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Addressing Perinatal Disparities in Urban Setting: Using Community Based Participatory Research

Saba W. Masho, MD, DrPH,

Associate Professor, Departments of Epidemiology and Community Health and, Obstetrics and Gynecology, Virginia Commonwealth University

Lori Keyser-Marcus, PhD,

Assistant Professor, Department of Psychiatry, Virginia Commonwealth University

Sara B. Varner, BA,

Virginia Commonwealth University

Derek Chapman, PhD,

Virginia Department of Health

Rose Singleton, and

Richmond Healthy Start

Dace Svikis, PhD

Professor, Departments of Psychology, Psychiatry, Obstetrics and, Gynecology, Virginia Commonwealth University

Saba W. Masho: swmasho@vcu.edu; Lori Keyser-Marcus: Lakeyser@vcu.edu; Sara B. Varner: Sbvarner@vcu.edu; Derek Chapman: Derek.Chapman@vdh.virginia.gov; Rose Singleton: Rose.Singleton@richmondgov.com; Dace Svikis: Dssvikis@vcu.edu

Abstract

Striking racial disparities in infant mortality exist in the United States, with rates of infant death among African Americans (AA) nearly twice the national average. Community-based participatory research (CBPR) approaches have been successful in fostering collaborative relationships between communities and researchers focused on developing effective and sustainable interventions and programs targeting needs of the community. The current paper details use of the Perinatal Period of Risk (PPOR) model as a method to engage communities by identifying factors influencing racial disparities in infant mortality and examining changes in those factors over a ten year period.

Keywords

Infant Mortality; Perinatal Periods of Risk; Community Based Participatory Research

Introduction

Infant mortality is a major public health problem in the United States. This is in large part due to the troubling racial disparities in infant deaths. A recent report from the National Center for Health Statistics indicated that infant mortality rate for African Americans

(13.6/1,000 live births) was nearly double than that of the U.S. average (6.8/1,000 live births).¹ This problem is pronounced in Richmond, Virginia; the site of this project. In the past decade, the rate of infant deaths in African-Americans in Richmond has consistently been at least four times higher than that of Whites.²

Pre-term birth and low birth weight are major contributors to infant mortality in both Blacks and Whites. Babies born before 37 weeks of gestational age and at the lowest birth weights represent a small proportion of births in the U.S. but account for many of the infant deaths.¹ African American women are disproportionately plagued by these problems and are 1.5 times more likely to deliver a pre-term baby compared to their White counterparts. Nevertheless, even when controlling for gestational age, birth weight, maternal age, and adequacy of prenatal care, racial disparities in infant mortality still persists.³

Many initiatives have been introduced to help alleviate this disparity, but much work remains to be done. A key factor in introducing successful programs and interventions is engaging the affected community from the outset and continuing engagement throughout the planning, development, and implementation of selected interventions. In November 2002, the Institute of Medicine recommended that community health initiatives should “focus on long-lasting change... [with an] emphasis on ongoing community engagement and leadership.”⁴ Community-based participatory research (CBPR) provides a theoretical framework in which researchers actively collaborate with community partners “in designing and implementing research and interventions intended to benefit them”.⁵ CBPR uses “an iterative process of action, reflection, and experiential learning” in conjunction with community engagement to develop programs that are easily embraced by communities.⁶

A key aspect of the framework is that the targeted communities are involved in all stages of the development. This involvement eases the translation of research to practice, a common barrier in more traditional research processes. CBPR emphasizes the relationship between researchers and community and the direct benefit to the community as an outcome of the research.⁷ This relationship facilitates community understanding of the purpose of the research, which in turn results in a more efficient and effective outcome. In the longer term, these community partners are more receptive to “research” involvement and more trusting of new collaborative ventures. Community involvement in program planning and implementation also serves to enhance sustainability.⁸

The CBPR framework can also be particularly useful in working with populations which have historically experienced distrust of researchers.⁸ This is common in African American communities, which have reported higher levels than Whites of distrust in research participation.⁹ CBPR methods utilizing high levels of community involvement in the planning process are more likely to result in high levels of benefit, trust, and satisfaction within the population being served, which in turn broadens the scope and sustainability of the intervention.¹⁰

Infant mortality is a complex issue that is affected by socioeconomic conditions such as poverty, racism, access to care, poor health behaviors and violence.^{11–18} These problems cannot be solved by a single organization. As such, community-based participatory research is an ideal mechanism to begin to address the problem. CBPR has been effective in developing recruitment strategies and planning for data collection in a project aimed at reducing infant mortality in African American women.¹⁹

To address the racial disparities in the Richmond infant mortality rate, a consortium was formed that facilitated a university-community partnership. This partnership utilized the Perinatal Period of Risk model (PPOR) to assess the major factors contributing to infant mortality and morbidity.²⁰ Developed by the World Health Organization, the perinatal

period of risk model provides a framework for addressing infant mortality that meshes well with a CBPR approach in its goal to engage community partners and identify opportunity gaps in an effort to ultimately target future intervention and prevention efforts. This approach is novel in its simplicity and the ease with which it can be communicated to community partners. Despite its benefits, this methodology has only been used in few localities in the US.^{21–23} Additionally, there is limited literature that utilized this methodology as an evaluation tool to examine changes in factors that contributed to disparities in infant mortality. The purpose of this CBPR was to: a) identify factors influencing the racial disparity in infant mortality; b) implement a CDC-funded REACH US initiative targeting health disparities by improving prenatal care attendance through interventions selected by community members; and c) evaluate a 10-year community wide effort and examine changes in the factors influencing racial disparities in Richmond City.

Methods

Community Engagement and Setting

This study was conducted by the Richmond Healthy Start Consortium. The Consortium is composed of social service recipients, neighborhood residents, medical, mental health and social service providers, nonprofit organizations, higher institution, and faith and business community representatives. The consortium continuously tracked trends of disparity in infant mortality and met regularly to discuss and seek solution to the problem. Despite a decade of intervention efforts, the disparity in infant mortality between African Americans and Whites in Richmond City persisted.

In order to identify priority areas for intervention, the consortium sought to examine factors that were associated with the widening gap of racial disparity in infant mortality. The consortium created a subcommittee consisting of community representatives and university researchers. The subcommittee was charged to examine and recommend priority areas for intervention. The subcommittee soon identified the need for community-specific data and decided to conduct the PPOR analysis.²⁰ This methodology was chosen because of its: a) simplicity to understand, b) ability to lend itself for CBPR and c) capability to offer a scientifically sound methodology.

PPOR uses infant and fetal mortality data to classify deaths into specific domains that can be targeted for intervention: maternal health/prematurity, maternal care, newborn care, and infant health. The PPOR approach can be summarized in a five-step process: 1) engage community partners, 2) map mortality by birth weight and age at death, 3) focus on a reduction of the fetio-infant mortality rate, 4) identify opportunity gaps, and 5) target future efforts on the identified gaps (PPOR workgroup).

Data source

The 1996 – 2005 birth, fetal and infant death data for Richmond City were obtained from the Virginia Department of Health. Death certificates for infant deaths and fetal deaths were linked to the corresponding birth certificate data. The data excluded spontaneous or induced abortions, fetal deaths occurring before 24 weeks of gestation and births and fetal deaths weighting less than 500 grams. Data for this analysis included 29,177 live births, 245 infant deaths and 112 fetal deaths.

Data analysis

In order to examine factors influencing perinatal disparity and evaluate changes occurring in the community, the data were divided into two time periods; 1996 to 2000 and 2001 to 2005.

The PPOR analysis was conducted for each time period in accordance to the Centers for Disease Control and Prevention/ CityMatCH protocol.²⁰

The PPOR analysis utilized a cross tabulation of birth weight and age at death. Birth weight was categorized into very low birth weight (500–1,499 grams), low birth weight (1,500–2,499 grams) and normal birth weight (≥2,500 grams). Age at death was categorized into fetal death (pregnancy loss 24+ weeks gestation and 500+ grams), neonatal death (death of an infant occurring between birth and 27 days of age) and post neonatal death (death of an infant occurring between 28 days and one year of age). The cross tabulation of these variables yielded a table with six distinct cells/groups. The first three groups included fetal, neonatal and post-neonatal deaths weighing 500–1,499 grams. The PPOR analysis suggests that factors influencing maternal health and prematurity were the major contributors to these deaths. These factors included maternal preconception health, perinatal care and health behaviors such as smoking, substance use, exercise and nutrition.²⁰ The fourth group included fetal deaths weighing ≥1,500 grams, which is influenced by the lack of maternal prenatal care and high risk pregnancy or obstetric care. The fifth group included death in the neonatal period among those weighing ≥1,500 grams. This period is highly influenced by perinatal management, neonatal clinical care including pediatric surgery. The sixth group included post neonatal deaths weighing ≥1,500 grams. Factors contributing to these deaths included Sudden Infant Death Syndrome (SIDS), injury, and breast feeding.²⁰

PPOR analysis was conducted for the total population (all races combined) and comparisons were made between the two time periods. Because mortality rates were higher in African Americans, a race-specific PPOR analysis was conducted for African Americans and Whites. Feto-infant mortality rate (FIMR) for each time period by race was calculated. The PPOR for African Americans and Whites were compared and excess risks were calculated. The reference group for this analysis was births to White non-Hispanic women.

The finding of the PPOR analysis was discussed among the consortium members. In an effort to prioritize community endeavors, small group discussions involving all consortium members and SWOT analysis (Strengths, Weaknesses, Opportunities and Threats) were conducted. This process resulted in the identification of priority areas and the development of a community wide action plan for intervention.

Results

Distribution of the study population is presented in Table 1. There was nearly equal number of births during the two study periods; 14,463 and 14,714 during the 1996–2000 and 2001–2005 time periods, respectively. However, the number of infant deaths was higher (N=139) during the 2001–2005 time period compared to 107 infant deaths in 1996–2000 time period. Overall, the number of births from African American women was two times higher than the White births. On the other hand, the racial distribution of fetal deaths was proportional to the racial distribution of live births.

Figure 1 shows that the infant mortality rate in the 2001–2005 period was higher than the 1996–2000 period. While the rate for Whites declined from 5.8 to 4.1 infant deaths per 1,000 live births, the rate for African Americans increased from 16.5 to 18.6 infant deaths per 1,000 live births. The infant mortality for the 2001–2005 period was nearly five-fold higher for African Americans compared to Whites.

Table 2 shows the PPOR analysis for all races by time periods. Overall, the FIMR was lower during the 2001–2005 time period. Analysis of the influencing factors showed that improved prenatal, high risk pregnancy and neonatal care contributed to the observed improvement. However, it is to be noted that maternal factors/prematurity such as preconception worsened

during this time period. Unlike the overall FIMR, the rate for African Americans worsened over time. The FIMR for African Americans during 2001–2005 was higher (15.0 per 1,000 live births) compared to the 1996–2000 time period (14.1 per 1,000 live births) (Table 2). The major contributors to this increase were factors influencing maternal health/prematurity and infant health. The rate attributed to maternal health/prematurity increased from 5.5 per 1,000 live births to 7.9 per 1,000 live births in 1996–2000 and 2001–2005 time periods. Although there was a significant improvement ($\chi^2=12.34$, $p<.001$) in maternal and newborn care during the later time period, the overall FIMR was not averted.

A comparison of the FIMR between African Americans and Whites for 2001–2005 period showed that the rate was three times higher for African Americans (Table 3). The excess risk of FIMR for African Americans during that time was 10 per 1,000 live births. The primary contributing factors for this excess death was influenced by maternal health/prematurity and infant health. The FIMR attributed to maternal health/prematurity for African Americans and Whites were 7.9 and 2.2 per 1,000 live births, respectively. Maternal health/prematurity factors were found to contribute to 50% of the FIMR during the 2001–2005 period. Additionally, a quarter of the deaths were attributed to factors influencing infant health such as Sudden Infant Death Syndrome (SIDS), injury and breast feeding.

After completion of the analysis, the consortium discussed the findings of the PPOR and decided to focus its efforts on preconception period. The action plan particularly targets to implement programs such as smoking prevention, male responsibility and fatherhood and education in racial health disparities and cultural competence. As a result of this community based activity, the following funded intervention projects were implemented: a) smoking prevention program funded by the National Institutes of Health, b) public campaigns to reduce SIDS funded by the local health department and healthy start initiative, and c) male responsibility and fatherhood initiatives funded by the local health department. Findings of these interventions will be reported upon completion of these projects.

Discussion

The current project provides a detailed illustration of how communities and researchers can utilize CBPR methods to mutually determine areas of interest and intervention goals, and develop a plan of action for implementation. Findings from PPOR analyses revealed alarmingly high racial disparities in FIMR within the Richmond community, with excess mortality rates of 10 for African-Americans in 2001–2005 period. Further, PPOR conducted by time periods (1996–2000 and 2001–2005) demonstrated an increase in African American FIMR over time (from 14.1 to 15.1) while the mortality rate decreased for Whites. When fetal deaths were examined by the standard prevention/intervention areas, maternal health/prematurity (MHP) emerged as the domain of greatest need for intervention, accounting for 5.5 IMR in 1996–2000 and 7.9 in 2001–2005. Additionally, the data showed nearly 50% of these deaths could be prevented by focusing on issues affecting maternal health and prematurity. The statistics clearly indicated that maternal health, including preconception care, should be a public health priority in reducing this disparity.

This study also identified infant health as a second priority area for intervention. Although the overall all race-FIMR was stable during the two time periods, there was a significant racial disparity. Furthermore, the rate for African Americans had worsened through time. This indicates the need to address issues related to SIDS, injury prevention, and breast feeding.

The data showed that there was a great improvement in the area of maternal care and newborn care. Improved rates in maternal care were observed in both African American and

White women. The reduction in the FIMR attributed to maternal care may be a reflection of the improved obstetrics care such as prenatal and high risk pregnancy care. For the past decade, the federally funded Richmond Healthy Start Initiative and local health care agencies have been providing these services to African American and underserved pregnant women. The finding of this study indicates that these city wide programs may have contributed to this improvement. Additionally, the reduction in the FIMR attributed to new born care may be due to the improved technology in perinatal management, neonatal clinical care including pediatric surgery.

Despite such gains, rates of prenatal care attendance at one urban hospital prenatal care clinic remained low among African American women. Of even greater concern was the association found between lower prenatal care attendance and probability of an adverse birth outcome, particularly admission to the Neonatal Intensive Care Unit (NICU) and length of stay in NICU. Through the Promoting Healthy Pregnancies Coalition, a CDC-funded REACH US program was launched with an initial focus on strategies to improve compliance with prenatal care and thereby hopefully improve birth outcomes and reduce health disparities. The three components of the intervention included: Health System Navigation to address individual barriers to attending prenatal care, behavioral incentives for attending prenatal care, and practitioner education in cultural diversity and empathic interviewing. The project is currently in its second year of funding and serves as another example of how CBPR can be used effectively as a bridge between the community and academic medical centers who often share common goals, but bring very different ideas to the table along with varied areas of knowledge and expertise. The synergy created when such groups meet with the goal of improving health is, in our experience, far greater than what can be achieved by either group alone.

These data were then used to drive subsequent community discussions and assist in targeting areas for intervention. Preconception health was identified as an area in which to focus intervention efforts. A SWOT analysis among consortium members was conducted: smoking, poor nutrition, high rates of unintended pregnancies were all identified as factors within preconception health which contributed to poor outcomes. It is clear that pregnancy is too short a period for many forms of intervention. Further, changes in behaviors such as smoking, substance use, exercise, chronic stress and poor nutrition must be revisited and reinforced beyond the perinatal period in order to sustain long-term change. Therefore, it is essential that emphasis is made on the preconception period with a life course approach for intervention.

The present study highlights the importance of utilizing CBPR methods to promote community-academic partnerships. Rather than researchers imposing pre-determined objectives onto the community, the two groups were able to convene and mutually determine the direction of their collaboration through the use of objective data derived directly from the community of interest. This approach captures the spirit of CBPR, by “equitably involving all partners in the research process”... with the “aim of combining knowledge with action” (Community Health Scholars Program website, as cited in Katz, 2004).²⁴ Such strategies not only serve to inform and educate stakeholders, but also assist in engaging the community in their own health.

For over a decade, researchers have sought to explain the causes and identify solutions for the substantial racial disparity in infant mortality. Similarly, communities have invested considerable time and energy developing programs and initiatives to combat this problem. CBPR partnerships allow each group to bring their insight, knowledge, and experience to the table and through this combined perspective generate solutions that may lead to healthier and sustainable outcomes.

This study provided the use of a simple and scientifically sound approach to evaluate and guide public health initiative to mobilize community wide effort in reducing disparities in infant mortality. Although its simplicity, clarity, and sound methodology are the major strengths of this study, it also has some limitations. This methodology utilized an unadjusted analysis and did not control for confounding factors. However, most of the factors that are examined in this data are known determinants and complex statistical modeling would complicate clarity of interpretation for community action. Another limitation of the study is the use of secondary data analysis which may lack accuracy.

In conclusion, this study provided the evidence that PPOR is a novel methodology in evaluating and guiding community based perinatal health initiative. Additionally, the study showed that maternal health and prematurity were major contributing factors for the disparity in FIMR in Richmond. Policy makers and health care providers should consider initiatives that target women during the preconception period.

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Figure 1.
Trend in Infant Mortality Rate by Race

Table 1

Distribution of the Study Population

Race	1996-2000				2001 – 2005			
	Live Births	Infant death	Fetal Death	Live Births	Infant death	Fetal Death	Fetal Death	
White	4,552	17	12	5,295	16	15	15	
African American	9,594	90	52	9,040	120	31	31	
rOther	162	0	0	372	3	2	2	
All Races	14,463	107	64	14,714	139	48	48	

Table 2

PPOR Analysis for All Races by Time Periods

1996–2000		
Maternal Health/Prematurity 4.9		
Maternal Care 2.3	Newborn Care 2.1	Infant Health 2.7

2001–2005		
Maternal Health/Prematurity 5.6		
Maternal Care 1.4	Newborn Care 1.3	Infant Health 2.8

FIMR = 12.0 per 1,000 live births

FIMR = 11.2 per 1,000 live births

Table 3

PPOR Analysis for African Americans by Time Periods

1996–2000		
Maternal Health/Prematurity 5.5		
Maternal Care 2.7	Newborn Care 2.5	Infant Health 3.4

2001–2005		
Maternal Health/Prematurity 7.9		
Maternal Care 1.5	Newborn Care 1.9	Infant Health 3.8

FIMR = 14.1 per 1,000 live births

FIMR = 15.1 per 1,000 live births

Table 4

PPOR Analysis by Race, 2001–2005

African American		
Maternal Health/Prematurity 7.9		
Maternal Care 1.5	Newborn Care 1.9	Infant Health 3.8

White		
Maternal Health/Prematurity 2.2		
Maternal Care 1.3	Newborn Care 0.3	Infant Health 1.3

Excess Risk		
Maternal Health/Prematurity 7.9-2.2=5.7		
Maternal Care 1.9-1.3=0.6	Newborn Care 1.9-0.3=1.6	Infant Health 3.8-1.3=2.5

FIMR = 15.1 per 1,000 live births

FIMR = 5.1 per 1,000 live births

Excess Risk = 15.1 - 5.1 = 10 per 1,000 live births