses who provided education, remarking some “were more like teachers than nurses – in a good way.” One parent acknowledged that the nurses “helped us to know our child better before going home” while another shared that she and her spouse returned “home as better parents because of the information given by the nurses at the NICU.” In addition, “willingness to answer questions,” “reassurances” for concerns, and using understandable terminology were also mentioned by white parents as nursing behaviors that enhanced the NICU experience.

Factors Negatively Impacting Parent Satisfaction by Race

Black Parents—Black parents were dissatisfied by: (1) inattentive nurses who communicated poorly and dismissed their concerns and requests (50% of respondents); (2)

nurses who were disrespectful and impersonal (35%); and (3) inconsistent care given by multiple caregivers in an understaffed NICU (15%). One parent noted that “because the other babies were sicker than mine, I felt like my baby did not get as much attention.” Others echoed that sentiment and felt that nurses “did not take urgency when my child was sick” and “didn’t take a lot of time with my son.” Another parent noted that the nurses were not considering her “opinion on how to take care of my baby, they just told me what they were going to do.”

Black parents were also dissatisfied with a lack of “common courtesy,” and dissatisfaction was expressed with nurses that were “frank,” “seemed like they didn’t care,” and “were not attentive.” Moreover, black parents felt certain nurses were not “sympathetic if they had bad news.” Some respondents noted that nurses “didn’t take their jobs seriously” and did not acknowledge that being in the NICU is a “very sad time for some people.” Black parents additionally described an “uncomfortable” setting. One respondent noted that “the nurses really treated me like an imbecile…they actually made me cry…they were treating me like I was a 14-year-old child that just had a baby.” These feelings of discomfort and disrespect were compounded by distress regarding nursing turnover. For example, one parent said her son had “far too many nurses assigned to him, not all of them were familiar with his case.” Another commented that “the rotation sometimes caused to have nurses that were not knowledgeable in the situation” of her child.

White Parents—White parents were dissatisfied with: (1) inconsistent care given by multiple caregivers in an understaffed NICU (56% of respondents); (2) inattentive nurses who communicated poorly and did not inform and involve parents in the care process (24%); and (3) disrespectful and impersonal nurses (20%).

More white parents mentioned that there were “too many babies for the staff” and that “the workload was too much for any nurse.” Nurses were often “too busy to stop and talk, but that was not their fault because they had so many babies to deal with.” One noted there was an obvious “lack of nurses to care for the patients with about five patients to one nurse.” Nursing turnover and schedule rotations led to numerous comments regarding lack of care continuity and inconsistent information. One parent noted that she had “a different nurse every day; the child was only there for six days and I had to go through explaining everything every day.” Others mentioned that they had “different nurses all the time” and that “select nurses who had been there for a long time had their own way of doing things and this created inconsistencies.” Moreover, parents revealed that “some nurses followed some rules and others didn’t” and that since “not all the nurses were always on the same page, the people caring for my child sometimes gave us different information.”

Other parents reported that nurses were not “listening” to them and acted like their questions and issues were “annoying or time wasting.” Additionally, parents noted that some nurses “were not very understanding,” presented with an “attitude when asked questions,” and “were not always pleasant.”

DISCUSSION

Similar to the studies highlighted in the introduction, our study found that the nurse/parent relationship and distinct positive and negative nursing behaviors are important factors affecting parental satisfaction with NICU care. However, different from other studies, we found that there were racial differences in how those factors impacted satisfaction. Black parents were most dissatisfied with how nurses supported them, wanting compassionate and respectful communication and nurses that were attentive to their children. White parents were most dissatisfied with inconsistent nursing care and lack informative exchanges, wanting education about their child's short and long-term needs. Both groups described a chaotic NICU environment with high nursing turnover, making it difficult to build trust and relationships.

Most studies looking at issues impacting parental satisfaction with NICU care have focused on white, middle income women and have not addressed differences between racial/ethnic groups.[29, 30] In a study including black, Asian, and Hispanic parents, overall satisfaction with NICU care was higher for white, older, and more educated mothers.[31] A study assessing the needs of 60 NICU parents found racial differences with black and parents of other races having higher overall needs than white parents. Assurance, comfort and support were rated more important for black parents than for white parents.[32] These studies did not specifically focus on NICU nursing care. This study is one of the largest to focus on families and their satisfaction with the NICU experience.

Racial differences in the satisfaction with nursing care have been described in non-NICU settings. Using the Consumer Assessment of Healthcare Providers and Systems (CAHPS) patient satisfaction questionnaire in a random sample of hospitalized patients at 32 not-for-profit hospitals, researchers found that both black and white parents identified nursing care as the most important factor influencing satisfaction; however, white patients placed more emphasis on the environment and black patients on general staff care.[3] In a study of nursing care of cancer patients, black patients placed higher value on individualized and patient-centered care than white patients.[33] Although not specifically focused on nursing, racial differences in satisfaction with pediatric care were demonstrated in the National Survey of Children with Special Health Care Needs: black and Hispanic parents were more than twice as likely as white parents to state that the provider "sometimes" or "never" spends enough time with the child and almost twice as likely to state that the provider is "sometimes" or "never" sensitive to family values and customs.[34] The findings described in non-NICU settings directly relate to our themes of attentiveness, compassionate communication, and family-centered care for black parents and informative exchanges, involvement in care, and a stable NICU for white parents.

Racial disparities in health care have been well described.[19, 20] Studies in other health care settings suggest that implicit bias by health care providers may explain our findings that black parents sought emotional support, individualized, and family-centered care.[25] Implicit bias impacts both clinician-patient communication process and content; for black patients, greater implicit bias was associated with longer visits with slower and less patient-centered

dialogue and more negative clinician affect.[23] How implicit bias plays a role in parental satisfaction with NICU nursing care is an area which should be further explored.

Understanding how racial and cultural differences can impact patient satisfaction with care is an important step towards diminishing health disparities. The Institute of Medicine has identified cross-cultural education of staff as one method of reducing disparities.[20] Education regarding techniques for effective communication in medical encounters[35] and ways to improve communication and continuity of care between providers during transitions in care[36] are some potential methods to meet the needs identified by families in the NICU setting.

Our research was subject to limitations. First, the participant sample and methods employed do not allow for generalization beyond the study sample. Second, the distribution of patients across the 27 NICUs was not controlled and thus this study does not address any potential confounding by site of NICU care. Lastly, our survey did not include questions specific to NICU nursing care which may have limited responses regarding factors that impacted parental satisfaction. However, as nursing care was such an integral part of parental perceptions of NICU care nearly half of the respondents commented on this area without prompting. The factors presented in this study were not chosen *a priori* but were developed from responses, which highlights the innate importance of nursing care in the NICU setting.

We found racial differences in satisfaction and expectations with NICU nursing care. Nurses that incorporate racially sensitive behaviors into their daily practice will be able to better support families through a premature birth, engage parents in their child's care, and promote a more positive NICU experience.

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Table 1
Sample Quotes by Race and Positive vs. Negative Comment

Code	
Black (+)	"They [nurses] made me feel like I was family. Although the NICU was or could be a scary place, they gave me a good outlook on the situation. They were warm and loving, and I never was afraid for my children." "They [nurses] not only took care of him [baby], but took care of me." "I was most satisfied with the nurses and their compassion for the children."
White (+)	"The good nurses were exceptional. They took the time even in the middle of the night to keep me up on what was going on, which meant a lot since I couldn't be there 24/7." "The doctors and nurses explained everything. They not only took care of our baby, but educated us on how to take care of him at home." "I was most satisfied with how nice the nurses were, how they listened to our concerns, and explained everything to us so we knew what was going on."
Black (−)	"The nurses really treated me as if I was an imbecile. They were very cold and frank. I think that they catered to some families more than others. They actually made me cry." "Because the other babies were sicker than mine, I feel like my baby did not get as much attention." "The nurses had other patients, but they weren't putting their all into my son. Didn't take a lot of time with my son."
White (−)	"The lack of nurses to care for the patients; they were very understaffed. They had about 5 patients to one nurse. At one point, our baby was left in her own vomit for at least 2 hours; it dried to her." "The information that was given was never consistent…too many different people." "Communication. We would find out after the fact that they had done things to her, like stopping her medications that she needed to take. They weren't listening to us. They were giving her fewer calories despite our wishes even though we knew her best."

Table 2
Parent Demographic Characteristics by Positive vs. Negative Comment

	Overall	Positive	Negative	P-Value
	120	69 (57%)	51 (43%)	
Race				<.**0001**
White	75 (62%)	50 (72%)	25 (49%)	
Black	45 (38%)	19 (28%)	26 (51%)	
Hispanic	5 (4%)	2 (3%)	3 (6%)	0.0768
Sex				0.1151
Female	116 (97%)	67 (97%)	49 (96%)	
Male	4 (3%)	2 (3%)	2 (4%)	
Age Category				**0.0391**
<= 18	1 (1%)		1 (2%)	
18 - 35	77 (64%)	41 (59%)	36 (71%)	
>= 35	42 (35%)	28 (41%)	14 (27%)	
Education				<**0.0001**
HS Diploma or Less	24 (20%)	12 (18%)	12 (24%)	
Some College	26 (22%)	14 (20%)	12 (24%)	
College Grad	70 (58%)	43 (62%)	27 (52%)	
Employment				0.0818
Full Time	63 (53%)	35 (51%)	28 (55%)	
Part Time	12 (10%)	7 (10%)	5 (10%)	
Student	6 (5%)	3 (4%)	3 (6%)	
Unemployed and Looking for work	14 (11%)	10 (14%)	4 (8%)	
Not Employed and not looking for work	19 (16%)	11 (16%)	8 (16%)	
Other	6 (5%)	3 (5%)	3 (5%)	
Income				<**0.0001**
< $30,000	28 (23%)	16 (23%)	12 (24%)	
$30,000-$50,000	16 (14%)	7 (10%)	9 (18%)	
$50,000-$100,000	28 (23%)	15 (22%)	13 (25%)	
>$100,000	42 (35%)	29 (42%)	13 (25%)	
Unknown	6 (5%)	2 (3%)	4 (8%)	
Marital Status				<**0.0001**
Married	75 (63%)	46 (67%)	29 (57%)	
Living With a Partner	18 (15%)	9 (13%)	9 (18%)	
Divorced	1 (1%)		1 (2%)	
Separated	1 (1%)		1 (2%)	
Never Been Married	25 (20%)	14 (20%)	11 (21%)	

	Overall	**Positive**	**Negative**	**P-Value**
Rent/Own				<**0.0001**
Own	79 (66%)	45 (65%)	34 (67%)	
Rent	35 (29%)	21 (30%)	14 (27%)	
Other	6 (5%)	3 (5%)	3 (6%)	
More than 1 resident under 18	75 (63%)	48 (70%)	27 (53%)	0.1312
Age	31.58 (5.75)	32.52 (5.5)	30.29 (5.88)	**0.0002**
Residents	4.1 (1.23)	4.22 (1.14)	3.94 (1.35)	0.1469
Residents Under 18	2.13 (1.14)	2.2 (1.07)	2.02 (1.24)	**0.0105**

Table 3
Parent & Infant Demographic Characteristics by Race

	Overall	White	Black	P-Value
	120	75 (62%)	45 (38%)	<**0.0001**
Hispanic	5 (4%)	5 (7%)	0 (0%)	0.0768
Sex				0.1151
Female	116 (97%)	71 (95%)	45 (100%)	
Male	4 (3%)	4 (5%)	0 (0%)	
Age Category				**0.0391**
<= 18	1 (1%)	0 (0%)	1 (2%)	
18 - 35	77 (64%)	43 (57%)	34 (76%)	
>= 35	42 (35%)	32 (43%)	10 (22%)	
Education				<**0.0001**
HS Diploma or Less	24 (20%)	7 (9%)	17 (38%)	
Some College	26 (22%)	10 (13%)	16 (36%)	
College Grad	70 (58%)	58 (78%)	12 (26%)	
Employment				0.0818
Full Time	63 (53%)	43 (57%)	20 (44%)	
Part Time	12 (10%)	8 (11%)	4 (9%)	
Student	6 (5%)	1 (1%)	5 (11%)	
Unemployed and Looking for work	14 (12%)	6 (8%)	8 (18%)	
Not Employed and not looking for work	19 (16%)	12 (16%)	7 (16%)	
Other	6 (4%)	5 (7%)	1 (2%)	
Income				<**0.0001**
< $30,000	28 (23%)	6 (8%)	22 (49%)	
$30,000-$50,000	16 (13%)	9 (12%)	7 (15%)	
$50,000-$100,000	28 (23%)	19 (25%)	9 (20%)	
>$100,000	42 (35%)	39 (52%)	3 (7%)	
Unknown	6 (6%)	2 (3%)	4 (9%)	
Marital Status				<**0.0001**
Married	75 (63%)	64 (85%)	11 (24%)	
Living With a Partner	18 (15%)	7 (10%)	11 (24%)	
Divorced	1 (1%)	0 (0%)	1 (2%)	
Separated	1 (1%)	0 (0%)	1 (2%)	
Never Been Married	25 (20%)	4 (5%)	21 (48%)	
Rent/Own				<**0.0001**
Own	79 (66%)	61 (81%)	18 (40%)	
Rent	35 (29%)	11 (15%)	24 (53%)	

	Overall	**White**	**Black**	**P-Value**
Other	6 (5%)	3 (4%)	3 (7%)	
More than 1 resident under 18	75 (63%)	43 (57%)	32 (71%)	0.1312
Age	31.58 (5.75)	33.04 (5.15)	29.13 (5.91)	**0.0002**
Residents	4.1 (1.23)	3.97 (1.08)	4.31 (1.44)	0.1469
Residents Under 18	2.13 (1.14)	1.92 (1)	2.47 (1.29)	**0.0105**
Comment Type				**0.0087**
Positive	69 (57%)	50 (67%)	19 (42%)	
Negative	51 (43%)	25 (33%)	26 (58%)	
Infants				
	Overall	White	Black	P-Value
	150	98 (65%)	52 (35%)	
Gestational age (weeks)				0.0009
34-<35	14 (9%)	3 (3%)	11 (21%)	
32-<34	32 (21%)	19 (19%)	13 (25%)	
28-<32	44 (30%)	35 (36%)	9 (17%)	
<28	60 (40%)	41 (42%)	19 (37%)	
Birth weight (grams)				0.0024
2500+	13 (9%)	3 (3%)	10 (19%)	
1500-<2500	35 (23%)	20 (21%)	15 (29%)	
1000-1500	82 (55%)	61 (62%)	21 (40%)	
<1000	20 (13%)	14 (14%)	6 (12%)	
Hospital Days	31.56 (27.42)	26.15 (21.89)	42.08 (33.72)	0.0239
Complication of Preterm Birth *	52 (35%)	25 (26%)	27 (52%)	0.0012
BPD	5 (3%)	1 (1%)	4 (8%)	0.0492
IVH	13 (8%)	6 (6%)	7 (13%)	0.1396
NEC	9 (6%)	3 (3%)	6 (12%)	0.0459

*Chronic illness was defined as bronchopulmonary dysplasia, necrotizing enterocolitis, intraventricular hemorrhage, asthma, seizures, short bowel syndrome, ventriculo-peritoneal shunt, colostomy, ileostomy, gastrostomy, tracheostomy, or supplemental oxygen