

Racial and Ethnic Differences in Use of Intubation for Periviable Neonates



WHAT'S KNOWN ON THIS SUBJECT: There are racial and ethnic differences in preferences for heroic measures and resuscitative care at the end of life among adult, terminally ill, and pediatric populations. However, little is known about racial/ethnic differences in the resuscitation of periviable neonates.



WHAT THIS STUDY ADDS: This study reveals higher use of neonatal intubation for periviable neonates born to black and Hispanic women. These findings may reflect differences in preferences for resuscitative care in periviability similar to those seen in end-of-life decision-making.

abstract

OBJECTIVE: Racial/ethnic minorities report preferences for resuscitative care at the end of life. The main objective of this study was to determine if there are racial/ethnic differences in use of intubation for periviable neonates. We hypothesized that infants born to black and Hispanic women are more likely to be resuscitated compared with infants born to white women.

METHODS: We conducted a retrospective cohort study of state-level maternal and infant hospital discharge data of women who delivered between 23.0 and 24.6 weeks' gestation linked to birth and death certificate data for California, Missouri, and Pennsylvania from 1995 to 2005 ($N = 9632$).

RESULTS: Overall, 78.9% of the population was aged 18 to 35 years, and almost half were nulliparous; 19.4% of the women were black, 36.6% were Hispanic, and 33.4% were white. Approximately 30% had less than a high school education, and 49.2% were federally insured. Overall, 44.7% of periviable neonates were intubated. In multivariable analyses adjusting for sociodemographic characteristics, black and Hispanic race/ethnicity was significantly associated with neonatal intubation (odds ratios [ORs]: 1.14 [95% confidence interval (CI): 1.01–1.29] and 1.22 [95% CI: 1.10–1.36], respectively). In models controlling for clustering at the level of the delivery hospital, black race remained a predictor of neonatal intubation (OR: 1.25 [95% CI: 1.07–1.46]), but differences among Hispanics dissipated (OR: 1.12 [95% CI: 0.98–1.27]).

CONCLUSIONS: Racial/ethnic differences exist in patterns of periviable resuscitation, which may reflect underlying differences in patient preference. Alternatively, institutional practices or resources may account for these differences. These findings have important implications for patient care and institutional practice. Our results lay the foundation for additional work to investigate how social, cultural, and institutional factors influence patient–provider decision-making regarding periviable care. *Pediatrics* 2011;127:e1120–e1127

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KEY WORDS

resuscitation decisions, NICU, fetal viability, minority health, health care disparities

ABBREVIATIONS

OR—odds ratio
CI—confidence interval

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When an infant is born at the threshold of viability, parents and physicians are faced with the unique and unfortunate challenge of making end-of-life decisions at the very beginning of life. A growing body of literature has documented racial and ethnic differences in end-of-life care. Black and Hispanic adults, in particular, are less likely to use hospice and palliative care services, less likely to complete advanced directives, and more likely to desire heroic measures and resuscitative efforts in end-of-life decision-making.^{1–8} However, relatively few studies have explored parental preferences for use of palliative versus resuscitative care for periviable neonates. Among these studies, the impact of race and ethnicity on preferences and behavior has not been explored.^{9–12}

As an initial step toward understanding decision-making regarding periviable resuscitation, we performed a retrospective cohort analysis to determine if there are racial or ethnic differences in use of neonatal resuscitation for periviable neonates. We hypothesized that infants born to black and Hispanic women are more likely to be resuscitated compared with infants born to white women. As a secondary aim, we describe additional maternal and neonatal sociodemographic and clinical characteristics that are associated with periviable neonatal resuscitation.

METHODS

Study Design and Population

We conducted a retrospective cohort study, analyzing state-level maternal and infant hospital discharge data, linked to birth and death certificate data, for California, Missouri, and Pennsylvania from 1995 to 2005. In accordance with the Common Rule (45 CFR 46.102[f]) and the policies of the Children's Hospital of Philadelphia institutional review board, this re-

search, which used a limited data set according to the terms of a valid data use agreement, was determined to not meet the definition of human subjects research. The institutional review boards of the Departments of Health in California, Missouri, and Pennsylvania approved this study. The records were created by linking birth certificate data with maternal hospital discharge records and newborn hospital discharge data records, or death certificate data in the event of a fetal demise. Records were linked using previously described methods.¹³ With these techniques, >98% of birth and death certificates can be matched to maternal and newborn hospital records.¹⁴

Live singleton births and in-hospital fetal deaths occurring between 23.0 and 24.6 weeks of reported or imputed gestational age were included in the analysis. Missing gestational age variables in ~8% of the data were imputed using a linear regression model containing birth weight, sociodemographic characteristics, neonatal characteristics, maternal comorbidities, and maternal complications. Because periviable births that are not resuscitated at the time of the delivery are likely to be classified as a fetal death, it was important that fetal deaths not be excluded entirely from the analysis. We sought to distinguish these types of fetal deaths from fetal deaths that occurred out of the hospital or as intrauterine demises. Deaths were designated as “outpatient” or “intrauterine” fetal deaths using criteria described previously by Phibbs et al¹⁵ and were excluded from the analysis (see Appendix 1).

Variable Selection and Data Analysis

The outcome of interest for this study was neonatal intubation (*International Classification of Diseases, Ninth Revision, Clinical Modification*

[ICD-9-CM] codes 96.01–96.05). The primary predictor of interest was self-reported maternal race or ethnicity, designated in 4 categories: white, black, Hispanic and other. Maternal sociodemographic characteristics, including age in 3 categories (<18, 18–35, >35); parity in 4 categories (0, 1, 2, and ≥3), education in 2 categories (less than a high school education or a high school education and higher), median census tract income (determined on the basis of zip code: <\$20 000, \$20 000–\$40 000, \$40 000–60 000, or >\$60 000) to approximate household income, early prenatal care (defined as entry at 0–3 months), and insurance payer (fee for service, health maintenance organization, federally insured, uninsured, and other), were included as potential confounders. In addition, maternal and fetal clinical characteristics, included in the full model, were as follows: preexisting diabetes, gestational diabetes, chronic hypertension, pregnancy-induced hypertension, birth weight, gender, and any fetal anomaly (see Appendix 2).

All analyses were performed by using SAS 9.2 (SAS Institute, Inc, Cary, NC). Descriptive statistics were calculated by using χ^2 tests. Logistic regression was performed for multivariable analyses. Logistic regression models were built in sequence, first controlling for sociodemographic factors that might confound the relationship between race/ethnicity and intubation, then additionally controlling for potential confounding by adding maternal comorbid conditions and neonatal characteristics to the model. This sequential model building allows us to determine which factors may explain any racial/ethnic differences in intubation of the periviable infant that appear in univariable analyses. Finally, we included delivery hospital as a fixed effect in the model to account for the

potential effect of clustering at the level of the delivery hospital. Hospital identifiers were included in the model if at least 25 deliveries occurred in the hospital. Hospitals with <25 deliveries were grouped according to state and represented in the model as 3 “small hospital” variables, which accounted for 2639 deliveries.

Sensitivity Analysis

We conducted a sensitivity analysis to determine the impact of potential misclassification of the outcome among the fetal deaths. Because fetal deaths do not have newborn discharge records and therefore do not have procedure codes available, in the original analysis, all fetal deaths are assigned a “not intubated” status. Excluding all fetal deaths would exclude deaths that resulted from withholding resuscitative care and thereby bias our estimates. However, some portion of fetal deaths were likely intubated; then, when the infant could not be resuscitated, the delivery was classified as a fetal death. Therefore, for our sensitivity analysis we assumed that 49.7% of the fetal deaths were intubated. This represents the same percentage of live births that were intubated. Using an analytic approach previously described in the literature,¹⁶ we conducted 1000 separate random samples, in which 49.7% of the fetal deaths were assigned an “intubated” status, and the final models were rerun. We calculated a distribution of odds ratios (ORs) from these 1000 random samples to estimate the effect of race on intubation status. Median ORs were reported with confidence intervals (CIs) constructed using the 5th and 95th percentile ORs.

RESULTS

Our study population comprised 9632 maternal and infant pairs. Table 1 provides baseline sociodemographic and clinical characteristics for the mother

TABLE 1 Baseline Maternal and Neonatal Characteristics According to Intubation Status (N = 9632); Values Are Given as n (%)

	Overall	Intubated	Not Intubated	P
Maternal characteristics				
Age, y				<.001
<18	697 (7.24)	271 (38.9)	426 (61.1)	
18–35	7595 (78.9)	3373 (44.4)	4222 (55.6)	
>35	1340 (13.9)	658 (49.1)	682 (50.9)	
Parity				<.001
0	4360 (45.3)	1998 (45.8)	2362 (54.2)	
1	2326 (24.2)	1053 (45.3)	1273 (54.7)	
2	1324 (13.8)	575 (43.4)	749 (56.6)	
3	1486 (15.4)	638 (42.9)	848 (57.1)	
Missing	136 (1.41)	38 (27.9)	98 (72.1)	
Race/ethnicity				.005
White	3213 (33.4)	1357 (42.2)	1856 (57.8)	
Black	1871 (19.4)	837 (44.7)	1034 (55.3)	
Hispanic	3527 (36.6)	1636 (46.4)	1891 (53.6)	
Other	1021 (10.6)	472 (46.2)	549 (53.8)	
Insurance				<.001
FFS	692 (7.18)	250 (36.1)	442 (63.9)	
HMO	3479 (36.1)	1661 (47.7)	1818 (52.3)	
Federal	4740 (49.2)	2122 (44.8)	2618 (55.2)	
Other	272 (2.82)	113 (41.5)	159 (58.5)	
Uninsured	449 (4.66)	156 (34.7)	293 (65.3)	
Education				<.001
≥High school	6198 (64.4)	2838 (45.8)	3360 (54.2)	
<High school	2939 (30.5)	1298 (44.2)	1641 (55.8)	
Missing	495 (5.14)	166 (33.5)	329 (66.5)	
Income				.726
\$20 000 or less	162 (1.68)	71 (43.8)	91 (56.2)	
\$21 000–\$40 000	4967 (51.6)	2218 (44.7)	2749 (55.3)	
\$41 000–\$60 000	3120 (32.4)	1379 (44.2)	1741 (55.8)	
More than \$60 000	1168 (12.1)	542 (46.4)	626 (53.6)	
Missing	215 (2.23)	92 (42.8)	123 (57.2)	
Prenatal care				<.001
Early	7395 (76.8)	3504 (47.4)	3891 (52.6)	
Late	1507 (15.7)	464 (30.8)	1043 (69.2)	
Missing	730 (7.58)	334 (45.8)	396 (54.2)	
Maternal comorbidities				
Preexisting diabetes	128 (1.33)	59 (46.1)	69 (53.9)	.743
GDM	195 (2.02)	90 (46.2)	105 (53.8)	.672
Chronic hypertension	143 (1.48)	71 (49.7)	72 (50.3)	.227
PIH	636 (6.60)	318 (50.0)	318 (50.0)	.005
Neonatal characteristics				
Birth weight				<.001
≥500 g	8160 (84.7)	3989 (48.9)	4171 (51.1)	
<500 g	1006 (10.4)	261 (25.9)	745 (74.1)	
Missing	466 (4.84)	52 (11.2)	414 (88.8)	
Gender				.826
Male	5128 (53.2)	2285 (44.6)	2843 (55.4)	
Female	4504 (46.8)	2017 (44.8)	2487 (55.2)	

FFS indicates fee-for-service, HMO, health maintenance organization; GDM, gestational diabetes; PIH, pregnancy-induced hypertension.

and infant pairs that comprise the study cohort. Overall, 78.9% of the maternal population was aged 18 to 35 years and almost half were nulliparous; 19.4% of the women were black, 36.6% were Hispanic, and 33.4% were

white. Approximately 30% had less than a high school education, and 49.2% were federally insured. Overall, 44.7% of periviable neonates were intubated. The percentage of neonates intubated differed significantly across

TABLE 2 Odds of Intubation According to Race/Ethnicity in Sequential Logistic Regression Models

	Unadjusted OR (95% CI)	Adjusted OR (95% CI) ^a	Adjusted OR (95% CI) ^b
White (reference)			
Black	1.11 (0.99–1.24)	1.14 (1.01–1.29)	1.15 (1.01–1.30)
Hispanic	1.18 (1.08–1.30)	1.22 (1.10–1.36)	1.20 (1.07–1.34)
Other	1.18 (1.02–1.36)	1.14 (0.99–1.32)	1.14 (0.98–1.32)

^a Maternal predictors model controls for race, age, parity, insurance, education, early prenatal care, and income.

^b Full model controls for race, age, parity, insurance, education, early prenatal care, income, maternal diabetes, maternal hypertension, gender, birth weight, and presence of anomalies.

all maternal and neonatal categories (age, parity, race/ethnicity, insurance, education, prenatal care, maternal pregnancy-induced hypertension, gestational age, birth weight, and anomaly) with the exception of income, maternal preexisting diabetes, maternal gestational diabetes, maternal chronic hypertension, and gender of the infant.

Compared with white women, the unadjusted odds of neonatal intubation was 18% higher among infants born to Hispanic women (95% CI: 1.08–1.30) and among infants born to women designating their racial/ethnic group as other (95% CI: 1.02–1.36). Table 2 describes the sequence in which the logistic regression models were constructed as additional covariates were included in the models. After adjusting for maternal sociodemographic characteristics, the odds of neonatal intubation was 14% higher among infants of black women (95% CI: 1.01–1.29) and 22% higher among infants of Hispanic women (95% CI: 1.10–1.36). In the final model, when maternal comorbidities and neonatal characteristics were also included, the odds of neonatal intubation were 15% higher for infants of black women (95% CI: 1.01–1.30) and 20% higher for infants of Hispanic women (95% CI: 1.07–1.34).

Age, parity, insurance status, prenatal care, and pregnancy-induced hypertension were also associated with higher odds of neonatal resuscitation (Table 3). Infants born to girls aged younger than 18 years were 12% less likely to be intubated (95% CI: 0.67–

0.96), whereas infants born to women aged older than 35 years were 22% more likely to be intubated (95% CI: 1.08–1.39). The odds of neonatal intubation decreased with increasing parity. Infants born to women with coverage from a health maintenance organization or federal insurance were 66% and 53% more likely to be

TABLE 3 Predictors of Neonatal Intubation in Full Model With and Without Adjusting for Hospital Identifiers with Fixed Effects (*N* = 9632)

	Full Model, Adjusted OR (95% CI)	<i>P</i>	Full Model + Hospital ID, Adjusted OR (95% CI)	<i>P</i>
Age, y				
18–35 (referent)				
<18	0.80 (0.67–0.96)	.019	0.87 (0.70–1.07)	.173
>35	1.22 (1.08–1.39)	.002	1.09 (0.94–1.25)	.258
Parity				
0 (referent)				
1	0.92 (0.82–1.02)	.110	0.93 (0.83–1.06)	.272
2	0.86 (0.75–0.99)	.030	0.89 (0.77–1.04)	.138
3	0.83 (0.73–0.95)	.007	0.86 (0.74–1.00)	.050
Missing	0.56 (0.37–0.84)	.005	0.49 (0.31–0.78)	.002
Race/ethnicity				
White (referent)				
Black	1.15 (1.01–1.30)	.035	1.25 (1.07–1.46)	.005
Hispanic	1.20 (1.07–1.34)	.001	1.12 (0.98–1.27)	.105
Other	1.14 (0.98–1.32)	.092	1.02 (0.86–1.22)	.783
Insurance				
FFS (referent)				
HMO	1.66 (1.39–1.99)	<.001	1.11 (0.88–1.40)	.370
Federal	1.53 (1.28–1.84)	<.001	1.03 (0.82–1.30)	.810
Other	1.30 (0.96–1.76)	.086	0.78 (0.54–1.13)	.183
Uninsured	1.06 (0.82–1.39)	.651	0.73 (0.53–1.00)	.047
Education				
≥High school (referent)				
<High school	1.00 (0.90–1.12)	.957	1.07 (0.94–1.21)	.322
Missing	0.69 (0.56–0.85)	<.001	0.51 (0.41–0.64)	<.001
Income				
More than \$60 000 (referent)				
Less than \$20 000	0.96 (0.68–1.37)	.831	0.71 (0.45–1.09)	.115
\$20 000–\$40 000	1.04 (0.90–1.20)	.589	0.88 (0.74–1.05)	.152
\$41–\$60 000	0.98 (0.85–1.13)	.793	0.88 (0.75–1.04)	.130
Missing	1.12 (0.82–1.53)	.494	0.87 (0.61–1.25)	.446
Prenatal care				
Early (referent)				
Late	0.45 (0.40–0.51)	<.001	0.43 (0.38–0.49)	<.001
Comorbidities				
Preexisting diabetes	0.93 (0.63–1.36)	.694	0.84 (0.55–1.28)	.411
GDM	0.86 (0.64–1.16)	.326	0.79 (0.57–1.09)	.149
Chronic hypertension	1.18 (0.82–1.69)	.374	1.15 (0.77–1.71)	.494
PIH	1.71 (1.43–2.05)	<.001	1.96 (1.60–2.39)	<.001
Neonate characteristics				
Birth weight				
<500 g (referent)				
≥500 g	3.04 (2.61–3.55)	<.001	3.67 (3.11–4.36)	<.001
Missing	0.33 (0.23–0.45)	<.001	0.28 (0.20–0.40)	<.001
Male gender	0.94 (0.86–1.02)	.145	0.97 (0.88–1.06)	.467

FFS, fee-for-service; HMO, health maintenance organization; GDM, gestational diabetes; PIH, pregnancy-induced hypertension.

intubated compared with infants of women with fee-for-service insurance (95% CI: 1.39–1.99 and 1.28–1.84, respectively). Neonatal resuscitation was 55% less likely among infants of women with late prenatal care (95% CI: 0.40–0.51).

After adjusting for delivery hospital (Table 3), the odds of neonatal intubation remained higher only among infants born to black women (OR: 1.25 [95% CI: 1.07–1.46]). Pregnancy-induced hypertension remained a significant predictor of intubation (OR: 1.96 [95% CI: 1.60–2.39]). Furthermore, uninsured status and late prenatal care each resulted in lower odds of intubation (OR: 0.73; 95% CI: 0.53–1.00 and OR: 0.43; 95% CI: 0.38–0.49, respectively).

In addition to maternal characteristics, neonatal birth weight was an important predictor of neonatal resuscitation. Neonates who weighed >500 g were 3.04 times as likely to be intubated than those who weighed ≤500 g (95% CI: 2.61–3.55). Birth weight remained a significant predictor of intubation after adjusting for delivery hospital.

In sensitivity analyses that assumed 49.7% intubation among fetal deaths, we continued to find racial differences in neonatal intubation. Infants born to black and Hispanic women remained significantly more likely to be intubated than infants born to white women (ORs: 1.12 [95% CI: 1.08–1.16] and 1.19 [95% CI: 1.16–1.23], respectively).

DISCUSSION

We conducted this retrospective cohort analysis to determine if black and Hispanic race/ethnicity were predictors of periviable neonatal resuscitation. In our cohort of periviable neonates, we found that neonatal resuscitation was more likely to be performed among infants born to

black and Hispanic women when we controlled for maternal sociodemographic characteristics as well as select maternal comorbidities and neonatal characteristics. Delivery hospital was an important confounder in the relationship between Hispanic ethnicity and intubation status. However, black infants remained more likely to be intubated even after accounting for these hospital effects.

Our findings bring an important addition to the growing body of literature that documents racial/ethnic differences in end-of-life care, primarily for adults.^{1–8} In a systematic review by Cohen,⁸ 12 of 13 studies that met the study selection criteria found that minorities were less likely to use hospice services. Moreover, black patients who choose hospice have 70% higher odds of ultimately revoking hospice care to pursue more aggressive treatment and life-prolonging therapies.² Most studies related to end-of-life care have been conducted among the elderly and chronically or terminally ill adults. However, a recent study found that black and Hispanic children use fewer pediatric palliative care resources.¹⁷ Similarly, in a smaller study of 38 critically ill infants in the NICU, 80% of families of white infants agreed with physician recommendations to limit life-sustaining medical treatment compared with 62% of families of black infants.¹⁸ Our study reported similar differences in intubation decision-making near the limits of viability.

Cultural factors—such as spirituality, views of suffering, mistrust of the health care system, and communication barriers—have been identified as factors influencing black and Hispanic preferences for aggressive care at the end of life.^{4,19–23} Our data on racial/ethnic differences in neonatal resuscitation may, therefore, reflect parental preferences that drive neonatal resuscitation decisions. As with end-of-life

decision-making in adult populations, there may be cultural or religious differences among racial and ethnic groups that result in preferences for periviable resuscitative care among minority populations. When Boss et al¹⁰ interviewed 26 mothers about their values in resuscitation decision-making, they found that spirituality, religiosity, and hope guided decision-making more than morbidity and mortality data that physicians provided. Partridge et al²⁴ conducted an international survey among parents of 379 very low birth weight infants and found that although those parents primarily considered their emotional attachment and risk of death, disability, or pain, they also considered financial and religious concerns in their decision-making.

The degree to which parental preference versus physician practice drives resuscitation decision-making still remains in question. Several studies have explored physician attitudes and decision-making about neonatal resuscitation among neonatologists and pediatricians,^{25–34} and there is evidence to suggest that parental preference plays a primary role in guiding physician practice. When Doron et al²⁶ surveyed pediatricians regarding their resuscitation practices among a cohort of 41 periviable neonates, they found that physicians typically honored parental wishes for resuscitation even when the physician preferred to withhold treatment. In a study of delivery room resuscitation decisions for extremely low birth weight infants, almost 70% of the neonatologists surveyed reported that they “often” or “always” considered parental wishes when deciding on resuscitation.³⁰

Our secondary aim was to determine additional maternal characteristics that are associated with neonatal resuscitation. Advanced maternal age, lower parity, and early prenatal care

were other maternal characteristics that were associated with a higher likelihood of neonatal resuscitation. These may serve as a marker of intended or highly desired pregnancies. We also found that infants born to mothers with health maintenance organization coverage and federal insurance were more likely to be resuscitated than infants born to women with fee-for-service insurance coverage. This finding was surprising, as one might expect women more financially burdened to be less likely to resuscitate. It is interesting to note, however, that the differences observed among women with health maintenance organization coverage and those federally insured dissipated when the relationship was controlled for delivery hospital. In fact, after controlling for hospital identifier, infants born to uninsured women were 27% less likely to be intubated. Likewise, maternal age and parity were no longer associated with intubation status after adjusting for hospital effect. The results of these models suggest that there may be an “aggressive hospital” effect at play. Women of similar sociodemographic characteristics may be more likely to receive care in a given hospital setting and that hospital’s institutional resources, practices, and policies may, in turn, determine the likelihood of interventional care being provided for the periviable neonates.

As a retrospective cohort study, there are several limitations to the conclusions we can draw from these findings. Because of the limitations of the data and the variables available in the data set, we are unable to determine if the racial/ethnic differences observed in patterns of neonatal resuscitation actually reflect maternal preference, physician guidance, or physician practice patterns. We cannot exclude the possibility that paternalism, bias, or

perceived patient preference drives physician practice without regard for expressed patient preference. Delivery room resuscitation decisions are thought to best be made in partnership, under a shared decision-making model, and so these patterns of care likely reflect some combination of both parental preference and physician guidance.³⁵ However, several studies have documented that physicians are not as proficient or effective at cross-cultural communication, so minority parents may be less likely to experience shared decision-making than white patients and parents.^{36–39} Therefore, where we propose that our findings could reflect a preference for more aggressive care among black and Hispanic patients, the findings might, conversely, reflect a greater degree of shared decision-making occurring with white parents desiring less interventional care.

A second limitation is that we identified our predictor and outcome variables using ICD-9 codes, not primary chart abstraction. This creates the risk for misclassification. However, this method allows for a large, population-based cohort that is needed to study racial differences in this relatively rare event. In addition, because of the differential documentation available for fetal deaths, we cannot be certain that misclassification of the outcome did not occur among the fetal deaths. Nevertheless, our sensitivity analysis suggests that the effect estimates are not altered significantly by misclassification bias.

Finally, unmeasured confounders may play a significant role in the decision-making process and account for the relationship observed between race/ethnicity and intubation status. For example, we did not have data about important elements of the obstetrical history such as gravidity, infertility

treatments, or previous poor obstetric outcomes. These elements could differ by race and may help explain the observed differences in resuscitation decisions. Or, as previously proposed,^{4,19–23} race/ethnicity may serve as a marker for religious beliefs, language barriers, or cultural norms that are associated with intubation.

CONCLUSIONS

Our study findings have important implications for patient care and institutional practice. Racial and ethnic differences in patterns of periviable neonatal resuscitation may reflect underlying differences in patient preference. If this is the case, then providers caring for black and Hispanic families may need to pay particular attention to faith practice, religious beliefs, and cultural norms and values around pain and suffering, so that they may provide culturally competent, patient-centered counseling. In doing so, providers can help to ensure that parents are making resuscitation decisions on the basis of shared meaning and shared understanding of the expected outcomes in a manner that upholds their values. If, instead, the sociodemographic differences observed here reflect differences in institutional practices or resources, additional consideration should be given to the ways in which patient preference may actually be constrained by virtue of the characteristics and policies of the nearest delivery hospital. Conversely, hospital level effects may actually reflect a response to the socioeconomic and demographic make-up of the geographic area that the hospital serves. More insight is needed to understand the role of race and ethnicity and its impact on patient preference, patient–provider communication, and shared decision-making models.

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APPENDIX 1 Outpatient or Intrauterine Fetal Deaths Designated According to ICD-9-CM Code by Using Criteria Described Previously by Phibbs et al¹⁵

Description	ICD-9-CM Code
Papyraceous fetus	646.01
Intrauterine death	656.40, 656.41, or 656.43
Decreased fetal movement	655.71
Cord entanglement with compression	663.20
Cord entanglement without compression	663.31
Ruptured uterus before delivery	665.01
Insertion of laminaria	69.93
Hysterotomy to terminate pregnancy	74.91

Fetal deaths with these diagnoses were excluded from the analysis. ICD-9-CM indicates *International Classification of Diseases, Ninth Revision, Clinical Modification*.

APPENDIX 2 ICD-9-CM Codes Used to Designate Maternal and Fetal Characteristics Included as Covariates in the Models

Description	ICD-9-CM Code
Preexisting diabetes mellitus	250.xx, 648.0x, 357.2, 362.0, 362.01, 362.02, 366.41
Gestational diabetes	648.8x
Chronic hypertension	642.0x, 642.1x, 642.2x
Pregnancy-induced hypertension	642.4x, 642.5x, 642.7x
Congenital anomaly ICD-9-CM codes (also used birth certificate variables where available)	
Gastrointestinal	756.70, 756.79, 750.3, 750.4, 750.5, 750.7, 750.8, 750.9, 751.1, 751.8, 751.9, 751.5, 560.2, 751.4, 751.0, 751.2, 751.3, 777.1, 751.61, 751.7, 751.60, 751.69
Genitourinary	753.0, 753.12, 753.14, 753.15, 753.10, 753.19, 753.3, 753.4, 753.21, 753.22, 753.23, 753.29, 753.6, 753.7, 753.8, 753.9, 753.20, 756.71
Cardiorespiratory	746.3, 746.4, 424.1, 747.10, 747.21, 747.29, 747.11, 747.22, 746.81, 746.7, 425.3, 746.5, 424.0, 746.6, 746.84, 745.10, 745.19, 745.12, 746.85, 425.1, 745.3, 745.11, 745.0, 746.01, 746.83, 746.2, 746.09, 745.2, 746.1, 745.60, 745.61, 745.69, 746.82, 747.41, 747.42, 747.40, 747.49, 746.9, 746.89, 746.87
Central nervous system	741.00, 741.01, 741.02, 741.03, 741.90, 741.91, 741.92, 741.93, 742.59, 742.0, 742.1, 742.4, 742.2, 742.3, 742.8, 742.9
Chromosomes	758.3, 758.5, 758.89, 758.9, 759.89, 759.9, 759.7, 759.4
Pulmonary	519.4, 553.3, 748.9, 750.6, 756.6, 748.3, 748.4, 748.60, 748.61, 748.69, 748.8
Skeletal	756.50, 756.51, 756.55, 756.56, 756.59
Skin	757.1
Other anomaly ^a	778.0, 759.6, 776.5

ICD-9-CM indicates *International Classification of Diseases, Ninth Revision, Clinical Modification*.

^a Anomaly diagnosis codes are not reported in records of fetal deaths. Because this results in misclassification bias, we do not report effect estimates from the logistic regression models for anomalies in the text.

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