

# Care Experiences of Women Who Used Opioids and Experienced Fetal or Infant Loss

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## ABSTRACT

**Objective:** To explore care experiences of women who used prescription or illicit opioids and experienced fetal or infant loss.

**Design:** A qualitative, descriptive design with secondary data analysis.

**Setting:** The Fetal and Infant Mortality Review program in an urban Midwestern county in the United States.

**Participants:** Eleven women with histories of prescription or illicit opioid use who experienced fetal or infant loss participated in the semistructured telephone or in-person interview portion of the mortality case review.

**Methods:** We used thematic analysis to analyze interview data.

**Results:** Five themes were identified related to the care experiences of participants throughout pregnancy and fetal/infant loss: *Frustration and anger related to not being heard, feeling minimized; Being overwhelmed with attempts to process and understand medical complications and outcomes; Profound sense of grief and coping with loss; Need to understand why and make difficult decisions; and Placing blame and guilt over death.*

**Conclusion:** Our findings suggest that women who use opioids and experience fetal or infant loss have complex care, educational, and emotional needs. In the development of interventions for these women, it is important to address their unique and complex circumstances.

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Winklbaur et al., 2008). Although coordinated care is critical for these women, little is known about care needs from the women's perspectives. The purpose of our qualitative study was to explore care experiences of women who used opioids throughout pregnancy and experienced fetal or infant loss.

## Literature Review

### Needs for Prenatal and Drug Treatment Care

From 2000 to 2009, the prevalence of opioid use in the prenatal period increased fivefold, from 1.2 to 5.6 per 1,000 live births (Patrick, Davis, Lehmann, & Cooper, 2015). Compared with the general population, women who use opioids have greater rates of preterm birth (25% vs. 9.6%), low birth weight (31% vs. 5% to 8%), and intrauterine growth restriction (30% vs. 8%; Pinto et al., 2010). In response to the rapid increase in the use and abuse of opioids, the federal government passed

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## Opioid dependence presents serious health risks for pregnant women and their infants, including potential fetal or neonatal death.

the Protecting Our Infants Act of 2015. With this legislation, agencies were directed to develop strategies to prevent and treat opioid use during pregnancy and neonatal abstinence syndrome (NAS) by assessing the comprehensive health care needs of women who use opioids during pregnancy and the long-term consequences of prenatal opioid exposure on infants (Ruble, 2016). The American College of Obstetricians and Gynecologists (ACOG; 2012) developed policy statements and clinical care recommendations to improve prenatal care, expand substance abuse treatment availability and accessibility, and reduce NAS. Prenatal care for women who use opioids includes assessment of substance use history; referral to tertiary obstetric services or drug treatment specialists; opioid substitution therapy during antenatal, birth, and postpartum stages; and management of relapse (Abrahams, Chase, Desmoulin, Roukema, & Uddin, 2012; Arunogiri, Foo, Frei, & Lubman, 2013; Winklbaur et al., 2008).

Opioid use remains one of the most common reasons that women do not seek early prenatal care (Friedman, Heneghan, & Rosenthal, 2009; Schempf & Strobino, 2009). The stigma attached to the use of drugs during pregnancy could be a barrier. Public discourse and media attention have been focused on the dangers of fetal exposure without taking into account the history of each woman (Kennedy-Hendricks, McGinty, & Barry, 2016). Also, the complex physical, psychological, and social needs of this population make it difficult to design appropriate, comprehensive, and coordinated care. Women who use opioids during pregnancy are at greater risk for perinatal complications and require high-risk pregnancy services; they have additional needs for substance abuse treatment, chronic pain treatment, behavioral health services, and social support.

Attitudes of care providers toward pregnant women who use opioids may also deter the women from seeking care. Goodman and Wolff (2013) found that 46% to 95% of physicians believed that drug or alcohol use during pregnancy is a form of child abuse and favored compulsory treatment for the women. However, drug treatment, such as opioid substitution

therapy, may not always be viewed by women as helpful. Chandler et al. (2013) found that some women perceived opioid substitution therapy as a barrier to normal family life because substitute drugs (e.g., methadone) gave them "a kind of fuzzy feeling," and drug treatment required frequent trips to care centers and disclosure of their drug histories to more people. As suggested by H. E. Jones et al. (2008), advancement of an evidence-based approach to optimal care for opioid-dependent pregnant women is possible only when we know more about their needs.

## Care and Support for Women Who Use Opioids as They Transition to Motherhood

In the Transition Framework developed by Meleis, Sawyer, Im, Messias, and Schumacher (2000), pregnancy, childbirth, and parenthood are viewed as life transitions. A healthy transition enables an individual to feel connected, better interact with others, and develop confidence and coping strategies. Although many women easily transition to motherhood, women who use opioids may be challenged by difficulties in developing the mother-infant relationship, loss of custody, or death of the infant. Prenatal opioid use was associated with insecurity in attachment to the infant, rehospitalization, and child abuse and neglect (Foulkes, 2015; Friedman et al., 2009; Terplan, Kennedy-Hendricks, & Chisolm, 2015; Worcel, Furrer, Green, Burrus, & Finigan, 2008). Women who use drugs may be less sensitive to infant cues and may have inadequate infant care knowledge and skills. The removal of an infant from a woman who uses opioids and placement in a different family environment is often done to offer protection to the infant (D. K. Smith, Johnson, Pears, Fisher, & DeGarmo, 2007; Young, Boles, & Otero, 2007). However, this course of action may be viewed by the woman as punitive and can be detrimental to her recovery and treatment compliance (Krans & Patrick, 2016; Ordean, Kahan, Graves, Abrahams, & Kim, 2015; Stone, 2015; Worcel et al., 2008). Nevertheless, loss of parental rights or custody is common for women who use drugs and constitutes an involuntary loss, which can cause grief and persistent anger. This could result in the need to blame others to minimize the consequences attributable to substance abuse and allow the woman to manage guilt and maintain her maternal identity (Sykes, 2011; Wells, 2011).

Another type of loss experienced by women who use opioids is perinatal or infant death. Women

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