

Stillbirth and Reproductive Justice: Addressing Disparities in Perinatal Loss and Biases in Care

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What Does Reproductive Justice (RJ) Mean To You?

- Think of three words or phrases you associate with reproductive justice
- Quickly share with the person next to you.

What is Reproductive Justice?

Reproductive Justice [is] the human right to:

- maintain personal bodily autonomy
- have children, or not have children
- and parent the children we have in a safe and sustainable communities

©SisterSong Women of Color Reproductive Justice Collective
Accessed June 2019 <http://sistersong.net/reproductive-justice/>

To achieve RJ

- Analyze power systems
- Address intersecting oppressions
- Center the most marginalized
- Join together across issues and identities

**Most definitions of
Reproductive
Justice
do not specifically
address:**

**perinatal loss
ectopic pregnancy
stillbirth
safe surrender
adoption
TFMR
lethal/non-lethal
anomalies**

#1

Analyze Power Systems

Case Study

- 34 yo G1P0 with unplanned pregnancy
- Single, heterosexual, cis-gendered
- Has full-time employment
- Has health insurance
- Father of the baby wants her to get an abortion. She is uncertain.
- She lives in a state with no legal barriers to elective termination and in a progressive urban area

Discuss

How, if at all, has your practice been affected by reproductive health legislation in your area?

Power Systems:

Legislation

- Criminalization of loss
- Pregnancy during incarceration and ICE detention
 - Shackling/restraints
- Termination options
- Unnecessary mandated procedures
- Lack of bereavement leave for perinatal loss

Power Systems: Structural Bias

- Urban/rural (care deserts)
- Occupational & environmental hazards
- Food and housing insecurity
- Racism
 - Explicit and implicit bias
 - Afterlife of slavery
- Citizenship

Mother Jones

Ga. Law Could Give Death Penalty for Miscarriages



Ga. Law Could Give Death Penalty for Miscarriages

JEN QURAISHI FEB. 23, 2011 12:32 PM

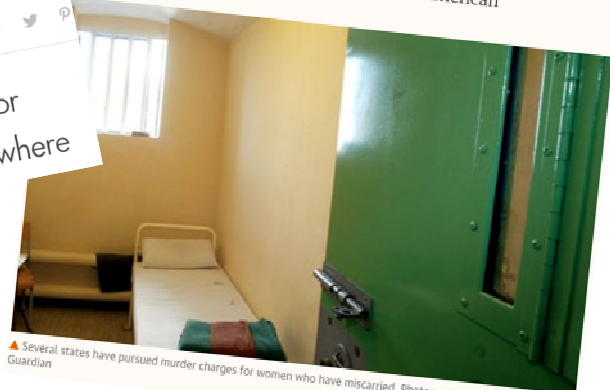
The effort to undo Roe v Wade threatens not just reproductive rights but the very definition of personhood for American women

BUSTLE

What The Personhood Bill Would Mean For Miscarriages Is Horrifying For Women Everywhere

Miscarriage of Justice

December 20, 2017 by Molly Scott Cato | 1 Comment



▲ Several states have pursued murder charges for women who have miscarried. Photograph: Graham Turner for the Guardian

Women are being sent to prison for having a miscarriage or stillbirth

Salvadoran woman jailed over stillbirth freed after 11 years

Teodora del Carmen Vázquez's 30-year sentence under country's total ban on abortions is commuted



▲ Teodora del Carmen Vázquez hugs her niece as she walks out of jail after her 30-year sentence was commuted. Photograph: Jose Cabezas/Reuters



Teodora del Carmen Vázquez was given a 30-year sentence after she was found guilty of "aggravated homicide" for a stillbirth in her ninth month of pregnancy. (Getty Images)

The New York Times Magazine

Purvi Patel Could Be Just the Beginning



Purvi Patel, who was sentenced to 20 years in prison for feticide and neglect of a dependent on Monday, at the St. Joseph County Courthouse in South Bend, Ind.

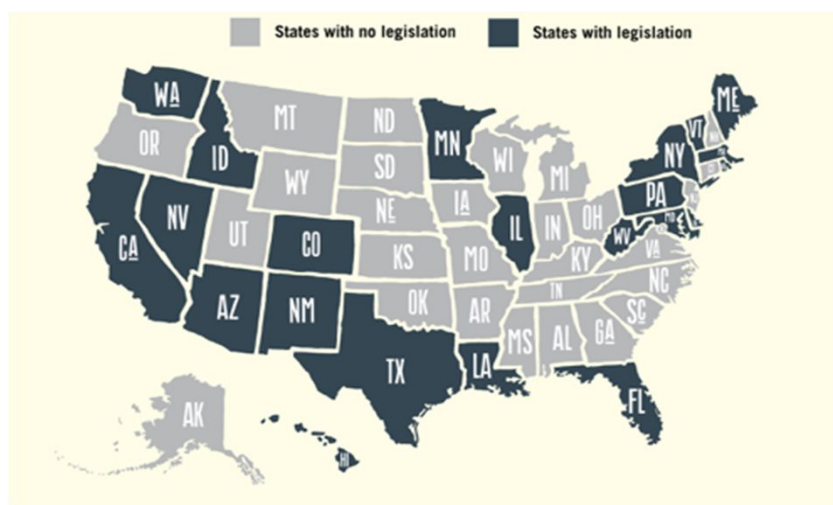
Miscarriage and Restraints/Shackling

Initial purpose of using restraints with pregnant, incarcerated people was to prevent escape or harm to self or others.

Vulnerable populations: incarceration, deportation and detention centers

No escape attempts have been reported among pregnant incarcerated people who were not shackled during childbirth (Feinauer, Lee, Park, & Walker, 2013).

Distribution of
(anti-)
shackling
legislation



Copyright © 2018 AWHONN [Terms and Conditions](#)
Nursing for Women's Health 2018 22, 17-23001; (10.1016/j.nwh.2017.12.005)

Restraints/Shackling Can *Lead to Loss*

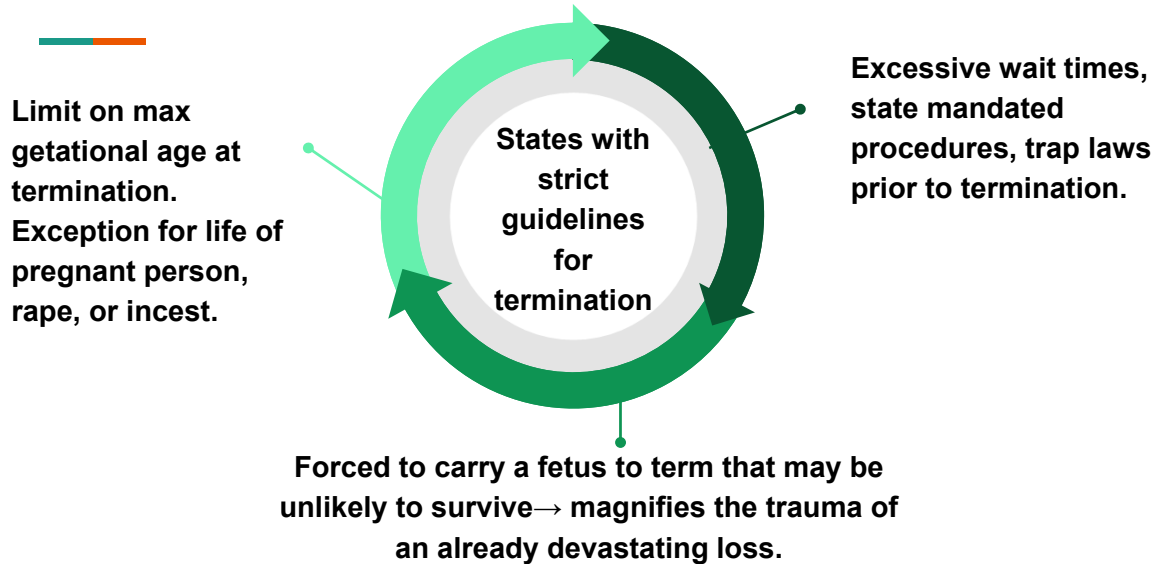
- Prevents ability to break a fall
- Limits ability of health care providers to assess and evaluate patient and fetus, especially when bleeding.
- Delays prompt transport for evaluation.
- Exacerbates stress, trauma, and can re-trigger PTSD events
- Delays in seeking care.



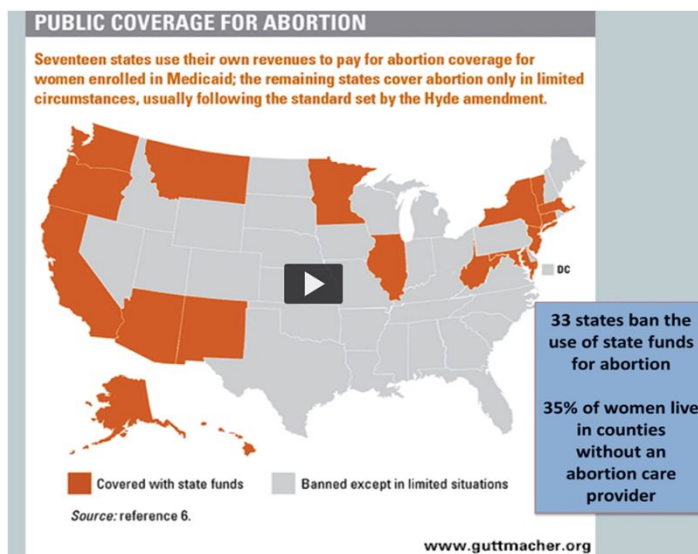
(ACOG, 2011; Sufrin, 2014; AMA, 2015)

One Woman's Story of Shackling While Pregnant

State Laws Can Limit Termination Options



Effects of State Laws



- 20% or more decline in # of abortion clinics since 2010
- 33 states ban the use of state funds for abortion.
- Gag rule—ban of use of federal funds for abortion services
- 35% of women live in counties without an abortion care provider

www.guttmacher.org

Geographic Disparities in Abortion Access

12 states** passed bans at or prior to 20 weeks gestation

27 abortion bans across 12 states have been enacted in 2019; 4 would ban abortion if Roe v Wade is overturned

378 abortion restrictions introduced in US in 2019; 40% are bans


Since Jan 1, 2019, 378 abortion restrictions introduced in US in 2019, 40% are bans; a total of 53 enacted in 17 states

Only 7 states do not have specific laws prohibiting abortion after a certain point in pregnancy

www.guttmacher.org, accessed June 2019

Federal Policies

- Mandated fetal burial or cremation
- Hyde Amendment
- Pain-Capable Unborn Child Protection Bill
- ICE and immigration detention of pregnant people



Impact of Power Systems on Perinatal Loss

(especially legislation)

1. May complicate ability to get timely, proximate access to a termination for a medical reasons (TFMR).
2. Mandates how families may grieve (or not) or want to process the loss.
3. Magnifies the grief and suffering of families with a lethal/non-lethal anomaly
4. May criminalize loss, especially in marginalized populations
5. Can actually *promote or contribute* to complications and trauma from loss

2 Intersecting Oppressions

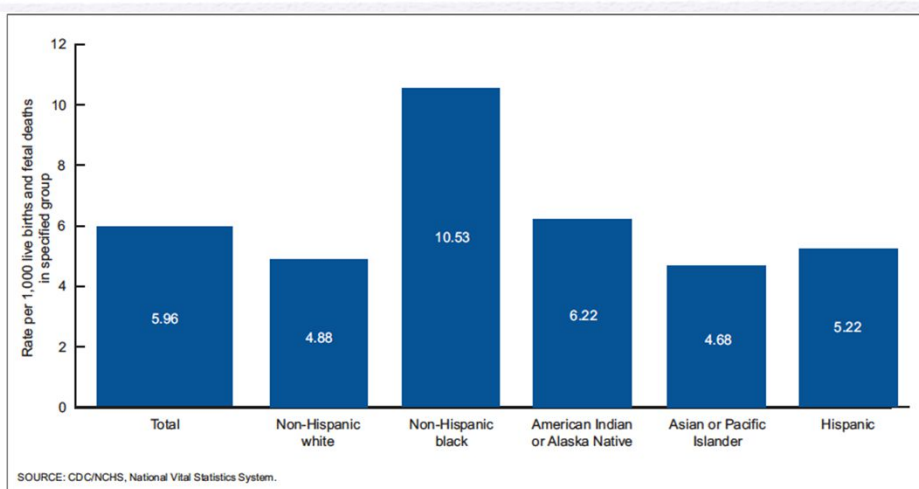
Race
 Sex
 Sexual orientation
 Socioeconomic class
 — Age
 Body size

Discuss

How might the options and experiences of perinatal loss change if the patient was:

a teen, a person of color, gender non conforming, LGBTQ, undocumented?

Racial Disparities in Stillbirth in the US



Disparities in Late Loss/Stillbirth

- Black women 2x more likely than white women to suffer late pregnancy loss and stillbirth.
- No genetic factors
- Rates do not vary with SES—not protected by money or education
- Less likely to be given info on bereavement or medical leave, be screened for depression or offered loss support groups.

(NIH)

“The continuous, low-grade stress of racism may be the factor that unifies all African-Americans, and may contribute to the increased risk of pregnancy loss.”

–Elizabeth Czukas

Afterlife of Slavery**

Impact of Segregation and Racism on Disparities in Reproductive Health

**Dr. Dana Ains Davis

1. Experimentation on black and brown women's bodies--mistrust of health care system
2. Residential segregation—redlining—more exposure to chemicals, industrial waste, poverty, and violence leads to increased stillbirth rates.
3. Racism increases chronic stress, inflammation, and metabolic dysregulation, all associated with stillbirth.
4. Race vs racism as a risk factor
5. Epigenetics as mechanism for intergenerational trauma
6. Medical complaints like pain less likely to be believed or acted upon

Contribution of racism to lack of support after loss

“As I was searching to make sense of my loss and find healing through sharing experiences, I continually butted up against myths about black women that made my search increasingly difficult.” —*Omise'eke Natasha Tinsley*

Myth #1: It's easy for black women to get pregnant and have babies. “Breeders”

Myth #2: Black women are survivors, strong enough to take a loss and keep going. “Superwomen”

“In a time where too many Black women are burying children, the loss of a fetus seemed too intangible to merit real grief. I wasn't far along, and at least I hadn't birthed a child who died after I'd gotten to know him or her, people told me to make me feel better. Of course, that only made me feel guilty for grieving my unborn child. So the current climate of violence against Black children impacted my lost pregnancies before and after the miscarriages: First it made me worry about the child I was carrying, then made me feel I had no right to grieve the child I'd lost.” —*Omise'eke Natasha Tinsley*

3

Centering the Most Marginalized

Reflect

**What does centering
the most marginalized mean...**

...to you?

...in relationship to perinatal loss?

Case

- Keeps pregnancy, gets good care.
- Medical risk factors: AMA, BMI
- Normal pregnancy except has a fall @ 23 weeks
- Post-fall assessment is reassuring.
- 1.5 weeks later, notices decreased fetal movement while on vacation.
- 3 days later, calls provider, triaged over phone, told to do kick counts.
- Day 4 of decreased movement, diagnosed with IUFD at 24 weeks.

Case

- Educated and a newspaper reporter skilled at doing investigative research.
- Has agency and resources to fill in gaps in understanding and corroborate what she has been told by her health care team.
- Support/memory building
- Health care team: the nurse and doulas are her friends

‘Perhaps the greatest obstacle to addressing stillbirths is stigma.’

Horton & Samarasekera, 2016, pg. 515

Blaming the Patient

Commonly cited stillbirth risk factors:

- **Maternal age** (OR 2.4 for age > 40 yo)
- **Nulliparity** (OR 3.1)
- **Race**** (OR 2.1)
- **Metabolic syndromes**

- Implies individuals can modify all risks when they can't
- We (may) blame them anyway
- Ignores the fact that reported maternal medical conditions account for only 2-5% stillbirths through 41 weeks

(Willinger et al (2010). Racial Disparities in Stillbirth risk across gestation in the United States. [Am J Obstet Gynecol](#). 201(5): 469.e1–469.e8)



Centering the Patient

- Evidence-based practice
- Patient-centered care
- True informed consent
- Shared decision making

Patient Centered Care: In-patient

In your setting, is there a formal perinatal care bereavement team in place?

Are the nurses/providers trained in bereavement/stillbirth care and support?

Where are the stillbirths occurring in your facility?

Is there a protocol in place for services and resources after stillbirth?

Patient Centered Care – Follow Up

In your setting, what is the follow up after discharge?

(education, support group access, lactation suppression, mental health, other postpartum transitions)

How are staff in the clinic alerted to the loss so there is sensitivity for the follow up appt?

Shared Decision Making

- Induction vs natural onset of labor
- Presence of support people and family
- TFMR or perinatal hospice
- Parenting through loss
 - holding baby, memory making, taking baby home
- Lactation suppression


#4

Join Together Across Issues and Identities

—

Discuss


**What does joining together across
issues and identities mean to you
when considering stillbirth
prevention, care and support?**



In relationship to stillbirth, this means coming together across our differences in:

- Our experiences in pregnancy and loss
- Our experiences and positionality around race and racism
- Our roles as clinicians and patients.
- Our beliefs about abortion and reproductive care

Polemic Language of Termination



Pro-life
Personhood
Life at conception
Baby
Parent

Pro-choice
Personal autonomy
Products of conception
Fetus
Patient

Case

- Believes life begins @ conception.
- Also believes in one's choice to decide whether or not to continue pregnancy, become a parent, and how to best parent one's child.
- Continued the pregnancy but the baby died anyway.
- Where was her choice?

Why not both/and?

What does both/and look like in relation to abortion access and stillbirth care?

Applying Reproductive Justice to Stillbirth:



LEGISLATIVE

- End criminalization of pregnancy, shackling and mistreatment of incarcerated and detained (ICE) pregnant people!
- Full access to termination services at all points in pregnancy
- Bereavement and postpartum leave (FMLA expansion)

Applying Reproductive Justice to Stillbirth:



STRUCTURAL

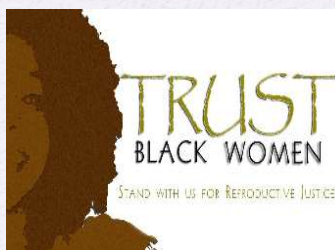
- Increase education about stillbirth risk factors (for patients and providers).
- Train care teams in bereavement and perinatal palliative care.
- Remove institutional barriers in perinatal loss care (fear of litigation, lack of time, traditional training in holding back emotion or silence until an explanation is available)
- Implicit bias and anti-racism training for health care team

Applying Reproductive Justice to Stillbirth:

PUBLIC/SOCIAL

- Decrease stigmas and silence around stillbirth, perinatal loss, TFMR, perinatal hospice
- Broaden abortion debate to include the impacts of legislation on those with wanted pregnancies and TFMR
- Consider how to hold both/and...

RESOURCES



www.trustblackwomen.org
www.latinainstitute.org/en
[www.Sister Song.net](http://www.SisterSong.net)
www.jailcare.org
www.reproductiverights.org

Sufrin, C. (2019). When the punishment is pregnancy: Carceral restriction of abortion in the United States." *Cultural Anthropology*, 34(1), 34-40.

Sufrin, C. (2017). *Jailcare: Finding the safety net for women behind bars*. Univ of California Press.

Dana Ain Davis (2009). *Beyond Reproduction: Women's Health, Activism, and Public Policy*

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