

“Following Through”: Addressing the Racial Inequality for Preterm Infants and Their Families

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**“Following Through”: Addressing the Racial Inequality
for Preterm Infants and Their Families**

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In this issue, Beck et al. review “how racism, segregation, and inequality affect the health and well-being of preterm infants and their families.”(1) They acknowledge thoughtfully that while structural racism embodies “mutually enforcing forms of discrimination” in society, the social determinants of health (SDH) are insufficient to explain the risk of preterm birth (PTB), even in the non-Hispanic black population of the United States.

Inequities in perinatal care have persisted for decades and are consequent to “mutually reinforcing” complex social, health system, and personal health factors.(2) SDH biologically influence maternal and fetal health as well as access to and quality of healthcare throughout pregnancy, birth, and NICU hospitalizations. With transition back into the community, the mother-infant dyad is again exposed to factors powerfully determining long-term development and health. Effective solutions for perinatal inequities require multi-pronged and integrated approaches at the levels of family, community, healthcare system, and policy. Beck et al. provide important practical advice for action at the healthcare system and community levels. Although implementation may prove difficult owing to misaligned financial incentives to ingrained structural, institutional, and interpersonal racism, we support the authors’ suggestions and provide a few others meant to promote feasibility and sustainability.

First, it is important to recognize that what is described as SDH have a biologic counterpart in a woman’s physical disposition. PTB results from biological processes, pathologic in nature and ill-timed. Psychological or physical stressors may further “inflame” the maternal disposition, increasing risk for PTB or stillbirth.

Genetics has a role in all which is biologic in nature, but it is not simply a matter of having or not having certain genes; it is a matter of gene expression regulated through epigenetics (i.e., methylation or histone modification) and interactions with other genes.(3)

Furthermore, inheritance is not just “passing on genes”, but also the passing on of gene expression patterns, literally reflecting a physical legacy of societal and personal stressors. The race disparity in PTB risk in African-Americans and non-Hispanic white women has not been sufficiently explained by sociodemographic factors, behavioral factors, or underlying biomedical conditions.(4) A pattern of results, where various environmental exposures, sociodemographic factors, and evidence of heritability and genetic variants do not adequately account for differences in disease risk, has led many experts to posit the likelihood that individual epigenetic variability – that is, genetic modifications – is the underlying etiology in complex conditions like PTB. Variations in DNA methylation can be altered by environmental exposures (e.g., air pollution) and by genetics. Studying these variations may reveal differences in disease susceptibility not identified by studies that have simply examined exposures or genes alone as epigenetic changes may be heritable and potentially reversible. The former offers a possible explanation for observations that women who were born preterm are at higher risk of having PTB. The latter notion of reversibility offers opportunities for future prevention strategies.

In the context of risk, one must also consider an individual’s resilience (resistance to risk). Most individuals who are seemingly at-risk for PTB do not experience that outcome. Understanding how their biology responds differently to the same stressors associated with PTB compared with others may help to develop preventive strategies, in particular when SDH seem intractable because of political or environmental circumstances (e.g. economic policies that disadvantage parts of our society or the location of residential area near an industrial complex or highway).

Ironically, some interventions, known to be effective biologically, can widen group disparities because of differences in access to healthcare or failures in “removing obstacles such

as discrimination, poverty, and lack of access to quality education, housing and healthcare.”

Indeed, such disparities are rooted in structural and interpersonal racisms and their amelioration requires herculean efforts by policy makers, community leaders, and healthcare providers.

Traditionally, these groups have often worked in silos – with good intentions but limited effectiveness. Fortunately, in this networked era, new opportunities have arisen to leverage local expertise to provide more powerful interventions, linking families with medical and social professional organizations. Such efforts require policy and financial support, aligning family with provider and payer incentives.

A disturbing observation made by Beck et al. is that quality of care is not equally distributed, varying within and between facilities. We have demonstrated that high quality of care does not always translate to equitable care.(5) Payers, regulators, and agencies that rank and rate hospitals, influence clinical practice and policies, but do not typically set standards for equitable care. Incentives linked to quality of care *AND* equity could increase partnerships between hospitals and community organizations serving high-risk populations.

Using large data sources and quality improvement (QI) principles, the California Perinatal Quality Care Collaborative (CPQCC) and the California Maternal Quality Care Collaborative (CMQCC) have launched concerted efforts to address inequities in healthcare delivery. They have developed health equity dashboards where member hospitals can identify gaps in quality of care by race and ethnicity. Feedback of such information is foundational for improvement. Also, a solution-based volunteer multi-stakeholder health equity task force, including parent representatives, has been established to address inequities in care during pregnancy, labor and delivery, birth hospitalization, transition back to the community, and

throughout infancy. Which approaches will be the most effective and for which populations and circumstances is unknown and will require rigorous testing, evaluation, and financial support.

In conjunction with California Children's Services, the CPQCC has implemented a statewide QI initiative for follow-up care since 2009. Although this would be just one component of "following through," it is notable that both referral and visits to high-risk infant follow-up clinics has been significantly lower for racial/ethnic minorities compared with non-Hispanic white families.(6,7) That those infants who are potentially at highest risk both medically and from a social perspective are less likely to receive attention in this critical period of development highlights the need for QI interventions in the transition period from NICU to home. These efforts are ongoing. Furthermore, noting that traditional programs such as high-risk infant follow-up clinics may not be feasible for some families in challenging socioeconomic circumstances, there is a need for innovative strategies to serve these patients, which may incorporate technologies such as mobile apps.

One example, *PretermConnect*, has been developed at Stanford and implemented at the population level in Allegheny County, PA, where patient-generated data from the mobile app are being integrated into county electronic and public health records to predict PTB and infant mortality rates. Routine inquiries on SDH items are made via in-app surveys as families' social circumstances such as marital status, employment, and issues related to food and housing may change over time. The app can also serve as an effector arm for interventions by sending notifications of age-based recommendations for follow-up care (e.g., retinopathy follow-up, etc).(8) Mothers can use the "Community" features to access useful tips and support. Educational materials are available on topics relevant to maternal and infant health and wellbeing (e.g., maternal depression, contraception, how to hold and breastfeed), with the ultimate goal of

improving the quality of care. Ancillary care partners and community-based organizations can also access the app to update and inform families with newly-available resources.

PretermConnect is an example for the “follow through” approach suggested by Beck et al. For such innovation to thrive in the market place, we suggest the following complements to the authors’ recommendations, recognizing the mother-baby dyad as the central focus for healthcare reform and research: 1) performing routine comparative measurements of family-centered care; 2) funding population-based health through accountable care organizations or value-based payments that include aligning maternal with infant quality of care; 3) extending Medicaid eligibility for a mother and child until at least one-year postpartum to improve access to healthcare during this vulnerable phase; 4) understanding what levels of social development of the mother-baby dyad generate the best outcomes with regard to PTB reduction and developmental outcomes; and 5) funding for research to better understand how to overcome resource constraints and build quality capacity at safety net hospitals is needed. Beck et al. provide a compelling case for change. It is time for pediatricians to lead concerted efforts to end health inequalities for mothers and infants.

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