The Albany Birth Justice Storytelling (ABJS) Project

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Empirical and Conceptual Foundations

1. Articles in *The Nation*

These three articles all touch on the theme that maternal mortality is not only a medical concern, but a social justice concern. Each article describes the jarring experience Black mothers face during clinical visits and how that ultimately leads to distrust of medical professionals as well as fear for their own wellbeing and that of their children. All three articles recount the many instances where the needs of Black mothers were ignored, drawing attention to the life-threatening disadvantage that race entails in maternal health outcomes. We used these articles to address the implications that racial bias has in the medical system and how that leads to disparate health outcomes and an internalized fear of medicine in the Black community.


We read the first three chapters of this book. Davis draws striking parallels between the chilling accounts of prematurity from the narratives of slaves (ambivalent about whether it is more humane to assist in their survival or let die) to those from professional, middle-class Black women today. She breaks down how Black women’s treatment in medical environments today for prenatal visits, labor and birth reflect extensions of earlier racial thinking. Her interviews with birth professionals, including neonatologists, reveal a persistent refusal to acknowledge race as a factor in premature birth. She critically assesses neonatal medicine not simply as life-saving, high technology, but part of a profitable medical industrial complex. Davis further unpacks how race is done in the NICU, including how parents are constructed as worthy (or not). Davis defines four realms of medical racism: diagnostic lapses, assumptions of obstetric hardiness, hardy babies, and menacing mothers. She elaborates each with the accounts from her extensive interviews with Black women who have or lost children. When reviewing the photovoice narratives from Albany storytellers we repeatedly recognized these same themes in our own data. The book’s central ideas were reinforced for us when Dr. Davis visited our class via Skype and spoke to us directly about her research process and findings. In the Q & A, we were able to address some of our own fears going into the field. She was very encouraging and supportive of our process.


Especially in Latin America the term “violencia obstetrica” has broadly encapsulated multiple forms of mistreatment during childbirth that range in severity. According to law scholar, Elizabeth Kukura, the negative experiences and harms related to maternity have remained invisible because of privacy norms that govern healthcare, women’s feelings of shame resulting from their experience of mistreatment, and because providers who witness it continue to deny
this reality (724). This conceptual frame attempts to describe a problem that persists even when women leave the hospital with a healthy baby. Kukura defines three categories of obstetric violence: abuse, coercion, and disrespect. Abuse, which constitutes the most extreme form of mistreatment, includes forced surgery, unconsented medical procedures, sexual violation, physical restraint and other forms such as the denial of pain relief or abusive verbal attacks. Coercion includes tactics doctors use to secure consent when a woman declines to follow medical advice. These include: seeking judicial intervention; instituting blanket policies restricting access to particular forms of care; threatening involvement of child welfare authorities; or withholding treatment, manipulating information, or applying emotional pressure. Finally, disrespect, a third category of mistreatment, includes humiliating comments directed at women in labor.


This introductory chapter explains why classic feminist theories of the medicalization of childbirth with their narrow focus on gender and paternalistic medicine provide inadequate explanations for the experiences of Black women in pregnancy and childbirth. Rehearsing the history of the reproductive justice movement, Oparah recounts the ways in which this movement was slow to take up the issue of birth oppression. The author points to a 2010 call by the National Advocates for Pregnant Women and a specific gathering at the 2011 SisterSong Conference on reproductive justice as catalytic moments in the formation of the U.S. birth justice movement. The author describes a dilemma faced by Black women: medical racism in the origins and contemporary practices of obstetrics and the “malign neglect” of the so-called natural childbirth movement that has overlooked the work of contemporary Black midwives and specific access barriers faced by Black women to “natural” childbirth. The author defines birth justice as a “movement to challenge medical violence and coercion during pregnancy and childbirth, to reclaim midwifery traditions in communities of color, and to raise awareness among women of color about strategies to overcome birth inequities” (7).


This accessible book designed for broad audiences is chock full of direct quotations from questionnaires answered by 100 Black women about their pregnancy, miscarriage, birth and postpartum experiences. Illustrations add to the inviting aesthetic. The book was the result of a multi-year, research project (2011-2015) undertaken by the Black Women Birthing Justice Collective in California. The authors address Black women’s unrealistic positionality of themselves based on the Strong Black Women Syndrome. What they found was that when Black women manifested tenets of SBWS during their birthing experiences, it could potentially lead to failure to ask for assistance during pregnancy, thus increasing mortality and morbidity rates. Other experiences that characterized negative relationships with providers included stereotyping based on race, class, age, sexuality and marital status; refusal to listen to women's wisdom about their bodies; not respecting women's boundaries or bodily autonomy; and suppressing advocacy and self-advocacy. The book describes elements of positive relationships with providers as well.
An extensive account of Black women's experiences in their own words, *Battling Over Birth* is the product of participatory action research. This book played a central role in our work. We read it in its entirety and used it as a basis for drawing up preliminary codes and themes to analyze our own data.


This report revealed racial disparities in birth outcomes through the indicators of infant deaths, preterm births and low birth weight particularly in zip codes 12202 and 12207 that cover the South End of Albany and Arbor Hill. Similar to other groups working on birth justice across the nation, we engaged these numbers and acknowledged the need to collect birth stories to accompany and elaborate statistical truths. We discussed how birth outcome statistics present an abstract reality that, while not necessarily distorted, can sometimes have unintended effects such as perpetuating deficit perspectives that re-stigmatize the very people they are meant to help.

**Methodological Foundations**


The need for Black Feminist Health Science Studies has always existed, but the impetus for the creation of a formal discipline can be accredited to the words of Fannie Lou Hamer. Hamer's famous quote, "I am sick and tired of being sick and tired" was an expression of disdain for the state of Black people, but also a testament to the negative health outcomes and disparities experienced in the Black community. Bailey and Peoples' research directly addresses the history of racialized medicine and abuse Black women faced at the hands of white men in medicine. Citing famous cases like the experiments of J. Marion Sims and Henrietta Lacks, the authors highlight how racism has been indoctrinated into health science. Instead they call for a Black Feminist Health Science Studies defined as “a social justice science that understands the health and well-being of people to be its central purpose” (1). We used this research to establish the lens from which we began our own photovoice narratives; it became extremely imperative that the center of our project was Black women, who have historically been erased and neglected from health science endeavors.


Transformative storytelling was one of two main methods we employed in this project. Prasetyo details eleven reasons why storytelling provides distinct advantages to direct questioning in standard interviews or focus groups in which an informant is asked to state their opinion. When the experience narrated may be traumatic storytelling provides emotional safety, a social function and legitimization through the concomitant act of listening, and rich contextual information. This reading was accompanied by a guest lecture by Prof. Vivien Ng, in which Dr.
Ng stressed that stories are “transactional and can be transformative.” Through the example of her own research with painter, Barbara Zuber, Dr. Ng shared the difference that storytelling can make through the comparative depiction of one particular moment in Zuber’s life – first in the context of a formal interview and then in a more relaxed narration with trusted listeners. Drawing on an online handbook, “Transformative Storytelling for Social Change,” Dr. Ng further emphasized the idea that ownership of the stories belongs to the storyteller, who must retain the ability to decide how their stories are used.

3. Photovoice

The second method we employed was photovoice. The selection of literature related to this method included the classic description of the method by Wang and Burris and a more recent application of the method by Jackson, et al. The latter article, like our own project, aimed to engage a particular community in Atlanta, Georgia on racial disparities in birth outcomes. Originally applied by Wang and Burris in Yunnan (rural China), the authors elaborate a basic description of the method, which can be adapted to other contexts. Particularly useful for community needs assessment purposes that can highlight the strengths of a community as well as areas needing improvement the method involves collective discussion and interpretation of photographs taken by community members. By fostering a form of self-representation, knowledge production and sharing, the process assists in directing a community towards specific action for change. These texts informed our own adaptation of the method. In our case, a collection of photographs provided by the storyteller was combined with their edited recorded story by the listener. In close consultation with the storyteller, the listener then added creative visual and sound enhancements as well as subtitles. Dr. Dána-Ain Davis, who visited our class in mid-September 2019 via Skype (author of entry #2) had employed photovoice in a study on the impact of welfare reform on two communities in New York City. We were able to ask her questions about method. Dr. Davis shared with us the culminating report of her own photovoice project and reassured us that our adaptation was sound even if we did not technically put cameras into the hands of community members.