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When Should Screening and Surveillance Be Used during Pregnancy? Nancy D. Campbell, PhD

Abstract

Using the ethical and legal concept of shared responsibility for healthy births, this article considers social, cultural, and historical contexts in which medicalization and criminalization have worked in tandem to widen surveillance in ways that intensify scrutiny of women's lives under the guise of child protection, bringing women who are pregnant, postpartum, or parenting under criminal justice control. Although pregnant and postpartum women are prime candidates for medication-assisted treatment (MAT), the expanding carceral system has not prioritized drug treatment or reproductive justice. This article investigates ethical and historical dimensions of the question, According to which principles and practices should screening and surveillance be carried out to reduce harm, safeguard civil and human rights—including reproductive autonomy—and ensure that treatment, when necessary, occurs in the least coercive settings possible?

Introduction

I could not believe my eyes: "Mom Is Part of the Cure for Tiny Opioid Victims" read the front page of the *New York Times* and, beneath the title, "Doctors Say Cuddling with Infants Helps Ease Withdrawal" [1]. Amnesia and ignorance pervade the topic of drugusing pregnant women, who have experienced increasing clinical surveillance within a culture that blames pregnant women for exposing "tiny opioid victims" to health risks such as neonatal abstinence syndrome (NAS). Was "Mom" to be at long last recognized as part of the solution to a problem for which cure has been elusive and compassion limited? Alas, the situation recounted in the article did not bear out the optimistic headline.

Women who use opioids or illicit drugs continue to be threatened with punishment rather than being met with supportive treatment designed to inculcate shared responsibility for healthy births. Despite reasoned opposition to punishing pregnant women from all major medical and public health organizations [2], illicit drug-using women remain vulnerable to disdain, discrimination, and criminal prosecution in the United States particularly when pregnant and seeking hospital-based delivery [2, 3]. Although surveillance has been undertaken for purposes of criminalization of pregnant

women in punitive contexts, willingness to prosecute pregnant drug-using women has varied by region and social location [4, 5]. If healthy births and breastfeeding are the desired outcomes, surveillance and reporting should support those goals rather than providing an entrée into the criminal justice system.

Clinical practitioners should screen and surveil pregnant and recently postpartum women *only* for purposes of supporting their health and safety as patients. In criminal justice contexts, diagnostic screening and surveillance technologies have been speculated to deter women from using drugs, but some uses of these technologies have been demonstrated instead to deter women from seeking prenatal care and even medical assistance in childbirth [6]. Decisions to carry a pregnancy to term are dramatically constrained in the population of drug-using women, which is highly heterogeneous. However, once a woman has decided to carry to term, healthy birth outcomes become a responsibility shared between the pregnant woman and her team of health care practitioners. Whereas biomedical surveillance may be used to provide better care and more accurate diagnosis and to reduce risk, it should also be borne in mind that surveillance has historically been deployed in ways that augment harm, detract from care, and increase risk.

History of Surveillance of Opioid Drug-Using Women

At the turn of the twentieth century, the typical US "addict" was a respectable white woman maintained by physicians on morphine [7]. Physicians knew how to taper off babies born to such women—who were pitied but viewed as nonthreatening—through the clinical practice of morphine maintenance. During a brief period following the passage of the Harrison Narcotics Tax Act in 1914, municipal clinics in many states dispensed morphine to those registered to receive daily doses [7]. The act, which is still in effect, regulates the production, import, and dispensing of opium and coca products [8]. Its early enforcement consequently led to the prosecution of thousands of physicians for maintaining patients on morphine [7].

Over the next three decades, the demographics of the opioid-addicted population changed. In the 1930s, this population was largely white and male aged 45 and older. During that time, the National Research Council Committee on Drug Addiction set out to identify substitutes for each of the "indispensable uses of morphine" so as to minimize its use [9]. Large-scale demographic shifts occurred after World War II as illegal drug markets burgeoned in urban communities of color [10]. Postwar heroin addicts were younger, poorer, and more often black or Puerto Rican than their forebears [10]. The 1950s also witnessed the first mandatory minimum sentences for drug crimes. In response, a cadre of progressive doctors and lawyers formed an American Medical Association (AMA)/American Bar Association (ABA) Joint Committee that in 1961 released a controversial report, *Drug Addiction: Crime or Disease?*, advocating morphine maintenance in the face of prohibitionist policy [11].

Caught up in these shifting patterns, women trickled into the ranks of the addicted; both pregnancy and addiction became symptoms of gendered psychopathology in the studies of the 1950s [12]. An early epidemiological study, *The Road to H*, explained that unlike men and boys, "females have available to them another technique of 'acting out' ... which is not available to males, namely, the out-of-wedlock pregnancy," a drama "enacted largely in the life of the female" [13]. Women were asked little about their experiences of pregnancy, birth, child removal, grief, and loss; archival and anecdotal sources confirm their lack of agency in these decisions. An enduring pattern took hold along color lines in which white women who used illicit drugs or became pregnant out of wedlock were diagnosed with personality disorder and mental illness, whereas similarly situated women of color were labelled "sociopathically disturbed," "deviant," and "criminal" [12, 14-16].

Women's reproductive decisions and practices periodically came under state and social scrutiny, but pregnant drug users came to very little notice until neonatologists began to see babies born to "heroin mothers" in the late 1960s. By this time, the combined lack of medical education about drug dependence—including detoxification techniques used in babies born to opioid-dependent women—and continuing prosecution meant that most clinicians knew little about addiction and were understandably reluctant to deal with a patient who was a "dope fiend" [17]. In *Robinson v California* (1962), the US Supreme Court cited the paucity of medical literature on addicted babies [18], a medical terrain that was charted anew later in the 1960s. A 1958 study had listed signs of neonatal withdrawal: hyperactivity, trembling, twitching, convulsions; shrill, high-pitched, prolonged cry; and an "almost constant sucking and chewing on the hands and fingers as if hungry" [19]. A 1966 study at Metropolitan Hospital in New York City study found that addicted women averaged less than one prenatal visit per pregnancy; slightly more than 40 percent experienced obstetrical complications; and 20 percent left the hospital early [20]. As to these mothers, most were "unconcerned with prenatal care" [21]:

She lives in conditions of poverty, her diet is poor, and she is liable to venereal disease and a multitude of infectious diseases.... Not only is her physical condition poor, but also she cares nothing about improving it as long as she can obtain enough heroin to stave off withdrawal symptoms and to give her the occasional lift above the conditions in which she lives [22].

Babies born to these mothers were immediately adopted out, treated by clinicians who had received no training on the specifics of maternal-fetal or neonatal abstinence despite rising numbers of babies born with "narcotic addiction" [23]. In response, physician Loretta Finnegan and colleagues identified neonatal abstinence syndrome

(NAS) and initiated a maternal education program, drawing attention to the health issues of drug-using women and their babies around the world [24].

The 1970s was an era of widening availability of reproductive health care and methadone maintenance, which had become standard treatment for opioid-dependent people by the 1980s [25]. However, this expansion drew ire from those proposing coercive measures such as mandatory treatment or compulsory commitment to control addicted women who became pregnant [26]. A politically adversarial discourse of the "unborn child" arose in the drug treatment arena. As Densen-Gerber, Wiener, and Hochstedler observed, "Unfortunately, there is at present no legal means of controlling the behavior of the pregnant addict in the interest of the unborn child" [26]. The authors advocated "narrowly drawn, closely defined statutes in every state providing for compulsory commitment and treatment of pregnant addicts for the duration of the pregnancy" [26]. Such views intensified with the advent of crack-cocaine in the late 1980s, when drug-using women's "decline of maternal instinct" became subject to Congressional hearings and surveillance invaded health care [27]. Right-wing activism around fetal personhood and "unborn victims" of drug-using pregnant women harnessed medicalization of maternity to the criminalization of addiction.

The medicalization of maternity with respect to opioid-dependent women also took progressive form during the 1990s, when some physician-researchers who treated opioid-dependent pregnant women began using the intake and assessment process to build a "therapeutic alliance" [28]. National Advocates for Pregnant Women (NAPW) enrolled many medical and public health practitioners and organizations, arguing against punitive reporting and criminalization all the way up to the US Supreme Court [29]. Yet medicalization and criminalization have long been intertwined, with the emphasis shifting from one to the other depending on which social locations and user populations were perceived to foster problematic drug use.

Medication-Assisted Treatment as a Special Need for Pregnant and Postpartum Women

States that do not provide the full range of reproductive health care often do not provide the full range of drug treatment services, an observation suggesting that the evidence base for both is being ignored. Access to medication-assisted treatment (MAT) for opioid dependence, which currently includes methadone maintenance therapy and the promising new partial agonist-antagonist buprenorphine [25], often has limited availability in the very places where opioid problems abound. These include criminal justice contexts where access to MAT has been particularly uneven and forced abstinence is common [30]. Despite abstinence being considered the cornerstone of recovery, I maintain that abstinence is also a risk factor for overdose and thus for overdose death; a pregnant woman's abstinence places the fetus she is carrying in a "risky situation." Social contexts in which women use drugs or associate with known

drug users, producers, or distributors are understood as risky. Risks are compounded in cases in which abrupt abstinence from opioid agonists place pregnant women and the fetuses they carry in harm's way. On the other hand, MAT is protective for pregnant women and the fetuses they carry.

Yet women on MAT have been denied not only medication but also compassionate care and humane treatment during detention, enduring dangerous withdrawals while detained by the criminal justice system [29, 30]. Despite the unethicality of this practice, which withholds a known effective treatment, pregnant women themselves are often viewed as "endangering" the fetus when they are identified as drug users [31]. Given the negative consequences and ethical implications of identifying women as drug users, Terplan and Minkoff warn against simply advocating universal voluntary screening to detect prenatal drug use as a technological fix that does not address the broader social and economic contexts in which pregnant women use illicit drugs [31].

In *Using Women: Gender, Drug Policy, and Social Justice* [16], I argued against heightened scrutiny into drug-using pregnant women's lives even on grounds of "protecting the unborn" [32] or "doing what's best for baby." In the midst of what Mayes et al. called the "rush to judgment" about crack-cocaine-using pregnant women [33], I adopted feminist-legal theorist Dawn Johnsen's promotion of the concept of shared interest in "promoting healthy births" [34]. In shouldering shared responsibilities with drug-using pregnant women, health care professionals should recognize the multiple stigmas that shape the lives of drug-using women's experiences of pregnancy, childbirth, and mothering and ally with them to confront a society that has rushed to judgment about who knows best what actions and decisions they are to take.

Therapeutic alliances must also address the racial politics and class inequities of the injustices that opioid-dependent pregnant women have experienced. Treatment trajectories diverge depending on the social locations of the women involved. Racial disparities influence who is able to access treatment and who is sent to prison [35]. But punitive sanctions serve only to deter women from seeking prenatal care, a point consistently made by every major professional organization dealing with pregnancy and addiction [2-4]. Such statements are regularly compiled and updated by NAPW, one of few organizations equipped to take on cases in which pregnant and parenting women are charged with crimes in the course of living out their lives [2, 3, 29].

Ethics in the kinds of risky situations described above is not a mere preoccupation with abstract principles—nor should ethics be understood as limited to technical details. Ethics is practical, often arising as a result of specific cases with particular histories of harm and injustice. Enjoined to do no harm, physicians arguably have a duty to reduce harm and certainly to provide care that does not coerce, stigmatize, or criminalize.

Physicians share responsibility to ensure access to the full range of reproductive health care and drug treatment for their patients who need it. Physicians also share with drugusing pregnant women responsibility to bring about healthy births and humane treatment for all concerned—mothers, babies, and children. Ensuring access to the full range of evidence-based drug treatment should be considered part of these affirmative duties. Biomedical surveillance should be conducted only for clinical purposes having to do with ensuring access to and delivering quality health care. Just because we have surveillance technology does not mean we should use it against the very women who need to be enrolled in caring for their infants. "Mom" is part of the cure, and compassionate care demands that surveillance be judiciously used in therapeutic spaces.

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