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CASE STUDIES IN SOCIAL MEDICINE

## Reproductive (In)justice — Two Patients with Avoidable Poor Reproductive Outcomes

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### Case A: California, 2017



In 2017, in a California hospital, Ms. W. turned her face away as the attending physician, a white woman, entered the room followed by two residents, a white man and an Asian American woman. The physician picked up her chart and read, “39-year-old African American woman. Opioid user. Possibly homeless. Preterm birth at approximately 24 weeks of pregnancy, most likely due to cervical insufficiency, resulting in neonatal demise.” The attending approached Ms. W.’s bed, saying quietly, “We realize you probably don’t have a place to go, or any family. We understand that you have experienced a loss. This might not be the first time? We would like you to stay the night

for monitoring, to ensure no infection develops. Do you understand?” Ms. W. nodded but still avoided eye contact.

The physician began educating the residents while walking out of the room: “This, sadly, is a typical case. These women are in such a bad way. It feels like there is very little we can do. They should be given an IUD along with their methadone. It’s terrible to say, but it might be a blessing that the baby didn’t survive — it probably would have just ended up in foster care anyway, after going through

opioid withdrawal.” A short time later, Ms. W. gathered up her belongings, took a roll of toilet paper to help manage her postpartum bleeding, and left the hospital against medical advice.

During this pregnancy, Ms. W. had received methadone maintenance treatment through a city-funded program for pregnant women with opioid dependency. After her daughter’s death, Ms. W. was informed that her access to methadone was immediately terminated; because of funding stipulations, her care had been depen-

dent on her being pregnant. She experienced severe opioid withdrawal and returned to street heroin use and homelessness.

During a subsequent pregnancy, Ms. W. avoided seeking prenatal care, including any clinical interventions to reduce the risk of another preterm birth — ultrasound surveillance of her cervix for potential cerclage or intramuscular injections of progesterone starting at 16 weeks. She had another obstetrical complication during the periviable period, resulting in a second stillbirth.

### Case B: Czechoslovakia, 1990

In 1990 in Czechoslovakia, Ms. J., a 23-year-old Romani woman who had previously given birth to a healthy baby by cesarean section, became pregnant for the second time. Although there were no difficulties during her pregnancy, when Ms. J. went into labor and was transferred to the delivery

room, the doctor performed an amniotomy. Ms. J. immediately started to bleed heavily, most likely from a placental abruption, and the doctor decided to perform a cesarean section. During transit to the operating room, a nurse told Ms. J. to sign an “antenatal form.” No one explained the form

to her. Because she was worried about her own life and her child’s life and was in serious physical pain, she signed without reading it. The form was a consent document for the cesarean section, but it included a line stating that the patient also consented to sterilization. The sentence about sterilization appeared in a different type-script from the rest of the form, which raises the possibility that it was added after she signed the document. No medical staff member had mentioned sterilization to her.

Ms. J. was first told about her sterilization postoperatively, but in technical medical language that she did not understand. She learned about the full consequences of the procedure later, when she returned for a follow-up visit. Ms. J. was shocked, since she desired more children, but the clinicians were unapologetic. She also thought about the negative consequences her sterilization would have for her family life and reputation in her Roma community. Ultimately, Ms. J.’s husband blamed her for having undergone the procedure and separated from her.



## Social Analysis: Reproductive (In)justice

The concept of reproductive justice (see box) was introduced by black feminist scholars and reproductive health activists to call attention to the relationship between structural racism and reproductive health outcomes in the United States.<sup>1</sup> The reproductive-justice organization SisterSong defines the concept as “the human right to maintain personal bodily autonomy, have children, not have children, and parent the children we have in safe and sustainable communities.”<sup>2</sup> Reproductive justice begins with the recognition that according to our social norms, certain people — such as members of racial or ethnic minority groups and pregnant

women who use substances — are deemed less deserving than others of reproducing and of reproductive care. The cases of Ms. W. and Ms. J. are both examples of reproductive injustice. Ms. W. overheard clinicians questioning her fitness for reproduction, and Ms. J.’s clinicians, adhering to a eugenic state policy targeting the Roma people, decided that she was not fit for future reproduction.

Ms. W.’s case echoes the history of reproductive injustice experienced by black Americans. That history includes sexual assault and denial of bodily autonomy during slavery, medical experimentation on black women used to establish the field of modern gynecology in mid-19th-century America, coercive sterilization policies in the 20th century that disproportionately targeted women of color,<sup>3</sup> and 21st-century disparities in criminalization and incarceration rates between women of color and white women with substance use disorders, despite similar rates of substance use.

Ms. J. is one of the thousands of Romani women who underwent coercive sterilization in Europe in the 20th century. In the former Czechoslovakia and its successor states, Slovakia and

Czechia, the 1971 Decree on Sterilization gave public authorities incentives to systematically sterilize Romani women without their informed consent during cesarean deliveries or unrelated surgeries. The government defined this sterilization as a public health need, deeming Roma reproduction to be pathological. Medical professionals and social workers also coerced Romani women to undergo sterilization by providing incorrect information on reversibility, promising financial rewards, or threatening to curtail social welfare opportunities. Though this policy was overturned in 1993, the practice continued; the latest documented case occurred in 2002.

Although Ms. W.’s and Ms. J.’s experiences took place in different times and sociopolitical contexts, both illustrate the fact that some women’s reproduction is deemed worthy of celebration and care while others’ is deemed problematic or undeserving — a phenomenon that scholars have termed “stratified reproduction,” which leads to reproductive injustice. This phenomenon is extensive and global, affecting indigenous, poor, immigrant, undocumented, and incarcerated women all over the world.

**Reproductive justice acknowledges and aims to address the relationship between disparities in reproductive health and the unequal treatment of women of color, substance-using women, and poor women. To improve health outcomes, clinical care and policy solutions must address structural racism, clinicians’ accountability for intentional harms, and access to treatments for opioid use disorder.**

## Clinical Implications

The reproductive-justice framework can be used productively to identify policies and practices that remediate and repair reproductive injustices and provide compassionate, individually tailored care for members of groups that have borne the brunt of these injustices.

1. Clinicians should be educated

*about how racism, racial bias,<sup>4</sup> and social discrimination affect health outcomes, particularly in reproductive health.<sup>5</sup> Using a reproductive-justice framework, educators can teach clinicians about the historical legacy and contemporary manifestations of eugenics and racism. Such training can address the ways in which individual bias-*

*es and institutional policies can lead to the devaluation of some women’s reproduction by health care providers.*

2. *Reproductive health clinicians should intervene to address substance use disorders during pregnancy and act as advocates for policy change.* Clinicians can be trained to screen and offer therapy for opioid use

disorder, including effective office-based therapy (buprenorphine), and they can collaborate as necessary with clinicians in other specialties, such as psychiatry and maternal–fetal medicine. Structural changes are also crucial for preventing disparities in reproductive outcomes. For example, clinicians are well situated to advocate for policies that create universal funding for medications for opioid use disorders,

expanding access to include not just pregnant people but all people regardless of their pregnancy status or reproductive desires.

3. *Clinicians can help patients seek redress for harmful practices.* Clinicians can initiate and become involved in medicolegal cases that address the motivations and drivers of coercive sterilization practices. Clinicians can also provide expertise, engage in public debates, and contribute to policy

proposals regarding forms of reparation such as formal apologies or processes for holding the offenders accountable. Clinicians can offer women who have been affected by coercive sterilization access to reproductive endocrinology and infertility specialists if future pregnancy is desired. Such actions can contribute to movement toward reconciliation and healing.

## Follow-up

After Ms. W.'s second stillbirth, she underwent tubal ligation during the same hospitalization. When queried about informed consent, she remarked, "They asked me if I wanted my tubes tied, and I said yes." Afterward, Ms. W. checked herself out of the hospital.

Recently, public conversations in print and social media have highlighted the severity of racial disparities in U.S. reproductive health outcomes, underscoring the critical need for black, Latinx, and indigenous women to shape policy and legal efforts to remediate reproductive injustice.

Ms. J. experienced psychological consequences, such as feelings of inferiority and mood swings, after learning of her unwanted

sterilization, as well as violence at the hands of her former husband.

Despite antidiscrimination legislation implemented throughout the European Union, Ms. J. and other Romani women harmed by coercive sterilization have not received substantial reparations, aside from compensation paid to a few Romani women in Czechia and Slovakia.

The patients' initials and identifying characteristics have been changed to protect their privacy.

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1. Ross L. Reproductive justice: an introduction. Oakland: University of California Press, 2017.
2. Ross L. Understanding reproductive justice: transforming the pro-choice movement. *Off Our Backs* 2006;36(4):14-9 ([https://www.law.berkeley.edu/php-programs/centers/crrj/zotero/loadfile.php?entity\\_key=6NK5BUG9](https://www.law.berkeley.edu/php-programs/centers/crrj/zotero/loadfile.php?entity_key=6NK5BUG9)).
3. Harris LH, Wolfe T. Stratified reproduction, family planning care and the double edge of history. *Curr Opin Obstet Gynecol* 2014;26:539-44.
4. Burgess DJ, Fu SS, van Ryn M. Why do providers contribute to disparities and what can be done about it? *J Gen Intern Med* 2004; 19:1154-9.
5. Collins JW Jr, David RJ, Handler A, Wall S, Andes S. Very low birthweight in African American infants: the role of maternal exposure to interpersonal racial discrimination. *Am J Public Health* 2004;94:2132-8.

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