Maternal Mortality in the USA: A crisis of justice

Lynn P. Freedman, JD, MPH

National WIC Association

Maternal Mortality Conference, New Orleans

September 24, 2018

COLUMBIA UNIVERSITY | MAILMAN SCHOOL of PUBLIC HEALTH

AVERTING MATERNAL DEATH AND DISABILITY (AMDD)

Maternal Health

MATERNAL MORTALITY—A NEGLECTED TRAGEDY

Where is the M in MCH?

ALLAN ROSENFIELD DEBORAH MAINE

Center for Population and Family Health, Faculty of Medicine, Columbia University, 60 Haven Avenue, New York, NY 10032, USA

THE LANCET, JULY 13, 1985

Maternal Health

MATERNAL MORTALITY—A NEGLECTED TRAGEDY

Where is the M in MCH?

ALLAN ROSENFIELD DEBORAH MAINE

Center for Population and Family Health, Faculty of Medicine, Columbia University, 60 Haven Avenue, New York, NY 10032, USA

INTRODUCTION

INTRODUCTION

THE World Health Organisation (WHO) estimates that 500 000 women in developing countries die every year from
[illegible] tion attempts, and
per 100 000 births are
es are much higher in
ntries have only 7–15
s. Morbidity rates are
for every woman who
g-term, complications.
little is being done to
suffering and death.
ion has been given to
), scrutiny of MCH
will do little to reduce
derstand why maternal
attention from health
liticians. The world's
al of their duty in this
to the problem and
changes in priorities,
bspecialties that puts
viewing the issue here
ed with international
n developing countries
ortality one of their

[illegible] EDICAL CARE

[illegible] orld countries usually
ems of medical care.[1-3]
ban medical centres,
ghly trained personnel
n technology. Halfdan
[illegible] as called such centres "disease palaces".[6] They consume a large portion of a poor nation's health budget, yet serve only a minute portion of its people. A large proportion of the population in developing countries live in rural areas; it ranges from 40% in parts of Latin America to 90% in parts of Africa and Asia. There are generally logistic or financial barriers to rural people using the urban hospitals effectively. Consequently, it can be argued that in many rural areas the delivery of services (sometimes modern in nature) by traditional practitioners and the over-the-counter availability of antibiotics and other medicines in village stores, along with changes in sanitation and nutrition, have done more to reduce death rates than has the formal medical system.[3]

Although the British had initiated several relevant approaches to rural health care in their colonies—namely, by training various types of health care personnel to deliver some of the care[3,7]—when national independence was achieved, the trend was to abandon such innovations and to build hospitals and medical centres in the capital cities, often with help from international donors.[1] During the past 15 years, however, more attention has been paid to tailoring medical systems to the needs and resources of developing countries. A major expression of this reorientation is the increased interest in primary health care (PHC), which was adopted as a global strategy for health at the Alma Ata conference in 1978.[8]

PHC concentrates on preventive care and management of the infections and nutritional deficiencies among children so common and devastating in poor countries. Moreover, PHC relies on the use of available personnel, including auxiliary health workers, villagers, and traditional health practitioners, and the small force of highly trained personnel is reserved for complicated tasks. Such an approach is necessary since in many rural areas of the Third World there are about 100 000 people per physician, compared with 1000 or less in the West and in many capital cities of developing countries.[9] This approach has even been adopted in developed countries, where various members of the health-care team have been given new responsibilities. There can be no doubt that the move away from Western medical models and towards PHC is a major improvement. However, there are some important health problems on which PHC (as currently defined) will have little impact. One of these is maternal mortality.

MATERNAL MORTALITY IN THE THIRD WORLD

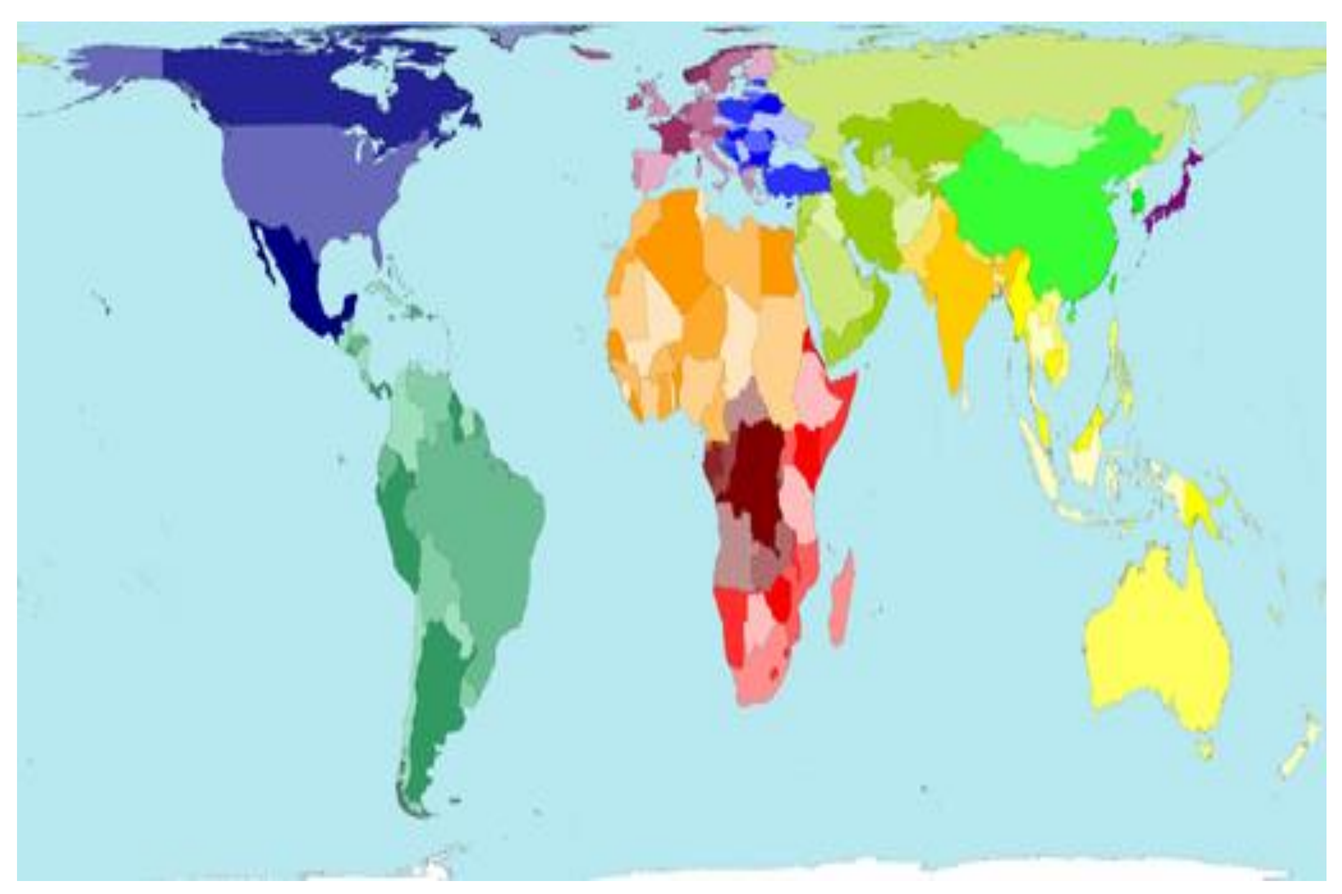
Even in the United States today, official statistics on maternal mortality are thought to underestimate incidence by 20–30%.[10] In developing countries the inaccuracies are much greater. For example, in 1978 the Egyptian government reported a national rate of 82 maternal deaths per 100 000 live-births.[11] In 1980–82, however, a well-designed community study in a wealthy area of Egypt found a maternal mortality rate of twice that—190 per 100 000 (ref 12 and Fortney JA, Rogers SM, personal communication). Perfect data, though, are not essential for formulating health policies and programmes. For example, according to WHO, maternal mortality rates in Africa range from 160 to 1100 deaths per 100 000 births.[2] Even if the true figure is near the lower end of this range, say 200–400, it is still unacceptably high. Another indication of the magnitude of the problem is that about 25% of all deaths among women aged 15–49 in developing countries are maternal deaths, compared with less than 1% in the United States.[12-14]

WHERE IS THE M IN MCH?

In discussions of MCH it is commonly assumed that whatever is good for the child is good for the mother. However, not only are the causes of maternal death quite different from those of child death but so are the potential remedies.

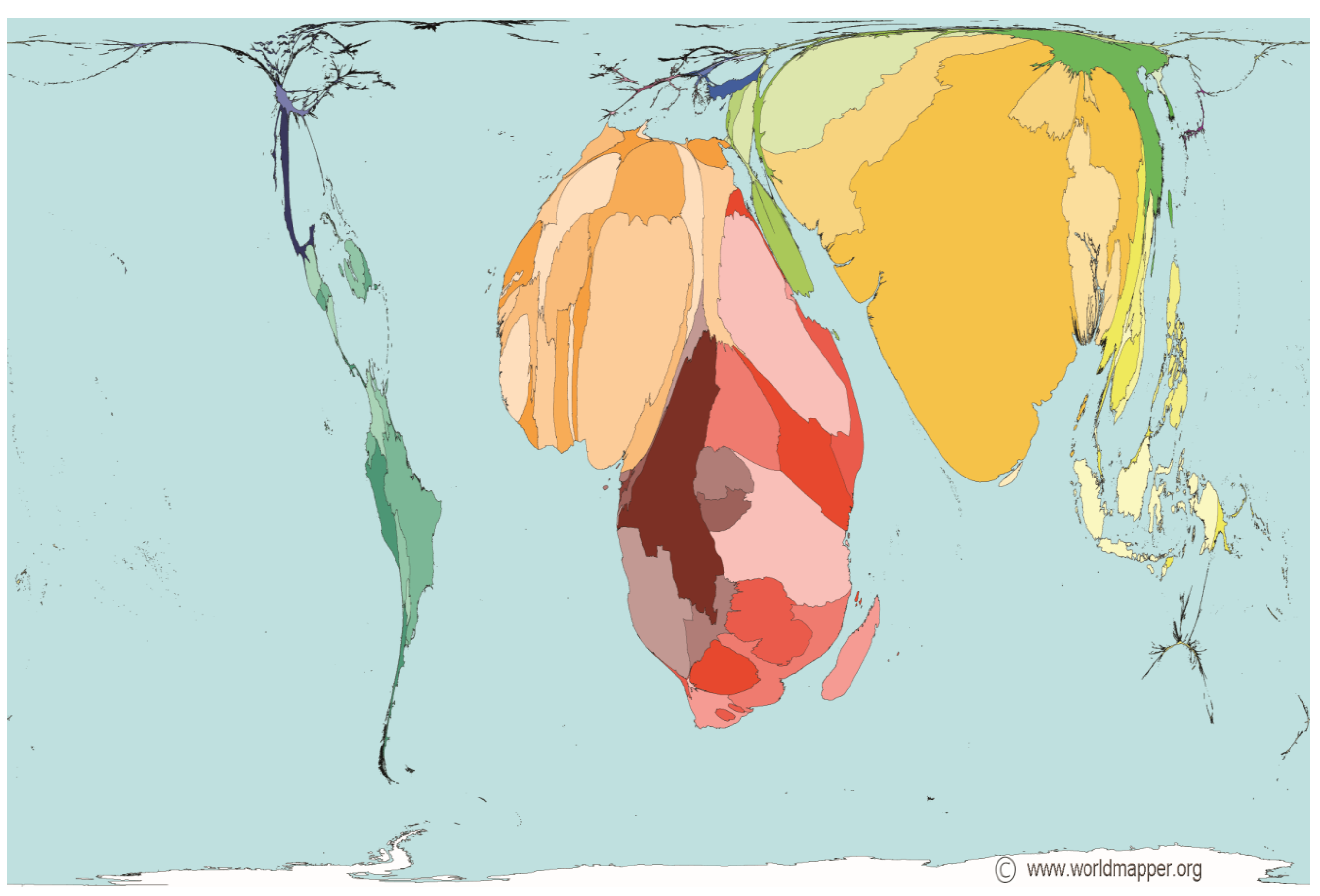
The major causes of illness and death among young children in the Third World are diarrhoeal and other infectious diseases (such as measles and pneumonia) and malnutrition. To reduce mortality among infants and young children in developing countries, national and international agencies are promoting several relatively simple preventive measures, including oral rehydration, growth monitoring, breastfeeding, and immunisation. Other components of what has come to be recognised as the basic MCH package are food supplementation in cases of malnutrition, and family planning. Only one of these services can substantially reduce maternal mortality—and that is family planning.

The World, actual size



Worldmapper.<http://www.worldmapper.org/display.php?selected=1>

Maternal Mortality



Territory size shows the proportion of deaths of women worldwide while pregnant or within 6 weeks of pregnancy and partly due to it, that occur there

UNIVERSAL MEANS EVERYBODY
HEALTH CARE IS A HUMAN RIGHT!
WELLNESS BABY
SUPPORT HEALTH CARE FOR THE HOMELESS IN THEIR FIGHT FOR TOTAL HEALTH CARE!

Reproductive Justice

Beyond reproductive health (service delivery focus)
Beyond reproductive rights (legal focus – individual choice)

Broader analysis of structural conditions that affect reproductive lives including rights

- to have children
- not to have children
- to parent children

Reproductive oppression: the control and exploitation of women, girls and individuals through their bodies, sexuality, labor and reproduction

Trends in facility delivery

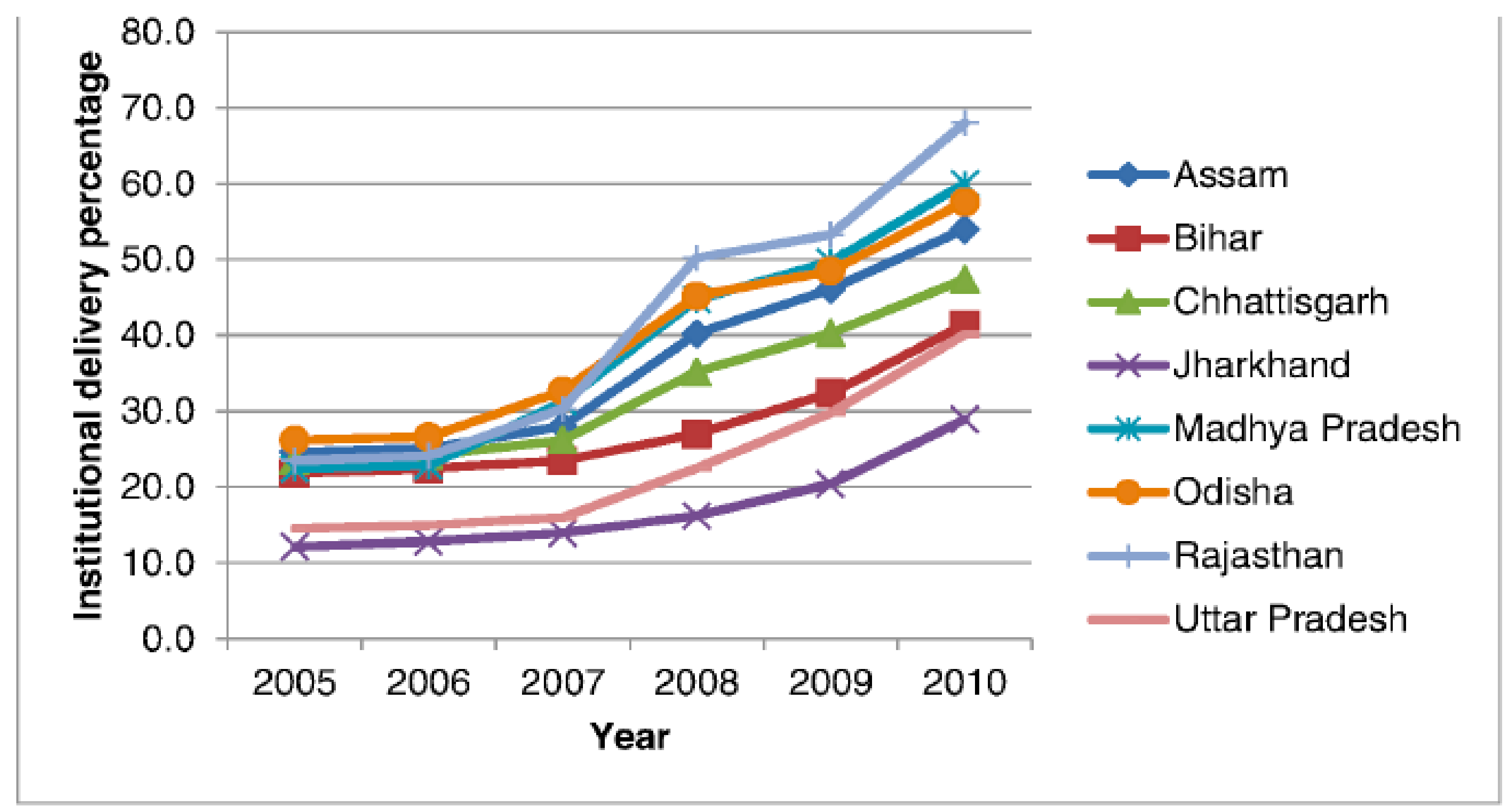


Figure.2. Trends in institutional births.
doi:10.1371/journal.pone.0067452.g002

Facility delivery and MMR

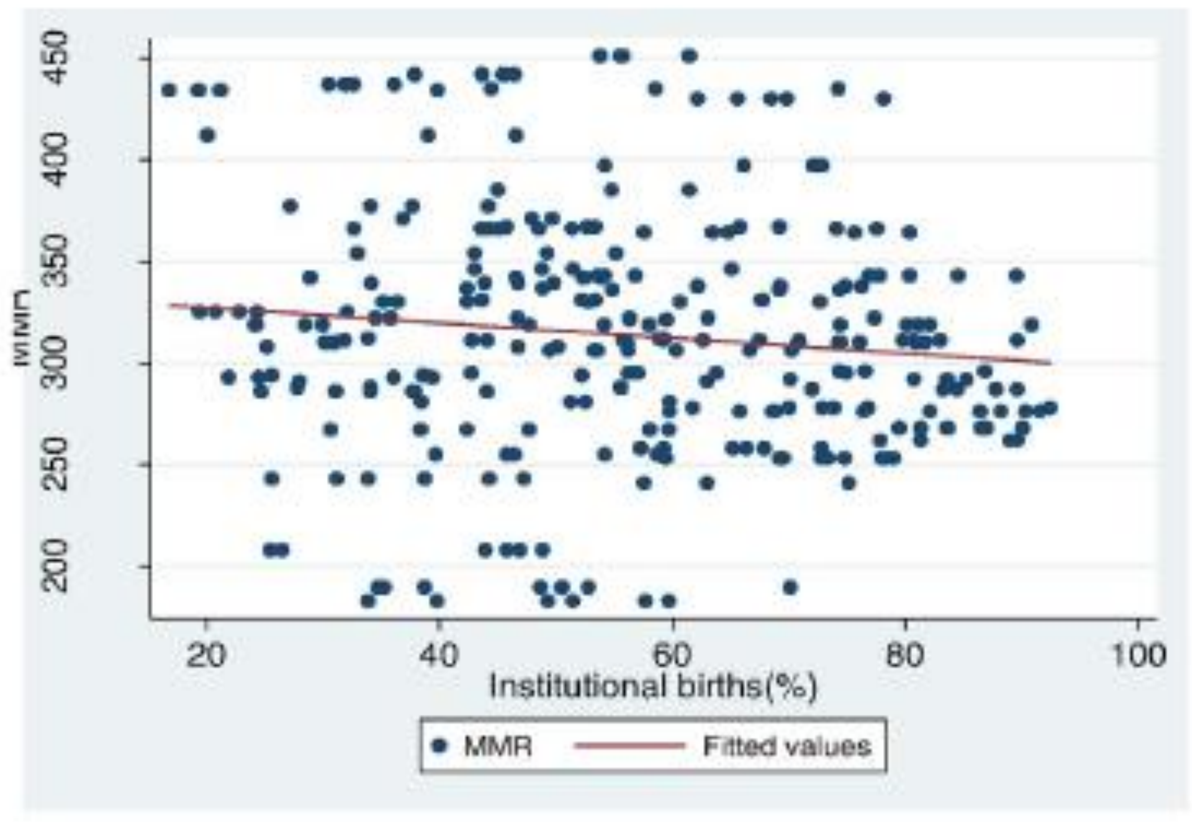
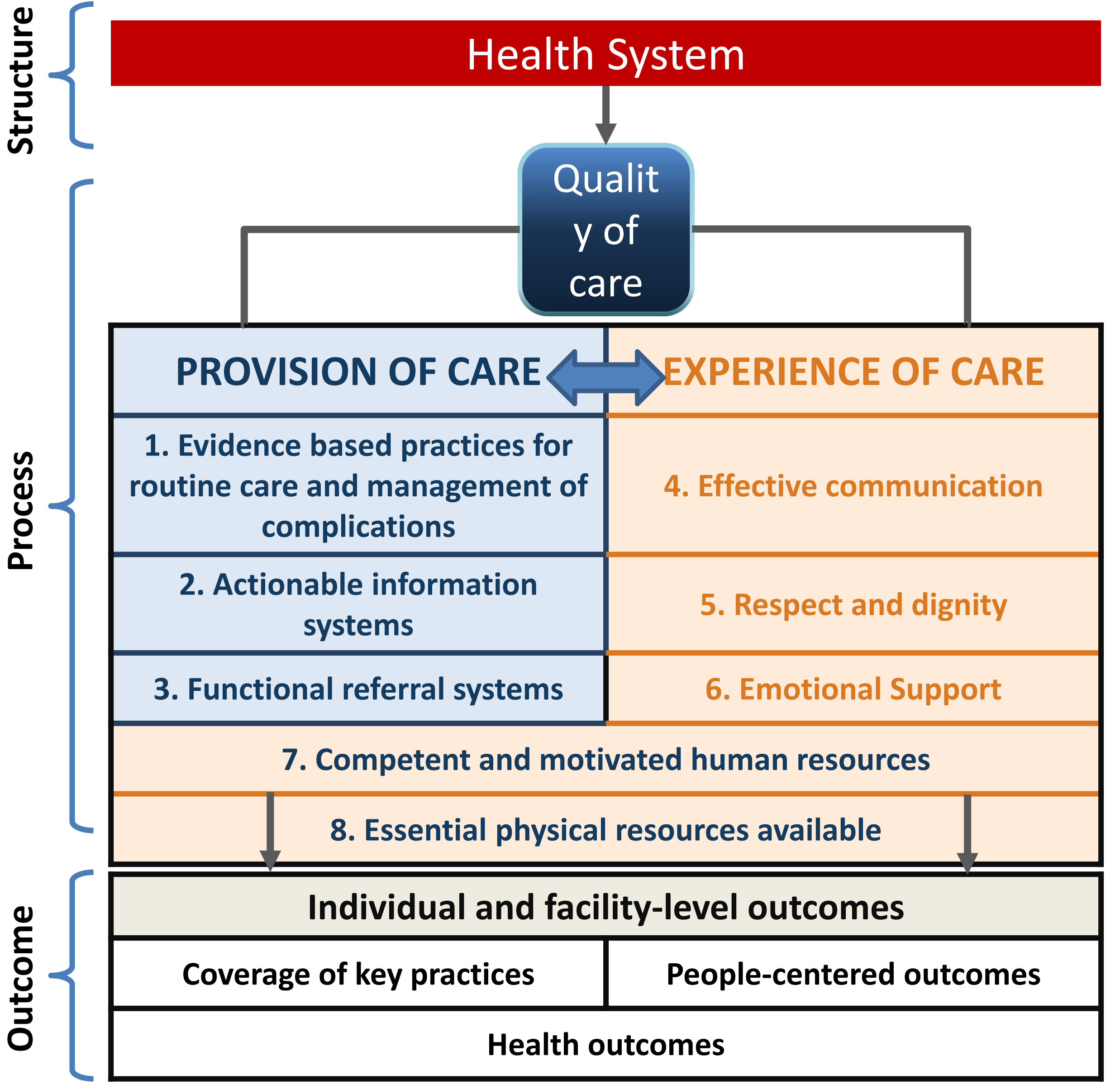


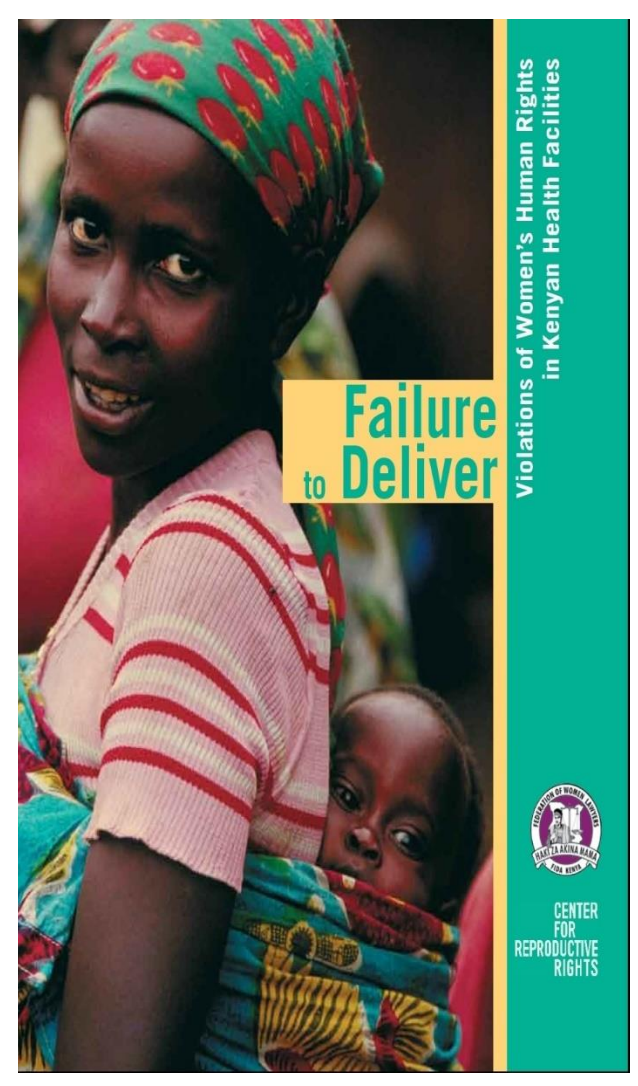
Figure.3. Scatter plot of MMR and proportion institutional births.

doi:10.1371/journal.pone.0067452.g003

WHO Quality of Care Framework for maternal and newborn health



- Prompted by a human rights report on incidents in Kenyan facilities
- USAID commissioned a study of the global evidence on disrespectful and abusive care



Terminology turmoil

What should we call this phenomenon?

- Disrespect & Abuse (D&A)
- Mistreatment
- Obstetric violence

It is NOT simply the lack of "Respectful Maternity Care" (RMC)

D&A categories and events

Category	Events
NON-DIGNIFIED CARE	• Shouting at/scolding patient • Threaten to withhold treatment • Negative or threatening comments to patient
NEGLECT	• Ignoring patients requests for assistance • No attendant at delivery
PHYSICAL ABUSE	•Hitting/slapping/pushing/pinching, etc. •Rape •Sexual abuse • Stitching of episiotomy without anesthesia
NON-CONFIDENTIAL CARE	•Discuss patient's private health information in public •Share patient's health information •Patient's body seen by others
NON-CONSENTED CARE	•Tubal ligation, caesarean or hysterectomy without consent
INAPPROPRIATE DEMANDS FOR PAYMENT	•Request bribes/informal payments •Mother or baby held at the facility due to failure to pay

Defining disrespect and abuse in facility-based childbirth

Individual level:
actions that all agree are D&A

Normalized D&A:
What women experience as D&A but providers consider normal
When providers are disrespectful and abusive but women consider it normal

Structural level:
What women and providers consider poor care, but is caused by

Structural level:
System deficiencies that lead to poor care that is accepted and normalized

Deviations from national standards of good quality care

Deviations from human rights standards (available, accessible, acceptable, quality)

Initial intervention target

Prevalence Measure

Policy Advocacy

Individual level

Structural level

Global RMC Movement

PLOS ONE

RESEARCH ARTICLE

Disrespect and abuse of women during childbirth in Nigeria: A systematic review

Abstract

Background

Methods

Results

Conclusion

PLOS MEDICINE

RESEARCH ARTICLE

Community and health system intervention to reduce disrespect and abuse during childbirth in Tanga Region, Tanzania: A comparative before-and-after study

Abstract

Background

Methods and findings

PLOS MEDICINE

RESEARCH ARTICLE

The Mistreatment of Women during Childbirth in Health Facilities Globally: A Mixed-Methods Systematic Review

Reproductive Health

Open Access

…women during childbirth …: a qualitative study on … experiences of women … providers

Reproductive Health Matters

DISCUSSION

Moving beyond disrespect and abuse: addressing the structural dimensions of obstetric violence

Systematic Reviews

Open Access

…d disrespect in childbirth process …tion situation in Latin America and …bean—systematic review protocol

CONFRONTING DISRESPECT AND ABUSE DURING CHILDBIRTH IN KENYA

THE HESHIMA PROJECT

CONFRONTING THE PROBLEM

WHAT IS DISRESPECT AND ABUSE?

World Health Organization

hrp

The prevention and elimination of disrespect and abuse during facility-based childbirth

WHO statement

Every woman has the right to the highest attainable standard of health, which includes the right to dignified, respectful health care.

Many women experience disrespectful and abusive treatment during childbirth in facilities worldwide. Such treatment not only violates the rights of women to respectful care, but can also threaten their rights to life, health, bodily integrity, and freedom from discrimination. This statement calls for greater action, dialogue, research and advocacy on this important public health and human rights issue.

Background

Ensuring universal access to safe, acceptable, good quality sexual and reproductive health care, particularly contraceptive access and maternal health care, can dramatically reduce global rates of maternal morbidity and mortality. Over recent decades, facility delivery rates have improved as women are increasingly incentivized to utilize facilities for childbirth, through demand generation, community mobilization, education, financial incentives or policy measures.

However, a growing body of research on women's experiences during pregnancy, and particularly childbirth, paints a disturbing picture. Many women across the globe experience disrespectful, abusive or neglectful treatment during childbirth in facilities. (1-3) This constitutes a violation of trust between women and their health-care providers and can also be a powerful disincentive for women to seek and use maternal health care services. (4) While disrespectful and abusive treatment of women may occur throughout pregnancy, childbirth and the postpartum period, women are particularly vulnerable during childbirth. Such practices may have direct adverse consequences for both the mother and infant.

Reports of disrespectful and abusive treatment during childbirth in facilities have included outright physical abuse, profound humiliation and verbal abuse, coercive or unconsented medical procedures (including sterilization), lack of confidentiality, failure to get fully informed consent, refusal to give pain medication, gross violations of privacy, refusal of admission to health facilities, neglecting women during childbirth to suffer life-threatening, avoidable complications, and detention of women and their newborns in facilities after childbirth due to an inability to pay. (5) Among others, adolescents, unmarried women, women of low socio-economic status, women from ethnic minorities, migrant women and women living with HIV are particularly likely to experience disrespectful and abusive treatment. (5)

Every woman has the right to the highest attainable standard of health, which includes the right to dignified, respectful health care throughout pregnancy and childbirth, as well as the right to be free from violence and discrimination. Abuse, neglect or disrespect during childbirth can amount to a violation of a woman's fundamental human rights, as described in internationally adopted human rights standards and principles. (6-9) In particular, pregnant women have a

MEDICAL ANTHROPOLOGY QUARTERLY, Vol. 29, Issue 4, pp. 437–454

Maternal Mortality in the U.S.

Maternal Deaths in the U.S. Are on the Rise

Maternal mortality ratio (number of maternal deaths per 100,000 live births)

United States   Developed Regions

30
25
20
15
10
5
0

1990   1995   2000   2005   2013

Maternal Mortality Ratio

	1990	2013	
World	380	210	-45% ↓
Developed Regions	26	16	-38% ↓
Developing Regions	430	230	-47% ↓
United States	12	28	+136% ↑

Source: World Health Organization

Mashable statista

Pregnancy-Related Mortality in NYC, by Race

2001-2005

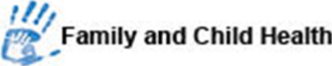
Deaths per 100,000 Live Births

80
70
60
50
40
30
20
10
0

Maternal Race/Ethnicity		
White non-Hispanic	8.6	4.7
Asian/Pacific Islander	17.5	19.9
Hispanic	19.1	15.9
Black non-Hispanic	61.7	56.3

Maternal Race/Ethnicity

Source: NYC DOHMH (2013) Pregnancy-Associated Mortality in New York City, 2006-2010 and 2001-2005

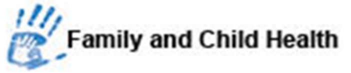


NYC
Health

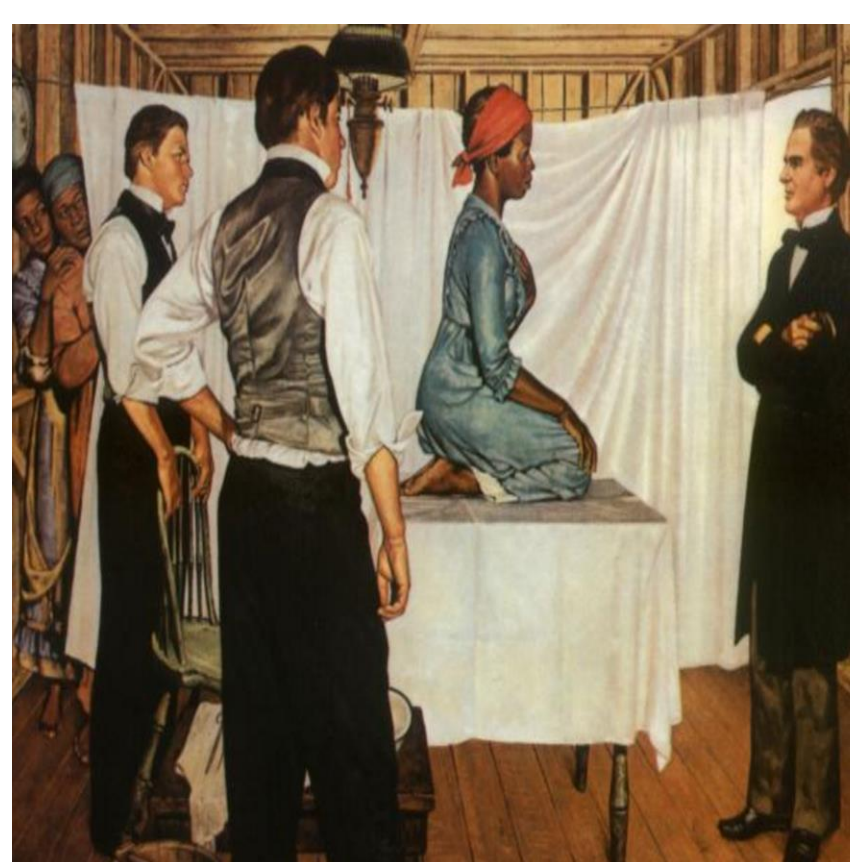
Severe Maternal Morbidity by Race, 2008-2012

Rate per 10,000 deliveries

Educational attainment	Puerto Rican	Other Latina	Asian and Pacific Islander	White non-Latina	
Less than high school	325	288	153	138	427
High school graduate	252	245	172	114	404
Some college	243	217	193	135	361
College graduate or higher	235	178	153	127	333



Women Of Color-led Reproductive Justice movement



Dr. J. Marion Sims with Anarcha by Robert Thom

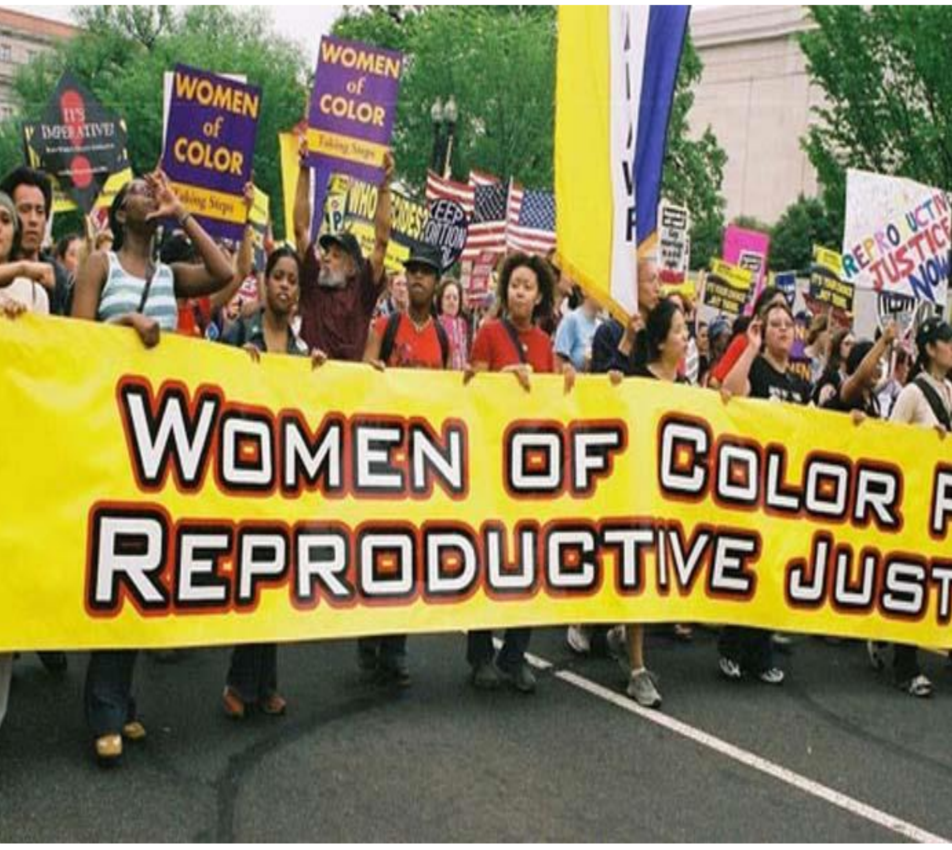


Photo credit: Trust Black Women

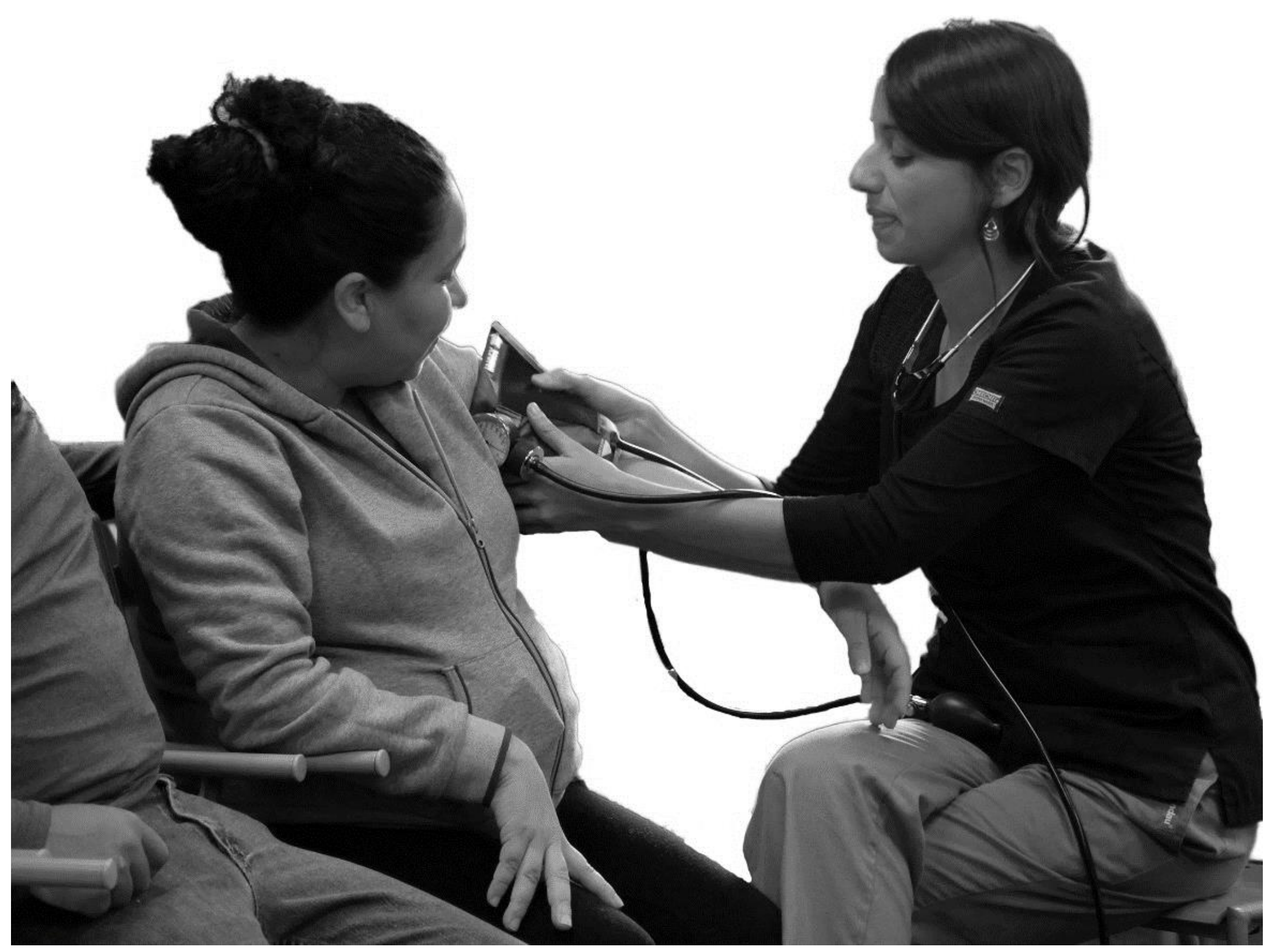
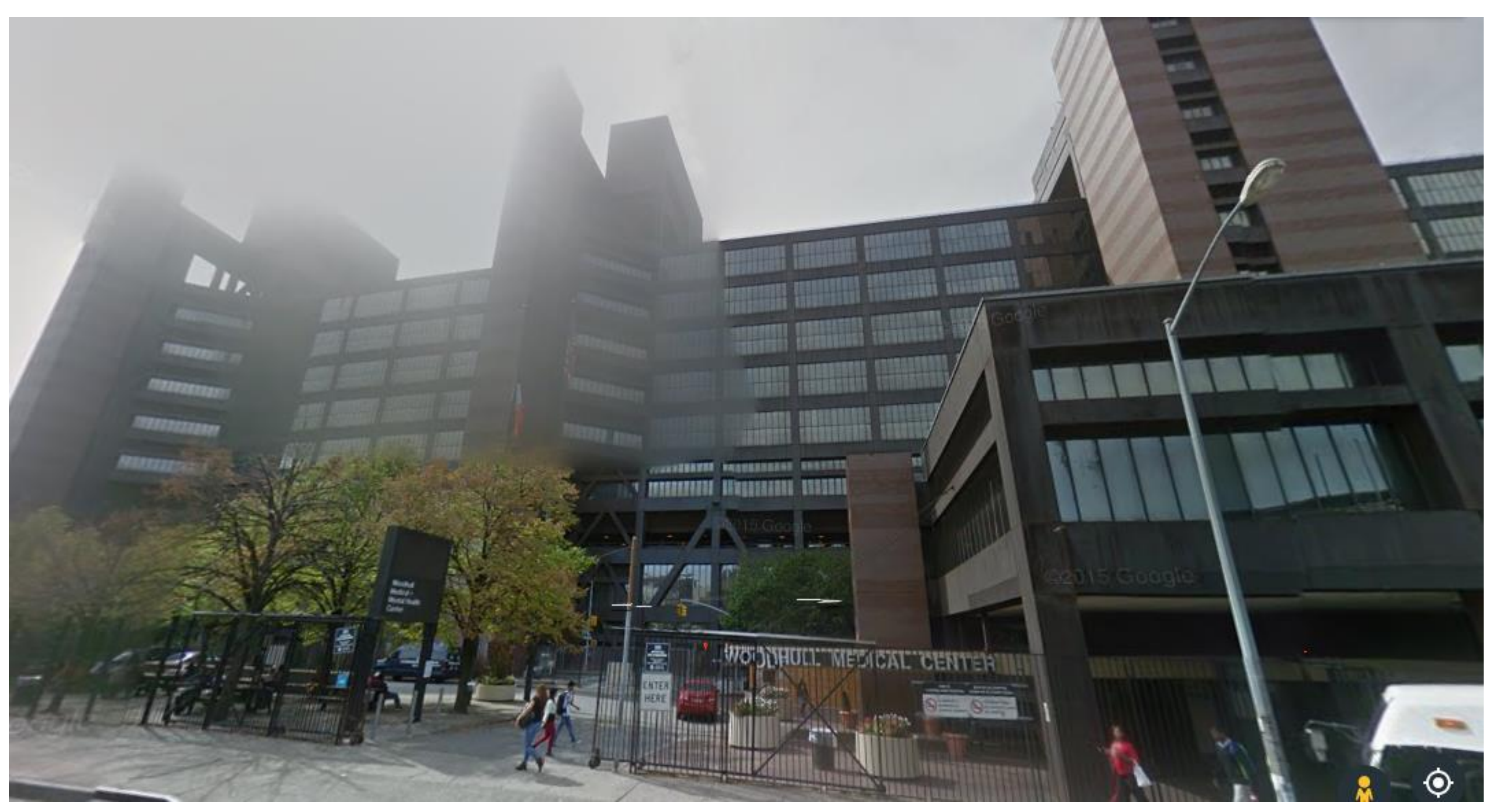
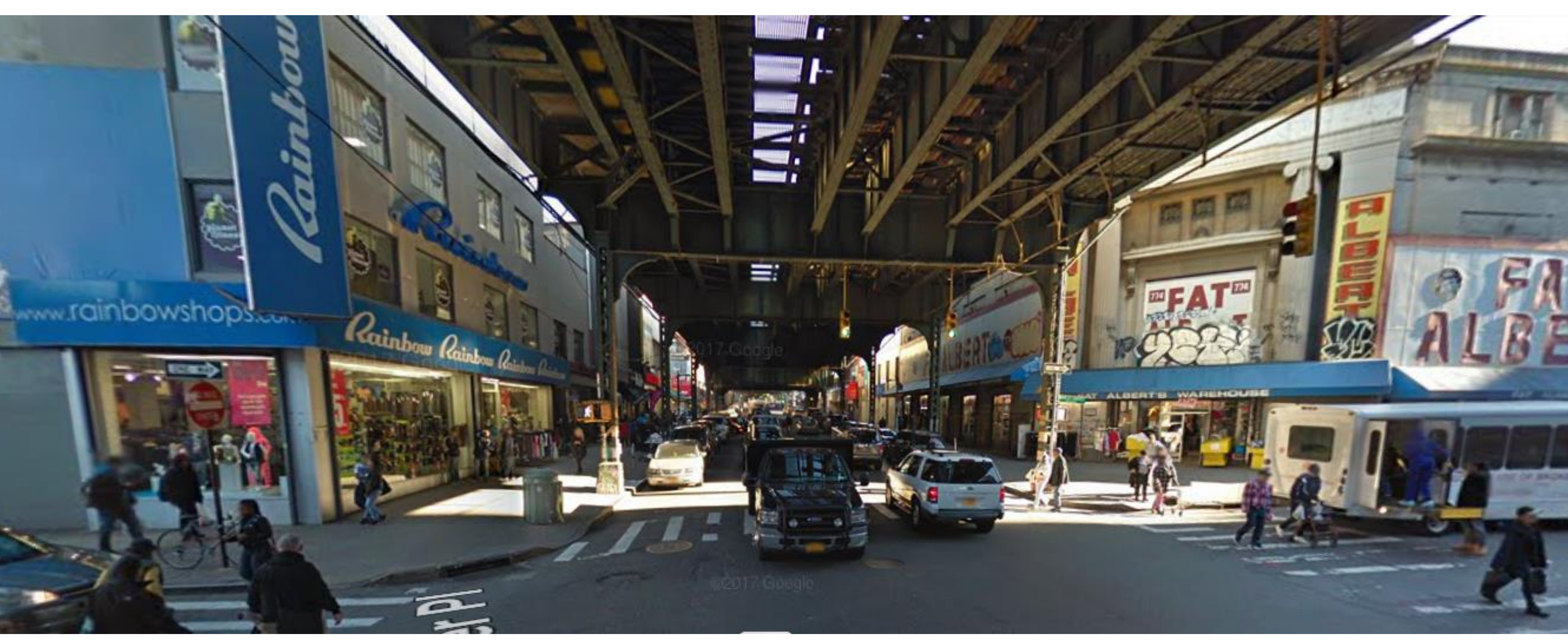


Photo credit: Jennie Joseph, Commonsense Childbirth


WOODHULL MEDICAL CENTER
ENTER HERE
©2015 Google


Rainbow
www.rainbowshops.com
Rainbow Rainbow
FAT
ALBERT
ALBERT'S WAREHOUSE
©2017 Google

Health System as Core Social Institution

Health systems are not just mechanical systems to deliver technical interventions

Health System as Core Social Institution

They are part of the very fabric of social and civic life

Health System as Core Social Institution

- Neglect, abuse and marginalization by the health system is part of the very experience of being poor
- Effective health claims are assets of "citizens" in a democratic society

Understanding D&A in the USA

- Timeframe: 2 years: December 2016 – December 2018
- Partners:
  - Head Start - Washington Heights
  - NYP Hospital and Allen Hospital
  - New York City Department of Health and Mental Hygiene (NYC DOHMH)
  - By My Side Doula Support Program
  - Ancient Song Doulas
  - Black Mamas Matter Alliance
- Locations of focus:
  - Washington Heights (NYC)
  - Central Brooklyn (NYC)
  - Atlanta, GA

Fundamental Premise:

To get meaningful, sustained change, we must:

Take a 360° approach to look at both patient experience AND provider experience.

Focus not on individual wrongdoing, but on broader contexts and drivers at the individual, institutional, structural, and policy levels.

Research questions

- How do women describe their experiences of mistreatment or disrespect during facility-based childbirth?

- What are the individual, institutional, structural, and policy drivers of the treatment that women experience as disrespectful?

- How common is it for women to experience mistreatment or disrespect during childbirth? Is it more common among some communities or some social/ethnic/racial groups than others?

Research Methodology

- Community-based participatory research
- In-depth interviews with providers/staff
- Focus groups with women, their partners, and doulas
- Two neighborhoods in NYC
- Atlanta – FGDs only
- Ongoing collaboration with the NYC Health Department
  - Prevalence measure in Pregnancy-Risk Assessment Monitoring System
  - Community engagement group

Some preliminary findings

Women feel:

- Disrespect: invisible, judged, stereotyped
- Distrust: Questioning procedures
- Fear: for children and themselves
- Grateful: They and baby survived

Some preliminary findings

Providers feel:

- Hospital culture undermines aspirations
- High stress and frustration
- Overworked and underappreciated
- Tension between cadres

Some preliminary findings

From both women and providers:

- Lack of continuity of care
- Misalignment of expectations

Potential for WIC

- Continuity of care:
  - antepartum, Intrapartum, postpartum and beyond
  - Radical redesign of postpartum care needed
  - Co-location of postpartum and postnatal visits
  - Education about future CV risks for women w preeclampsia
- System navigation (accompaniment; peers)
- Building trust

FIONA BASILÉ
PHOTOGRAPHER & WRITER

NOT MY PRESIDENT
DO NOT

Thank you