Pregnant and Afraid: Opioid-Using Expectant Mothers Facing Injustices in Rural Appalachia

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Abstract

The United States Food and Drug Administration first approved several opioids—oxycodone, hydrocodone, codeine, etc.—for prescription use in the late 20th century. What started as simple, effective painkillers quickly led to a nationwide addiction epidemic, perhaps creating more problems than it solved. In the case of pregnant women, both mother and unborn child face the effects of addiction. The newborn often suffers from Neonatal Abstinence Syndrome, a condition frequently associated with motor-disabilities, upon birth. Many pregnant women in rural Appalachia face a myriad of additional problems including, but not limited to, finding available treatment providers, facing charges from the criminal justice system, and receiving care for underlying childhood traumatic experiences. Though the roots of this crisis require action on a national level, I address the injustices facing rural mothers already caught in the cycle of addiction and present solutions for diminishing them. To expand the accessibility and effectiveness of opioid agonist treatment (OAT) for expectant mothers residing in rural Appalachia and improve outcomes for both mother and newborn, rural primary care physicians should become DATA-waivered buprenorphine prescribers, politicians should avoid legislature that criminalizes the mother, and treatment facilities should integrate a trauma-informed care (TIC) environment.

4-5 Key Words for search engine use:

Opioids; Pregnancy; Neonatal Abstinence Syndrome; Appalachia; Trauma Informed Care

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It's only been four hours, but she needs it. She needs it so bad that nothing else matters, not even the unborn child she's carried in her womb for the past nine months. Oxycontin. Her body calls out for it. She reaches for the pill bottle tucked under her mattress, but it's empty. Where can she get more? The sound of water hitting the linoleum beneath her feet diverts her attention, and her mind begins to race. She panics as the last memory of her youngest son floods her consciousness. A Department of Child Services (DCS) worker whisked him away screaming, but the screams weren't for want of his mother. They were cries of physical pain and an unrelenting desire, the symptoms of withdrawal. How could she pass these brutal pangs of addiction onto her innocent child? She had tried to get clean, time and time again. She wanted the best for her children, but somehow the craving would always find a way to creep back and overtake every desire. Would they take this baby away from her, too? Should she even go to the hospital?

Unfortunately, the situation described above is not an isolated one. The United States Food and Drug Administration first approved several opioids—oxycodone, hydrocodone, codeine, etc.—for prescription use in the late 20th century. What were marketed as simple, effective painkillers have now led to a nationwide addiction epidemic, perhaps creating more problems than they solved. In the case of pregnant women, both mother and unborn child face the effects of addiction. The newborn often suffers from Neonatal Abstinence Syndrome, a condition frequently associated with motor-disabilities, upon birth. For the mothers, fear often replaces the excitement of motherhood and new life. Many pregnant women in rural Appalachia face a myriad of additional problems including, but not limited to, finding available treatment

providers, navigating charges from the criminal justice system, and receiving care for underlying traumatic childhood experiences. To expand the accessibility and effectiveness of opioid agonist treatment (OAT) for expectant mothers residing in rural Appalachia and improve outcomes for both mother and newborn, rural primary care physicians should become Drug Addiction Treatment Act of 2000 (DATA) waivered buprenorphine prescribers, politicians should avoid legislation that criminalizes the mother, and treatment facilities should integrate a traumainformed care (TIC) environment.

The opioid crisis affecting pregnant women needs to be dealt with immediately. It is argued that "Pregnancy should be protective and that women have personal control over their opioid use", so "they are, therefore, to blame for adverse perinatal outcomes" (Johnson, 2019, p. 133). Furthermore, treatment providers often claim that these women are "'bad' mothers who do not love their children enough to cease drug use" (Buer, 2018, p. 190) when they don't successfully complete treatments programs, rather than recognizing the lacking quality of the treatment programs. These harmful arguments place an unjust stigma on these pregnant and opioid dependent women. In America, widespread popular culture marks drug users as "'others' who harm themselves, their children, and society" (Buer, 2018, p. 104).

Many Americans stereotype women living in Appalachia, putting them up against an additional layer of stigma. Politicians blame the stigmas of "inherent lawlessness" and drug use in Appalachia as reasons there are few employers in the region (Buer, 2018, p. 104). The media and popular culture effectively spread this, intensifying the already harmful stigma placed on these women. Massey (2007) summarizes the major points of Anthony Harkin's book *Hillbilly:* A Cultural History of an American Icon, that notes that American culture views the Appalachian, in many cases, as "degenerate, uncouth, and lazy" and embodies "a composite figure of all of

those things that a national identity majority... wishes to expel from its national corpus" (p. 126). This intense stereotype leads many Americans to feel reluctant to support the funding of programs like the expansion of rural treatment availability for opioid-using expectant mothers. It also disregards the systemic poverty that plagues the Appalachian region of the United States. State governments and politicians use stereotypes and stigmas surrounding the "undeserving poor" to justify their oppression of these people. This failure to support rural communities continues the cycle of unemployment and poverty that frequently leads women to support their families through involvement in drug economies (Buer, 2020, p. 48).

The parental role of a mother further works against opioid-using mothers. Van Olphen et al. (2009) notes, "the degree of stigma [being] much greater for women because of gender-based stereotypes that hold women to different standards" (p. 2). Women give birth to and nurse newborns, which results in their association with and the subsequent expectation of their domestic duties regarding child rearing (Rosaldo et al., 1974, p. 7). Mothers receive extra pressures to raise children without any mistakes from American government organizations, like the DCS; the slightest sign of a slip up receives intense judgement and questioning as to whether a woman is fit to parent. Fathers, on the other hand, often receive a pass when they neglect their children because American culture has placed most of child rearing duties on women. One woman recognizes this in her community and claims, "[A] dad can make up for that lost time" (Buer, 2018, p. 192).

Drug use during pregnancy and motherhood categorizes these women as neglectful and absorbed by their drug use. It fails to recognize the love that these women have for their children and their desire for change. One woman describes the moment she decided to face her addiction: "[My daughter] was almost two years old. And she came over to me and put her hand on me and

looked at me and said, 'Mommy, I love you.' And the fight was on from there" (van Olphen, 2009, p. 6). The love for these children is present; it is the lack of support for these women that is missing and hinders their prospects for positive outcomes.

Studies (Johnson, 2019) have shown that opioid agonist treatment, or "[replacement of] short-acting opioids with long-acting opioid medication" (Government of British Columbia, 2019, "How does OAT work?" section), during pregnancy leads to birth outcomes that resemble those of women who didn't use opioids during their pregnancy (p. 136). OAT also produces superior outcomes to assisted opioid withdrawal which may put the baby in distress (Johnson, 2019, p. 136). When prescribing OAT medications, clinicians will utilize either methadone or buprenorphine. Methadone can only be prescribed and taken in Substance Abuse and Mental Health Services Administration (SAMHSA) approved opioid treatment programs (OTPs). DATA-waivered physicians have the capability of prescribing the newer treatment drug buprenorphine.

A study from Nguyen et al. (2018) around buprenorphine shows this drug as an especially useful option for expectant mothers. It is associated with a "lower drug interaction profile, lower overdose potential, and less severe NAS" (p. 2). In addition, buprenorphine can be taken in a private setting, reducing the stigma surrounding frequent visits to a methadone clinic. One patient in a study from Yarborough et al. (2016) describes his/her experience, "'When you take [buprenorphine], it's in the privacy of your own home... It made me feel normal'" (p. 8). Regular visits to the clinic pose a barrier to some individuals who work full time jobs and/or live far away. Another patient from this study (Yarborough et al., 2016) claims, "'It's a lot easier to get off buprenorphine than it is methadone" (p. 9). Reduced stigma, less frequent visits to the

clinic, and easier withdrawal all make buprenorphine an excellent candidate for the majority of expectant mothers.

Despite the evidence to support buprenorphine use, the number of pregnant women who have access to buprenorphine prescribers is alarmingly low. Research from Rosenblatt et al. (2015) notes that

only 2.2% of American physicians have obtained the waivers required to prescribe buprenorphine... 90.4% of these physicians were practicing in urban counties, leaving the majority of US counties (53.4%)—most of them rural—with no physician with a DEA DATA waiver. (p. 25)

This discrepancy is attributed to lack of opioid use disorder training in the residencies of young doctors and aversion to bringing the stigma of opioid use disorder (OUD) treatment into the practice (Rosenblatt et al., 2015, p. 26). Though integrating substance abuse treatment with prenatal care would be ideal, almost half of rural counties in the United States lack an obstetrician-gynecologist (Rayburn, 2012, Results section). An increase in primary care buprenorphine prescribers would be more practical because they represent "the predominant providers of health care in rural America" (Rosenblatt et al., 2015, p. 25).

A clinician seeking to become DATA-waivered must meet one of two requirements. The individual must either possess "a board certification in addiction medicine or addiction psychiatry" or "provide medication-assisted treatment (MAT) in a 'qualified practice setting'" (Substance Abuse and Mental Health Services Administration [SAMHSA], 2020, paras. 6-7). Though many primary care physicians may not have a certification in addiction medicine or psychiatry, most will qualify through having an approved practice setting. After approval, practitioners can "treat [up to] 100 patients in their first year" (SAMHSA, 2020, para. 5). Even

the slightest increase in the number of buprenorphine prescribers helps to increase availability for pregnant women seeking treatment.

Another significant injustice placed on pregnant women with OUD involves convicting them as criminals. Tennessee's fetal assault law, enacted in 2014 and expired in 2016, "amended the general assault statute to apply to the 'illegal use of a narcotic by a pregnant woman if the child is born "addicted to or harmed by" the *in utero* drug use" (O'Connor, 2019, p. 114). Though this law expired, similar laws have been proposed since and have the potential to pass in the future. The enactment of this law further intensified the stigma surrounding opioid use through the characterization of these women as criminals, a result that still prevents many from seeking out treatment today.

Lisa Carter, CEO of Niswonger Children's Hospital and Vice President of Pediatric Service for Ballad Health in Johnson City, TN, was elated when the bill finally expired in 2016 (L. Carter, personal communication, October 12, 2020). She works within the Northeast Tennessee region to advocate for opioid-using expectant mothers, and the stories of women avoiding prenatal care and traveling across state borders to give birth disheartened her (L. Carter, personal communication, October 12, 2020). The fetal assault law seeks to deter drug use during pregnancy to benefit newborn outcomes, yet the fear of arrest these women experience leads them to refrain from receiving vital prenatal care, ultimately leading to negative health outcomes for the child.

Oftentimes, expectant women charged with fetal assault are sent to prisons with inadequate health care services, especially for prenatal care, labor, and delivery: "Thirty-eight states received failing grades" in a report from 2010 (O'Connor, 2019, p.120). Many jails and prisons ignore the standards of care set by national organizations, like the American College of

Obstetricians and Gynecologists, which recommend prenatal diets, prohibit the use of restraints during labor and delivery, and support mother-child bonding (Kelsey et al., 2017, Introduction section). The especially disheartening use of shackles during labor and delivery interfere with healthcare providers ability to detect successfully pregnancy complications (Kelsey et al., 2017, Introduction section). Furthermore, many women are forced to give birth in jail cells, despite the significant number of women with high-risk pregnancies in need of proper care from hospitals (O'Connor, 2019, p. 121). This outcome, once again, goes against the intention of criminalizing drug use during pregnancy, which is to improve health outcomes for mothers and newborns.

A criminal record significantly decreases the chances of a prospective employee obtaining a job and places a "double stigma of being a drug user and having a history of incarceration" (van Olphen et al., 2009, p. 2, 7). The majority of rural Appalachian females already struggle to stay afloat without steady employment. Additionally, criminal charges can restrict the number of housing and education options available to these women (van Olphen et al., 2009, p. 1). One previously incarcerated woman stated that she returned to selling drugs because it was the only way she could earn money as a felon. She bluntly describes her situation, "It's not like I sold drugs to become a rich person or anything. I sold drugs to pay my rent" (van Olphen et al., 2009, p. 4).

Criminalization puts these women at a further disadvantage and often leads them to return to familiar environments that support the use of drugs. One woman in a study from van Olphen et al. (2009) described her experience after her release from prison as follows:

I didn't have a safe place to go to. I went right back to the same environment and I kept all the same friends... And it's all triggers. And it's just all bad... I don't know how to get a job. I just barely learned how to fill out a application. (p. 6)

She didn't know a life without drugs and lacked the support and resources to develop a way of life without them. It is crucial that lawmakers avoid legislature that scares women away from receiving treatment, threatens their health in prison conditions, and places them at a disadvantage for obtaining employment and community resources.

In addition to the quantitative lack of prescribers, there is a qualitative deficit surrounding currently available treatment options. Women who feel stigmatized or unsafe in treatment environments are more likely to leave programs prematurely, leading to a higher rate of negative outcomes for mother and newborn. Gannon et al. published a study in 2020 that sought to determine the prevalence of adverse childhood experiences (ACEs) among mothers in OUD treatment that reports, "the majority of women reported 4 or more ACEs (65%), and only 5.0% reported 0 ACEs" (Results section). Examples of ACEs include witnessing violence against loved ones, experiencing abuse in verbal, physical, and/or sexual forms, and living in a household with an individual who has mental illness and/or went to jail. A concerningly high number of mothers experienced trauma during their childhood, putting their children at elevated risks for encountering similar ACEs in their developmental years (Gannon et al., 2020, Introduction section). Johnson (2019) points out the "increase in vulnerability [during pregnancy] that may further trigger previous trauma" (p. 137). A heighted level of care is needed in treatment facilities to help these women feel safe.

The introduction and integration of trauma informed care (TIC) for pregnant Appalachian females, especially victims of ACEs, can positively impact the effectiveness of OUD treatment.

Morgan et al. (2020) define TIC as

A strengths-based framework that is grounded in an understanding of and responsiveness to the impact of trauma, that emphasizes physical, psychological, and

emotional safety for both providers and survivors, and that creates opportunities for survivors to rebuild a sense of control and empowerment. (Trauma Informed Care section)

TIC can be applied in all areas of the treatment process, including the involvement and empowerment of patients through developing an individualized treatment plan, an atmosphere of safety and respect, and the support of peers.

This TIC framework can also serve to bridge the gap many patients contrive from the perceived high status of being a doctor. Many patients assume healthcare providers will judge, stigmatize, and make them feel guilty in the same way that their family and friends do (Jones et al., 2014, p. 2). One woman recounts her discouraging interaction with a doctor at a treatment clinic, recalling that her provider said, "'Can you think of all the tax dollars it's cost for you to go to detox?... What is the matter with you?'" (Powell, 2019, page?). Disheartening stories like this dissuade many opioid-users from seeking out treatment. Morgan et al. (2020) suggests that physicians initiate "conversations with clients that do not directly relate to their health care treatment" ("Trustworthiness" section) to build relationships and trust with skeptical clients. Providers should also use tactics to show empathy, like maintaining eye contact, avoiding interruption when the patient is speaking, and indicating listening through the use of nonverbal cues (Jones et al., 2014, p. 2).

Many doctors are viewed as outsiders when they are unfamiliar with Appalachian culture. Physicians that immerse themselves in the local culture will alleviate one of the barriers in the way of a trusting relationship for the patient. Additionally, physicians should aim to involve their patients in developing their treatment plans. This tactic aims to empower patients, rather than evoking past experiences of trauma through making decisions for them. Individualized care

that works with the livelihood of the woman increases the likelihood that she will remain in the treatment program. A trusting relationship may also lead to patients willing to share an accurate and comprehensive history of their drug use, of both licit and illicit substances, which, in turn, assists the physician in coming up with strategies for combatting addiction and addressing reasons for opioid use that could lead to relapse (Jones et al., 2014, p. 3).

In her recently published book *Rx Appalachia: Stories of Treatment and Survival in Rural Kentucky*, Buer (2020) claims, "Treatment is represented as saving white children" (p. 30), rather than focusing care on the mother. These women's opioid dependence automatically characterizes them as "'bad' mothers" in the eyes of many "community members and service providers" (Buer, 2020, p. 61). Women will stop attending programs that degrade them or don't work with their recovery goals. The importance of retaining women in treatment increases when pregnancy is involved because the health of the child is also at stake. Prescribers need to communicate with patients to "make the choices that work best for her individual life situation" (Johnson, 2019, p. 134), whether that be choosing buprenorphine over methadone due to inability to attend frequent appointments or adjusting dose sizes to ease of the symptoms of withdrawal.

The environment of the treatment clinic can be altered to implement TIC. A study from Devlin and Arneill (2003) shows that a lack of control over environmental factors in a clinic, such as noise levels, brightness of lights, and privacy, can lead a patient to feel additional stress on top of anxiety associated with their illness (p. 673). Morgan et al. (2020) recommend a "quiet, calming atmosphere" that is "[sensitive] to light and sounds" and provides "the privacy of parking offsite" (Safety section). All employees in the health care setting, from physicians to secretaries, should "possess a basic understanding of the complexities of trauma" (Morgan et al.,

2020, Trauma Informed Care section) and maintain neutral language and a non-threatening and respectful tone. It is crucial for the clinic to prevent clients from "feeling physically, socially, or emotionally unsafe" because this might "potentially [cause] re-traumatization" (Menschner & Maul, 2016, p. 4).

Supplementary care in the form of peer support further creates a comfortable treatment process for women. Patients find it easier to relate to and trust individuals who have been in similar situations. These individuals can offer "encouragement based on lived experience" (Morgan et al., 2020, Peer Support section) as well as dissolve the idea of health care workers as outsiders. Patients will gradually lose some feelings of isolation that are commonly associated with experiencing trauma (Menschner & Maul, 2016, p. 6). Just as the women coming out of prison find themselves in need of support, opioid-using women need the support of someone who will not judge them for their addiction and will help them in the recovery process.

There is an established link between the growth of the opioid epidemic and the rise in the number of children in foster care. In 2017, thirty-six percent of cases of child placement in foster care was attributed to parental drug use (Waite et al., 2018, p. 1). The high costs associated with the foster care system might be used to fund the establishment of trauma-informed care and counseling services for opioid-using pregnant women. In a span of six years, from 2011 to 2016, over 2.8 billion dollars were attributed to opioid abuse, making up approximately 2.1 percent of child welfare costs for this period (Crowley et al., 2019, p. 260). If states directed their allotted federal funds for foster care to the comprehensive treatment of opioid-using women during pregnancy, the need for foster care could be significantly reduced. Likewise, the negative psychological effects on children removed from their parents at a young

age will decrease. From birth to the age of three, babies develop "trust, safety, self-esteem, and social skills" (Waite et al., 2018, p. 5) that carry over into their adult lives.

Many women in the Appalachian area lack skills in job searching, application and retention, not to mention parenting skills (L. Carter, personal communication, October 12, 2020). For this reason, it is paramount that primary care clinics and OUD treatment centers provide patients with community resources to help them support themselves and their families. Most Appalachian women want to work and support their families, but they have difficulty finding jobs that pay a living wage (Powell, 2005, p. 63). Women also need to be connected with affordable childcare services to ensure that they will be able to go to work.

Finally, providers need to ensure women that they are good mothers, despite what their friends, family, and community might say. Healthcare providers and patients should establish connections that fight the negative stereotypes aimed at demeaning these women (Buer, 2018, p. 214). One woman Buer interviewed reminds herself, "Neglect sounds to me like someone who beats their kids, don't feed their children, leaves them unattended. I neglected myself, not my children" (Buer, 2018, p. 213). This statement succinctly combats the widespread stereotype surrounding drug-using mothers and puts a new perspective on the stigma.

The opioid epidemic affecting pregnant women in the rural Appalachian region of the United States is a pressing issue. Readers can show their support through making a donation to an organization actively fighting the crisis. Shatterproof, an American-based nonprofit, takes an all-encompassing approach to opioid addiction. The organization seeks to increase treatment availability, as well as slow the rise in cases of addiction by working to end over-prescription (Healthline, 2019, Shatterproof section). It works to advocate especially for pregnant women using opioids and more widespread treatment options for them. Eighty one percent of its

donations go towards programs for education and awareness, five percent to programs for advocacy, and fourteen percent for event planning and administration (Healthline, 2019, Shatterproof section). Shatterproof accepts donations through its website, Shatterproof.org.

The opioid crisis in the United States, especially for pregnant women of rural Appalachia, is a complex, multifaceted issue with no simple solution. Community clinicians and politicians need to act in ways that support the availability and effectiveness of treatment for expectant mothers through the increase of DATA-waivered buprenorphine prescribers, avoidance of criminalization, and implementation of trauma-informed care. With these powerful strides, women in rural Appalachia will be better supported to break the generational cycle of opioid addiction.

After delivering in the hospital, the opioid addicted mother gave birth to a beautiful girl, whom she named Hope. The screams of her infant daughter were difficult to bear but pushed the mother to seek out treatment once again, driven by love for her newborn and fear of losing another child to the DCS. She sought out OAT from her local primary care physician, who developed an individualized plan with her and referred her to community programs that showed her how to find a job and affordable child care. Eventually, the mother tapered off her treatment, and the skills she developed with her behavioral counselor helped her whenever she felt tempted to relapse. The road was not easy, but she was grateful for the chance to overcome her addiction and the support she received from her community along the way.

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