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

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
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

Ga. Law Could Give Death Penalty for Miscarriages

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

Salvadoran woman jailed over stillbirth freed after 11 years

Teodora del Carmen Vasquez’s 38-year sentence under country’s total ban on abortions is commuted

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
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)

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**One Woman's Story of Shackling While Pregnant**
State Laws Can Limit Termination Options

Limit on max gestational age at termination. Exception for life of pregnant person, rape, or incest.

States with strict guidelines for termination

Excessive wait times, state mandated procedures, trap laws prior to termination.

Forced to carry a fetus to term that may be unlikely to survive → magnifies the trauma of an already devastating loss.

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

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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

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### # 2

**Intersecting Oppressions**

- Race
- Sex
- Sexual orientation
- Socioeconomic class
- Age
- Body size

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Discuss

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

a teen, a person of color, gender non conforming, LGTBQ, 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.


“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

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

**Dr. Dana Ains Davis

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 buttressed against myths about black women that made my search increasingly difficult.” –Omise’eko 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’eko Natasha Tinsley
# 3 Centering the Most Marginalized

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Reflect

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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
Commonly cited stillbirth risk factors:

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

Blaming the Patient

- 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

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 at 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?

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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)

**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


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

www.trustblackwomen.org
www.latinainstitute.org/en
www.SisterSong.net
www.jailcare.org
www.reproductiverights.org
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