

Addressing Disparities in Perinatal Care Delivery

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By the numbers











CPQCC

CPeTS

HRIF

CMQCC



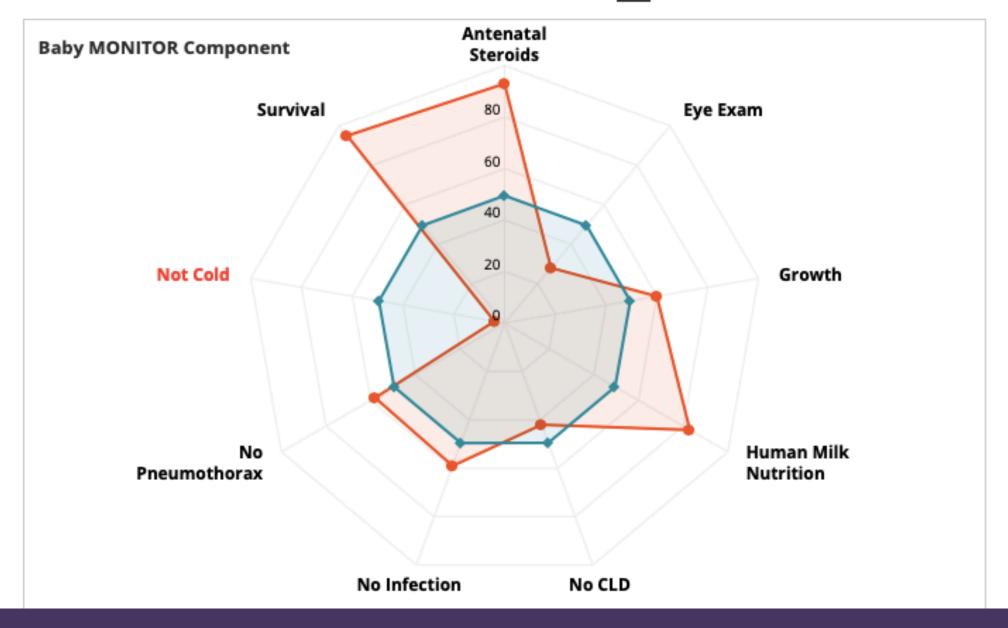


Big Babies

Early Sepsis Moderate/Severe HIE Active Therap. Hypothermia High Acuity

Compare 60.64 **

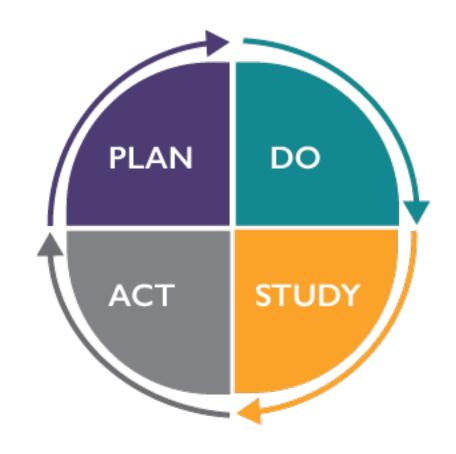
CPQCC DASHBOARD



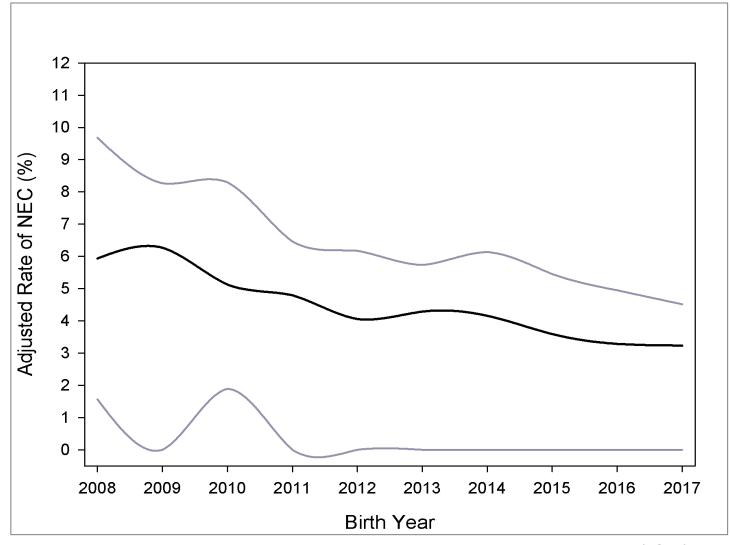
CPQCC BABY-MONITOR

Quality Improvement – Turning data into action

- Use IHI Collaborative QI Model
 - 2018 projects include optimizing growth and nutrition (Grow, Babies, Grow!)
 - Quality Improvement Toolkits containing evidence-based "Promising Practices."



Necrotizing Enterocolitis



^{*} Lower and upper bands represent the 25th and 75th percentile (IQR)

-46

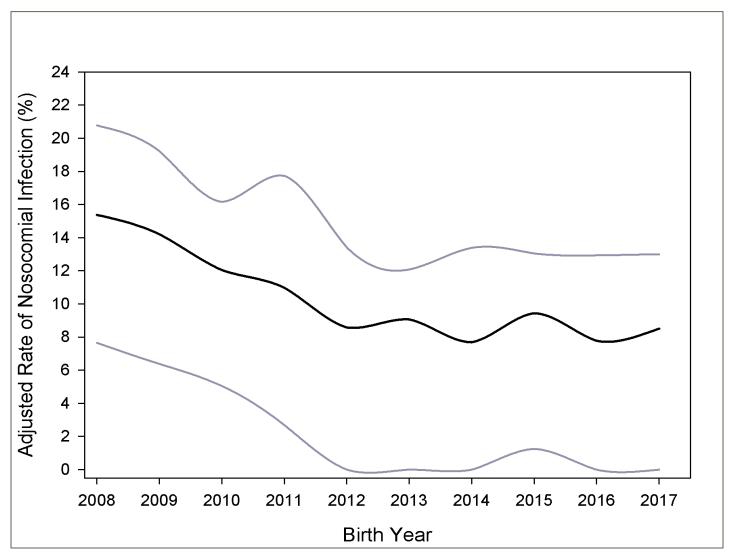
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Lee, Profit, et al. J Perinatol 2020, in press





Healthcare Associated Infection



Lee, Profit, et al. J Perinatol 2020, in press

^{*} Lower and upper bands represent the 25th and 75th percentile (IQR)

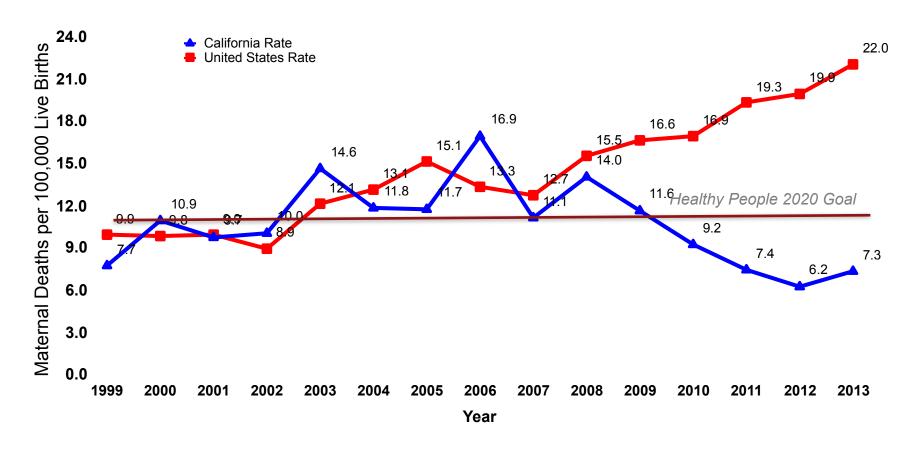




^{-45%}



Maternal Mortality Rate, California and United States; 1999-2013



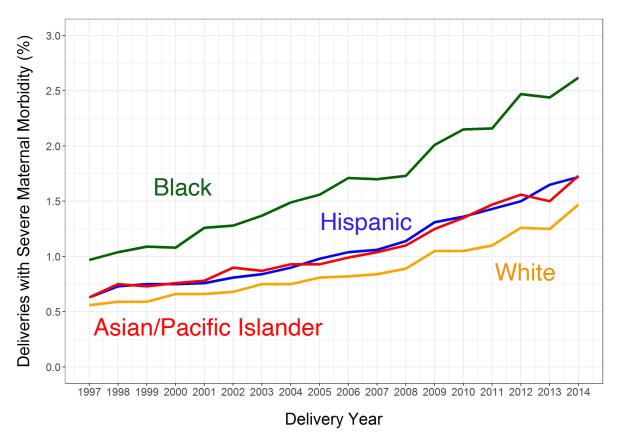


SOURCE: State of California, Department of Public Health, California Birth and Death Statistical Master Files, 1999-2013. Maternal mortality for California (deaths ≤ 42 days postpartum) was calculated using ICD-10 cause of death classification (codes A34, O00-O95,O98-O99). United States data and HP2020 Objective use the same codes. U.S. maternal mortality data is published by the National Center for Health Statistics (NCHS) through 2007 only. U.S. maternal mortality rates from 2008 through-2013 were calculated using CDC Wonder Online Database, accessed at http://wonder.cdc.gov on March 11, 2015. Produced by California Department of Public Health, Center for Family Health, Maternal, Child and Adolescent Health Division, March, 2015.

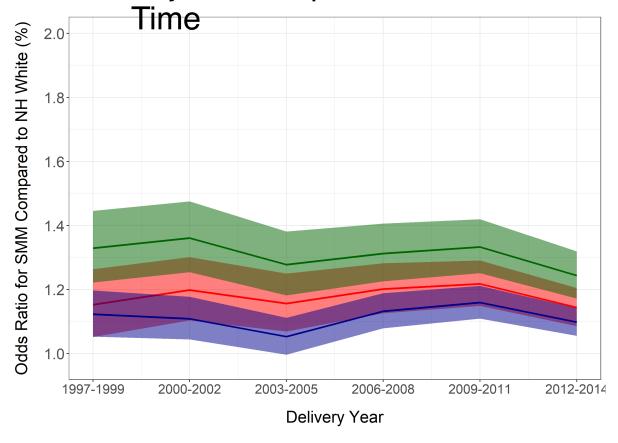
Disparities in Severe Maternal Morbidity

Leonard S, Profit J, et al. Racial and Ethnic Disparities in Severe Maternal Morbidity Prevalence and Trends. Ann Epi 2019 May;33:30-36

Observed Trend over Time



Adjusted Disparities over









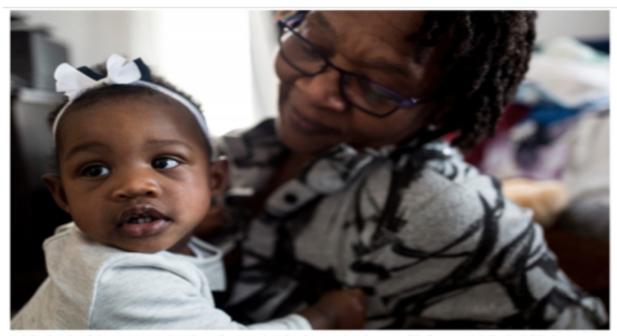


LOST MOTHERS

Nothing Protects Black Women From Dying in Pregnancy and Childbirth

Not education. Not income. Not even being an expert on racial disparities in health care.

by Nina Martin, ProPublica, and Renee Montagne, NPR News, Dec. 7, 2017, 8 a.m. EST



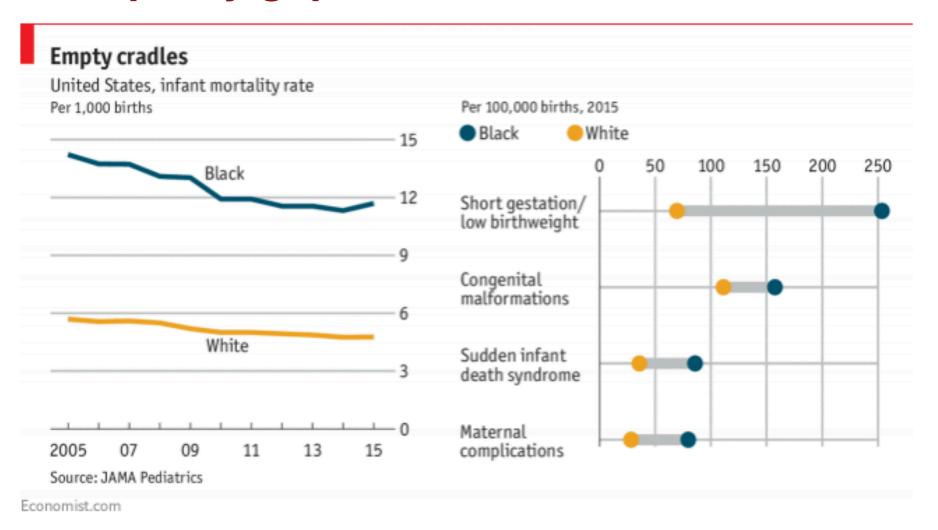
Soleil Irving "just lights up a room when she smiles," Wanda Irving, her grandmother, says. (Sheila Pree Bright for ProPublica)

Serena Williams' Story of Not Being Listened To

Despite history of multiple PE, her doctors and nurses minimized her PP complaints and refused a CT scan (later positive for multiple small PE)

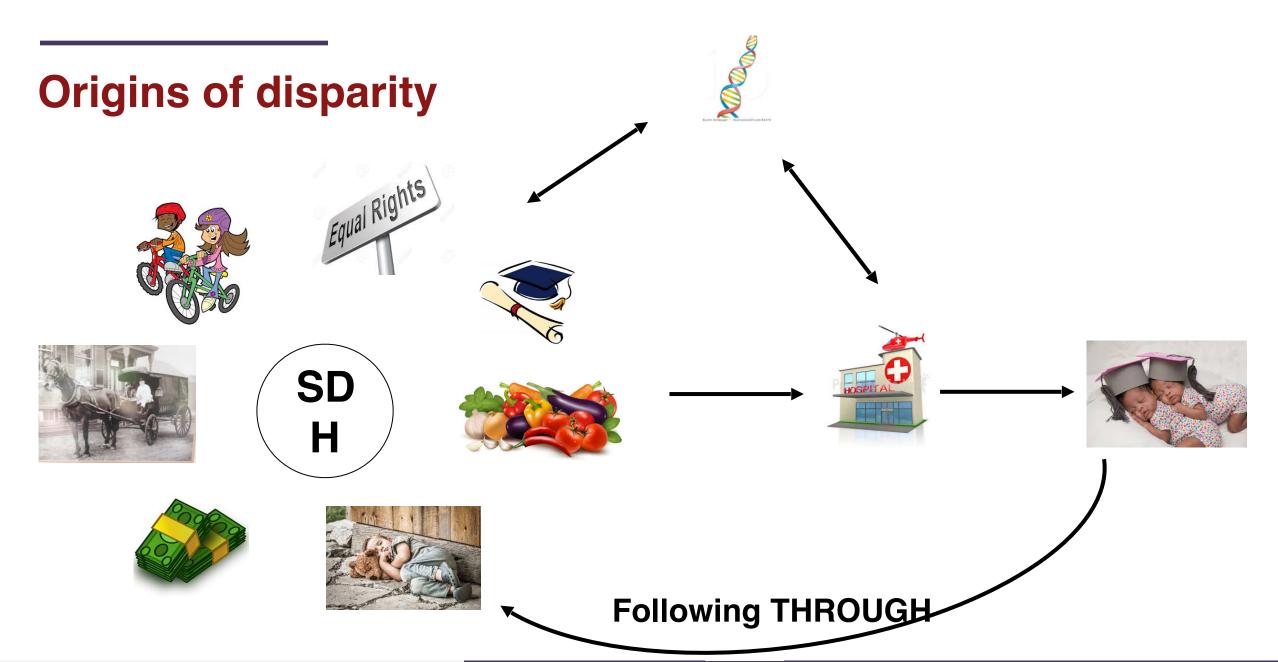


Persistent disparity gap













Are there Disparities in Perinatal Care



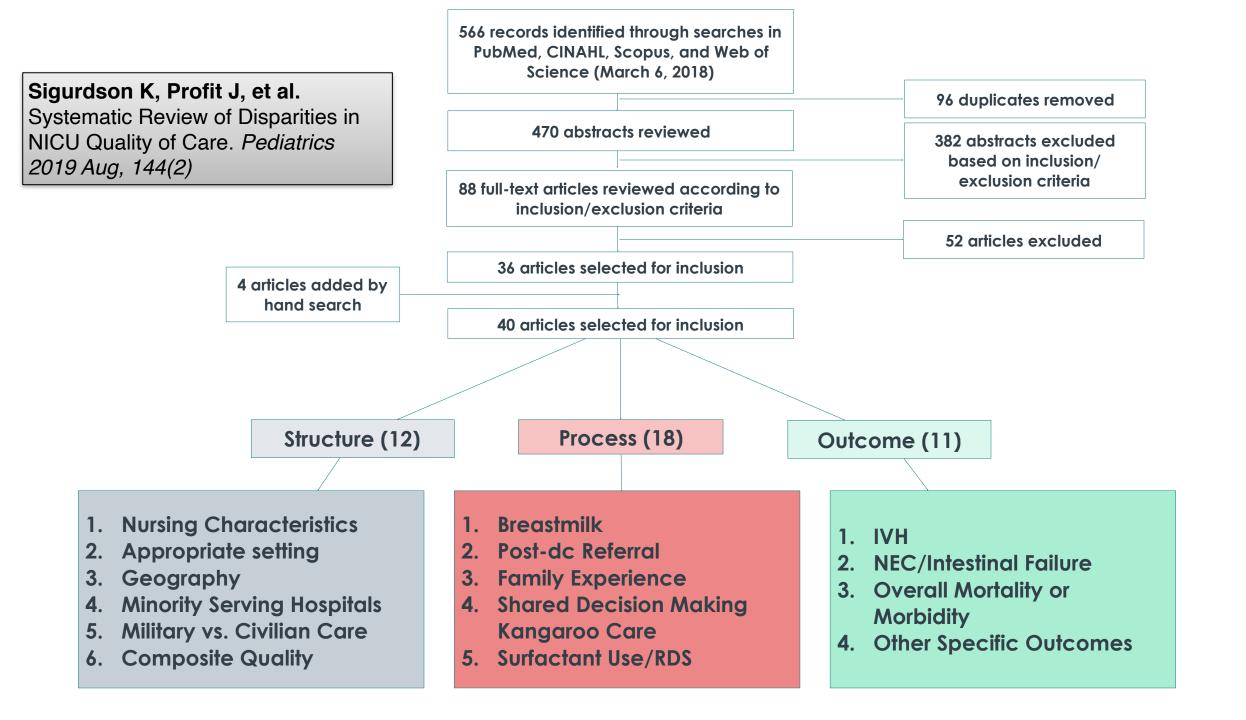
Context matters – always exposed to bias











What are the mechanisms for disparities in NICU Care?





Mechanisms for Disparity

Minority mothers and neonates can have worse outcomes than whites because

- 1. Receive care from facilities that treat patients with poor quality of care (BETWEEN),
- 2. Receive worse quality of care than white mothers in the same facility (WITHIN)



Racial Segregation and Inequality of Care in Neonatal Intensive Care Units Is Unacceptable

Despite significant improvements in the survival of very prea growing body of evidence

quality of care in creating disparities. Black and Hispanic very data, allow for population-based estimates, these administrapreterm infants are more likely to be born in hospitals with worse outcomes than white infants after adjustment for risk sure quality more directly (eg, receipt of medications, vital factors, and differences in hospital of birth explain a signifi-signs, and growth). cant proportion of the black-white and Hispanic-white disparities for these vulnerable infants. Additional research has cludes nearly 90% of very low-birth-weight and very preterm documented that racial and ethnic disparities in quality exist infants born annually in the United States, making it possible between and within NICUs for very low-birth-weight infants.4

hospital level for black. Hispanic, and Asian infants relative to groups of black. Hispanic, and Asian infants. white infants. They found significant segregation across NICUs in the United States for all 3 racial and ethnic groups and

care associated infection, and mortality) that have been used ous literature on the contribution of quality of care to neonaadministrative data. While morbidity and mortality are direct would likely affect estimates of inequalities.

term newborns in neonatal intensive care units (NICUs) over are indirect measures of quality, and comparisons between hosthe last decade, significant racial and ethnic disparities exist pitals are more strongly reliant on the ability to carry out risk for very preterm infants. 1-3 While these disparities are rooted adjustment than process measures. Furthermore, they do not in a complex web of factors, identify specific areas that can be targeted in the NICU to improve outcomes. While the use of administrative data, such has documented the role of as state discharge abstract data linked with birth certificate tive data lack many of the data elements necessary to mea

Another strength is the use of a national data set that in to confirm that previous findings from specific regions apply In this issue of JAMA Pediatrics, Horbar et al⁵ explore the more broadly to the US population. Horbar et al⁵ also propose extent of segregation and inequality for very low-birth- an interesting index for inequality. In our previous research, weight and very preterm infants in NICUs across the United we ranked hospitals by risk-adjusted morbidity and mortality States. They developed indices at the hospital level to mea- and examined where black and Hispanic very preterm insure segregation (ie, uneven distribution of racial and ethnic fants were born.2 In this article, Horbar et al5 rank NICUs by a groups across NICUs) and inequality (ie. concentration of racial or ethnic groups in lower-quality NICUs). Using data from infants in those NICUs. Their index of inequality has the pothe Vermont Oxford Network and a cohort of more than 117 000 tential to be used in future research investigating disparities. infants born at 401 g to 1500 g or 22 to 29 weeks' gestation from Future research would benefit from more granular data on race 2014 to 2016, they measured segregation and inequality at the and ethnicity to measure disparities in care for specific sub

Patient-level quantitative measures of quality, such as those used in the study by Horbar et al.5 are critical to solving regional variation in quality of care. Compared with white infants, black infants received care at lower-quality NICUs; Asian tential to illuminate the pathways by which racial disparities and Hispanic infants received care at higher-quality NICUs. Region of residence explained differences for Hispanic but not a nates can have worse outcomes than white mothers because (1) they receive care from facilities that treat all mothers with This article has a number of strengths in relation to pre- poor quality of care, (2) they receive worse quality of care than vious studies. First. Horbar et al5 used a comprehensive measure of quality, the composite Baby-MONITOR (Measure of Neoscial risks that are beyond the control of the hospital. Withnatal Intensive Care Outcomes Research) score, rather than out patient-level measures of quality, we cannot distinguish solely relying on risk-adjusted mortality or morbidity to assess hospital performance. The Baby-MONITOR score includes 9 infant-level process and outcome measures (eg, an more, this composite measure builds on previous work to identenatal steroid exposure, hypothermia on admission, health tify evidence-based interventions in neonatology and illus trates the health impact of failure to implement them in current to measure quality in California NICUs. 4.6 Much of the previsearch to identify which components of care contribute most tal disparities has relied on measures of risk-adjusted neona- to disparities. Although each component is weighted equally tal morbidity and mortality ascertained through the use of in the score, the authors point out that changing these weights

IAMA Pediatrics Published online March 25, 2019 E1

Howell E, et al. JAMA Pediatr 2019





Poor care between hospitals

Neonatal mortality by hospital in NYC

JAMA Pediatrics | Original Investigation

Differences in Morbidity and Mortality Rates in Black, White, and Hispanic Very Preterm Infants Among New York City Hospitals

Elizabeth A. Howell, MD, MPP; Teresa Janevic, PhD, MPH; Paul L. Hebert, PhD; Natalia N. Egorova, PhD, MPH;

Figure. Hospital Rankings for Risk-Adjusted Neonatal Morbidity and Mortality, New York City, NY, 2010-2014

Amy Balbierz, MPH; Jennifer Zeitlin, DSc, MA 0.8-PORTANCE Substantial quality improvements in neonatal care decade yet racial and ethnic disparities in morbidity and mor whether disparate patterns of care by race and ethnicity 40%(95%CI, 30%-50%) of the black-white non-Hispanic black (black), Hispanic, and non-Hispan disparity and infants in each hospital. Hospitals were ranked using t distribution of black, Hispanic, and white very preter **30%** (95%CI, 10%-49%) of the Hispanic-white or severe neonatal morbidity (bronchopulmonary dy: disparity was explained by birth hospital. (28%) and was higher among black (893 [32.2%]) and (0.40: 95% CL 0.38-0.41) as for those born in the low 95% CI, 0.14-0.18). Black (1204 of 2775 [43.4%]) and in the highest morbidity and mortality tertile (2-tailed P

Howell et al. JAMA Pedatr 2018

95% CI, 18%-23% and Hispanic-white difference, 11%; 95% of proportion of the explained disparities can be attributed to difference.

hospitals with higher risk-adjusted neonatal morbidity an

ONCLUSIONS AND RELEVANCE Black and Hispanic VPTB infants are

JAMA Pediatr. doi:10.1001/jamapediatrics.2017.4402 Published online January 2, 2018. emsalons are listed at the end of this article.

Corresponding Author: Elizabeth A. Howell, MD, MPP, Isahn School of Medicine at Mount Sinai, One Gustave L. Levy Pisce, Box 1077, New York, New York 10029 (elizabeth howeli



among black, Hispanic, and white VPTB infants. However, 40% (95% CI, 30%-50%) of the black-white disparity and 30% (95% CI, 10%-49%) of the Hispanic-white disparity was



.27-0.29)



in the NICU

Jessica Liu, Ph.D, MPH^{1,2} Charlotte Sakarovitch Henry C. Lee, MD, MS1,2 Jochen Profit, MD, MI

¹ Perinatal Epidemiology and Health Outcomes Research Unit. Division Ne cnatclogy, Department of Pediatrics, Jucile Packard Children's Hospital, Stanford University School of Medicine, Palo Alto, Californ ²California Perinatal Quality Care Collaborative, Palo Alto, Calif 3 Division of Biomedical Informatics Research, Department of Medicine, Stanford University, Stanford, California

⁴Medical Data Lab. Université Côte d'Azur, Nice, France

Am J Perinatol

Abstract

Objectives This stud associated infection (H Study Design This i between 2011 and 2 Results Risk-adjus units (NICUs), rang higher odds of HA Non-Hispanic bla tertile of infecti

Conclusion

with infection.

variation in infection acro-

Keywords → infant

► health care-

 disparity ► risk factors

associated infection

practice-related factors 1-3,5,6,8-11

Health care-associated infection (HAI) is a serious complication among very low birth weight (VLBW; < 1,500 g) preterm infants hospitalized in the neonatal intensive care unit (NICU), and infection rates in these infants have ranged from 21 to 30%. 1-4 VIBW infants are especially susceptible to HAI. They are immune-incompetent hosts, require prolonged hospitalization, undergo frequent invasive procedures, and receive prolonged broad-spectrum antibiotics and intravenous nutrition. 1,5-7 In addition, infection risk is

At the time of this research, Dr. Sakarovitch was a senior statistician at the quantitative sciences unit

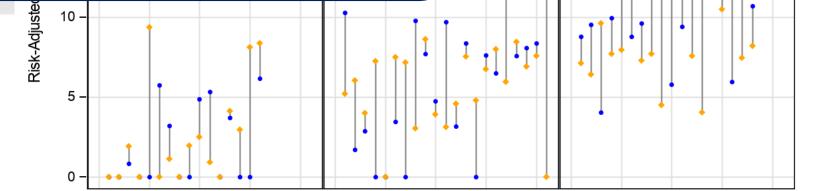
conveyed by a combination of maternal health and clinical

HAIs are associated with increases in neurodevelopmental impairment, mortality, length of stay, and as a result, increased financial costs of care 3.6,12-17 Payne et al reported that the occurrence of just one single type of HAI would increase costs of treating VLBW infants by \$100 million.12 Reducing HAI has been a priority in recent years, and successful efforts have been reported from individual NICUs and through collaborative networks, such as the Vermont Oxford Network and the California Perinatal Quality Care Collaborative (CPQCC), 7,18-20

Vulnerable populations may be differentially affected by HAI because they may receive care in challenged hospitals, which provide lower quality of care, 21-23 or differential treatment within hospitals.24 HAI is more dependent on



Hispanics more likely to have a HAI



Non-hispanic Black → Non-hispanic White

Med-infection Tertile

Liu et al. Am J Perinat 2019; Apr 30



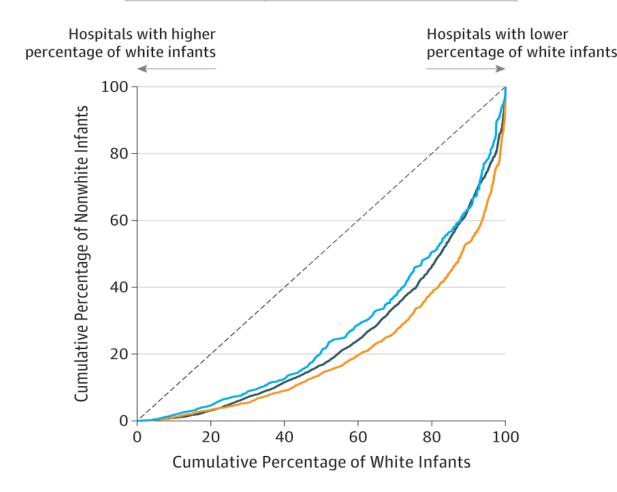


High-infection Tertile



Racial Segregation in the NICU

	NICU Segregation Index (95% CI)
Black	0.50 (0.46-0.53)
——— Hispanic	0.58 (0.54-0.61)
Asian	0.45 (0.40-0.50)



responsibiliti-weight and Very Preterm Infants Jeffrey D. Horbar, MD. Erika M. Edwards, PhD; Lucy T. Greenberg, M5; Jochen Profit, MD; David Draper, PhD; Daniel Helkey, MS; Scott A. Lorch, MD; Henry C. Lee, MD; Giaran S, Phibbs, PhD; annette Rogowski, PhD; Jeffrey B, Gould, MD; Glenn Firebaugh, PhD ANCE Racial and ethnic minorities receive lower-quality health care than white non-Hispanic individuals in the United States. Where minority infants receive care and the role that may play in the quality of care received is unclear. OBJECTIVE To determine the extent of segregation and inequality of care of very low-birth-weight and very preterm infants across neonatal intensive care units (NICUs) in the IGN, SETTING, AND PARTICIPANTS This cohort study of 743 NICUs in the Vermont Oxford Network included 117 982 black, Hispanic, Asian, and white infants born at 401 g to 1500 g or 22 to 29 weeks' gestation from January 2014 to December 2016. Analysis began January IES AND MEASURES The NICU segregation index and NICU inequality index were calculated at the hospital level as the Gini coefficients associated with the Lorenz curves for black, Hispanic, and Asian infants compared with white infants, with NICUs ranked by proportion of white infants for the NICU segregation index and by composite Baby-MONITOR (Measure of Neonatal Intensive Care Outcomes Research) score for the NICU inequality ESULTS Infants (36 359 black [31%], 21 808 Hispanic [18%], 5920 Asian [5%], and 53 895 white [46%]) were segregated among the 743 NICUs by race and ethnicity (NICU segregation ndex: black: 0.50 [95% CI, 0.46-0.53], Hispanic: 0.58 [95% CI, 0.54-0.61], and Asian: 0.45 -0.10 [95% CI, -0.17 to -0.04], and Asian: -0.26 [95% CI, -0.32 to -0.19]). There was marked variation among the census regions in weighted mean NICU quality scores (range: -0.69 to 0.85). Region of residence explained the observed inequality for Hispanic infants but not for black or Asian infants.

Ethnicity in US NICUs ranked by the proportion of white infants from highest to lowest, and the cumulative population percentages of white and minority infants were plotted on the x- and y-axes. If all NICUs had the same racial distribution as the overall population, the curves would fall on the diagonal.

Horbar, Profit et al. JAMA Pediatr 2019

But we treat all patients the same!



Overlapping Dimensions

Types of Disparate Care

Neglectful C are: 83 (26%). NICU staff ignore, avoid or neglect family needs (e.g. breastfeeding support) when considered difficult or unpleasant or when obstacles considered too great to overcome.

Judgmental Care: 82 (26%): Staff evaluate a family's moral status based on race, class or immigration. Circumstances or behaviors judged more harshly. Discrimination occurs through staff attitudes or resource allocation.

Suboptimal Care: 312 (96%)

Language Barriers 151 (47%)

Systemic Barriers: 139 (44%): Staff unable or unwilling to address barriers families face such as transportation, child care, housing, employment, translation needs, or religious or cultural needs.

Social, Economic or Racial Privilege: 12 (3%)

Priority Treatment and /or Assertive Families: 12 (3%). Families connected to NICU receive priority treatment. Assertive families receive more attention.

Privileged Care: 12(3%)

Sigurdson K, Profit J, et al. Disparities in NICU Quality of Care: A Qualitative Study of Family and Clinician Accounts. *J Perinatol* 2018

Neglectful care

A Spanish-speaking mother of a 23 week infant was **not provided with** a **translator before**, **during**, **or after delivery** to explain what has happening with her baby. I asked for an interpreter to come in to the hospital to help and faced push back because it was late at night. The L&D staff thought a translator phone should be sufficient. I **felt that the situation would not have been met with such a lack of em** the mother been of a different ethnicity.







Judgmental care

I see this all the time... the way we treat Black moms is definitely different than how we treat White moms. And age plays a factor too-young moms are judged very unfairly. One black mom was judged very harshly for being late for a feeding even though she had a long and challenging transit ride to get to the hospital. A white mother who was late on the same day was greeted with sympathy. A small example to get to the hospital because I see moments like this every single day.

Family advocate regarding family identified as Black



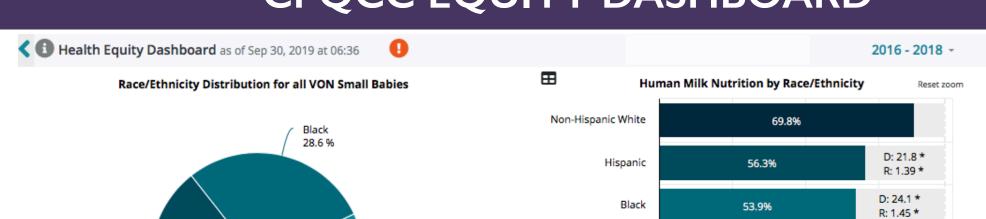


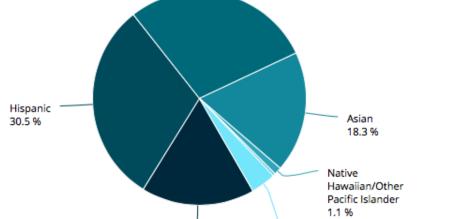
Accounts told of disparate care of families, not strictly infants





CPQCC EQUITY DASHBOARD



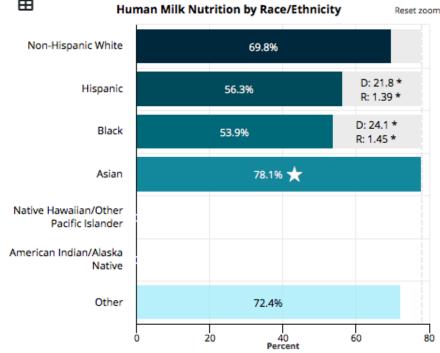


Other

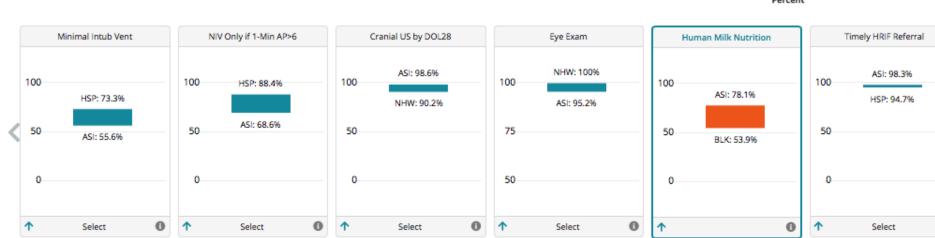
3.8 %

Non-Hispanic White

17.2 %

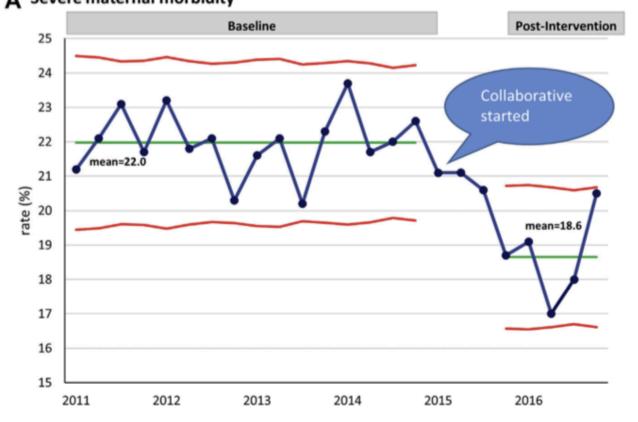


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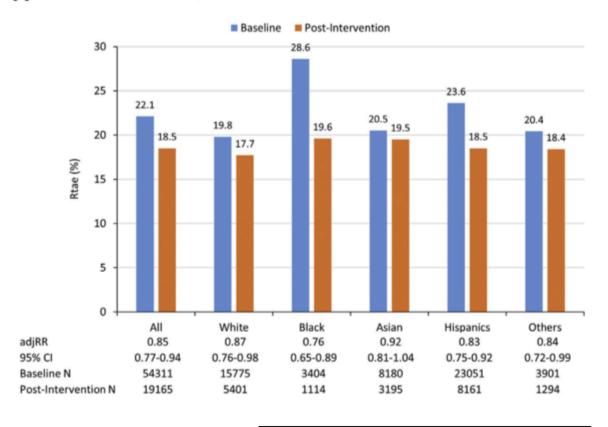


Disparity reduction through technical QI

A Severe maternal morbidity



Severe maternal morbidity

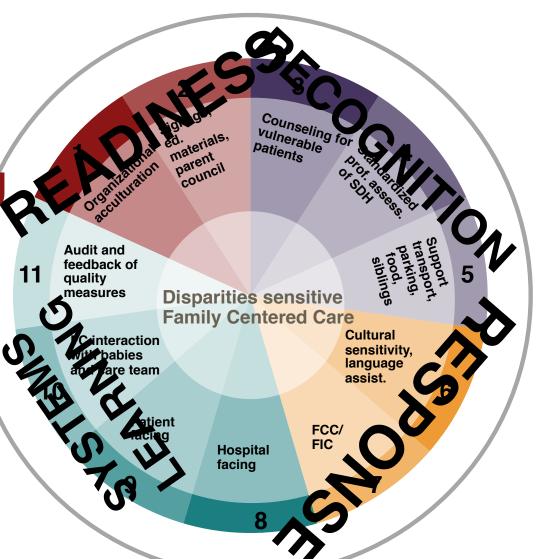


Main, Profit et al. AJOG 2020





Changin g what we do in the NICU



FCC or Family Auditrarid feedback of quiality ameiasure shby babrase/ethoicity/eam in perlanguageer the phone/video Language concordance mes.





REVIEW ARTICLE OPEN

The color of health: how racism, segregation, and inequality affect the health and well-being of preterm infants and their families

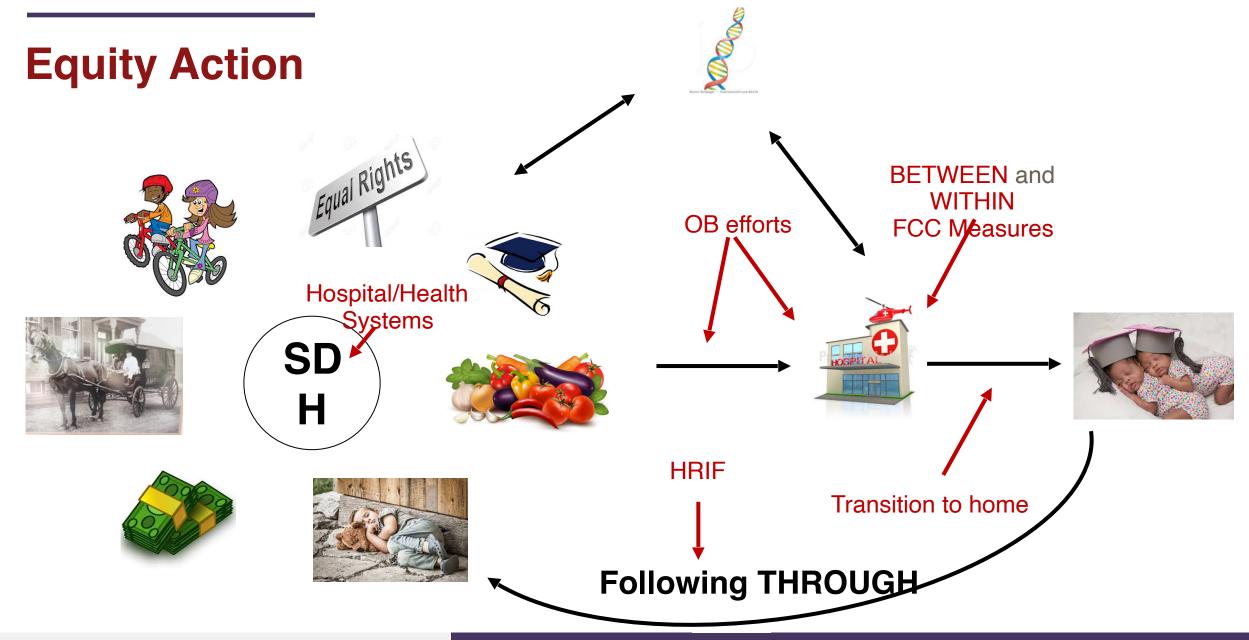
Andrew F. Beck^{1,2}, Erika M. Edwards^{3,4,5}, Jeffrey D. Horbar^{3,4}, Elizabeth A. Howell^{6,7,8}, Marie C. McCormick^{9,10,11} and DeWayne M. Pursley^{9,11}



high

- 1. Identify, prevent, and mitigate social risks
- 2. Recognize our responsibility does not end at NICU discharge
- Develop robust quality improvement efforts to ensure equitable quality NICU care
- 4. Advocate for social justice at the local, state, and national level









Summary

We don't practice in a social cocoon

 Disparities in NICU care exist within and between NICUs

Prioritize disparities

 Routinely measure processes and outcomes by race/ethnicity

Incorporate disparities into all Ql effor

Engage your family advisors

Try Something Tomorrow!!



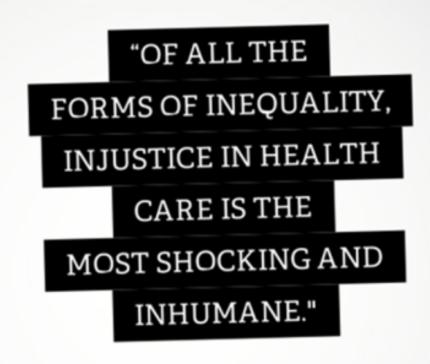


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Dr. Martin Luther King, Jr.





Acknowledgements

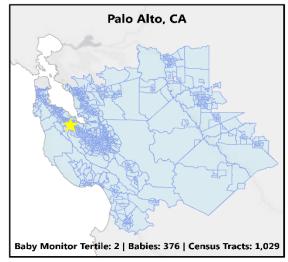
- Ravi Dhurjati, PhD, Krista Sigurdson, PhD
- Briana Mitchell, BS; Christine Morton, PhD; Family Representatives: Lelis Vernon; Ashley Randolf
- Linda Franck, PhD, Ciaran Phibbs, PhD, Henry Lee, MD, Melissa Scala, MD, Jeffrey Gould, Jeffrey Horbar, MD
- National Advisory Board of Experts: Darius Bradley, Wally Carlo, Jimmy Collins, Wakako Eklund, Marybeth Fry, Balaji Govindaswami, Yolanda Ogbolu, Jean Raphael, Joaquin Rodriguez, Vincent Smith, Eileen Steffen, Paul Wise

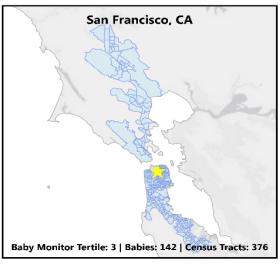
Supported by funding from Eunice Kennedy Shriver National Institute of Child Health and Human Development R01 HD083368-01, R01 HD084667, PI: Profit, J

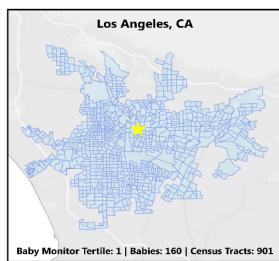


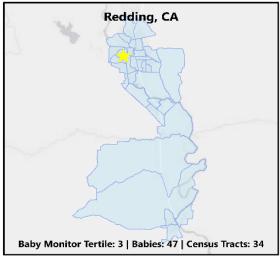


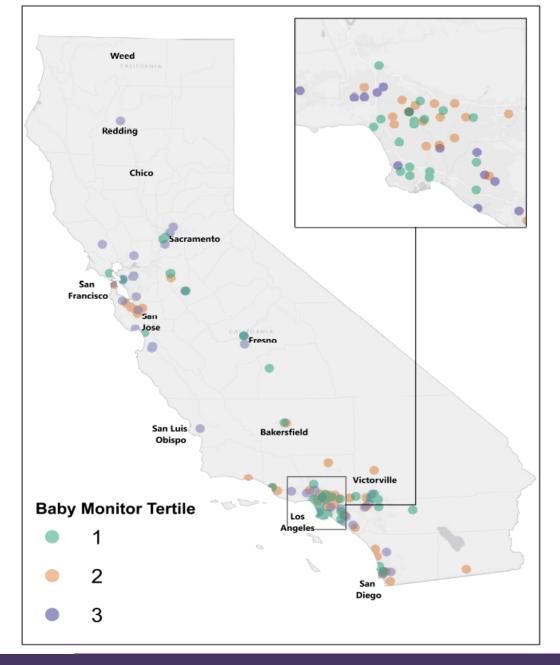
Dashboard













Measures of Family Centered Care

- NICU family advisory council
- Days to first skin-to-skin care
- Time to priming with oral colostrum
- Delayed social worker encounter
- Frequency of updates to families by MD/NNP/RN

Point-of-care derived measures developed in collaboration with disadvantaged families. Measures selected through a modified Delphi panel that included family representatives.



Importance of community based participatory research



Former NICU moms conducting interviews and focus groups

Findings re: Latino families:

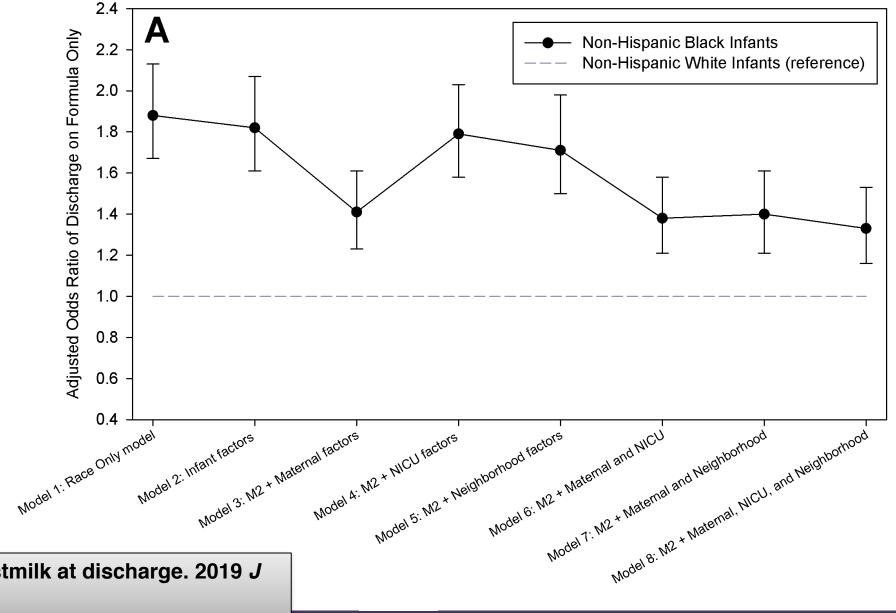
- Concept of family
- Perception of care quality







Maternal Effects Greater than Neighborhood Effects



Liu J, Profit J, et al. Any Breastmilk at discharge. 2019 *J Pediatr*



