

FIMR Narcotic Users

## 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 in an urban Midwest 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 semi-structured telephone or in-person interview portion of the mortality case review.

**Methods:** Thematic analysis was used 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; Placing blame and guilt over death.

**Conclusions:** Our findings suggest that women who use opioids and experience fetal/infant loss have complex care, educational, and emotional needs. When developing interventions for these women, it is important to address their unique and complex circumstances.

**Keywords:** *maternal narcotic use, maternal opioid use, perinatal bereavement, infant loss, prenatal care*

**Call Outs**

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- 1) Opioid dependence presents serious health risks for pregnant women and their infants including potential fetal/neonatal death.
- 2) Women who are dependent on opioids and experience fetal/infant loss have multiple medical and behavioral health issues and often reported that care providers minimized their concerns.
- 3) Interdisciplinary care, skillful communication, and patient-centered care are needed for women with histories of opioid use who experience fetal/infant loss.

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Use of prescription and illicit opioids in the United States has increased significantly in the past 10 years (Ailes et al., 2015; Patrick, Kaplan, Passarella, Davis, & Lorch, 2014; Tolia et al., 2015). This increase has created a public health crisis of increased opioid dependence and addiction, drug overdose, and corresponding infectious disease (Degenhardt & Hall, 2012; Jones, Mack, & Paulozzi, 2013; Paulozzi, 2006; Roy et al., 2011). Opioid dependence during pregnancy presents unique perinatal health risks for women and their infants, including intrauterine fetal demise, low birthweight, preterm labor, and fetal and infant loss (Goettler & Tschudin, 2011; Pinto et al., 2010; Whiteman et al., 2014). Women who use opioids during pregnancy have complex needs, including addiction therapy, behavioral evaluation and treatment, and social support that are frequently not available through conventional prenatal care approaches (Jones et al., 2013; Jones & Kaltenbach, 2013; Winklbaaur, Kopf, Ebner, Jung, Thau, & Fischer, 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.

{Insert Callout #1}

## Literature Review

### Needs for Prenatal and Drug Treatment Care

From 2000 to 2009, the prevalence of opioid use in the prenatal period increased five-fold from 1.2 to 5.6 per 1,000 live births (Patrick, Davis, Lehmann, & Cooper, 2015). Compared to the general population, women who use opioids have higher rates of preterm birth (25% vs. 9.6%), low birth weight (31% vs. 5-8%), 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 the Protecting Our Infants Act of 2015. This legislation directed agencies to

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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 (Miller et al., 2016; Ruble, 2016). The American College of Obstetricians and Gynecologists (ACOG, 2012) has developed policy statements and clinical care recommendations to improve prenatal care, 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; Winklbaaur et al., 2008).

Opioid use remains one of the most common reasons why 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 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 higher 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

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compulsory treatment for the women. However, drug treatment, such as opioid substitution therapy (OST), may not always be viewed by women as helpful. Chandler et al. (2013) found that some women perceived OST 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 Jones et al. (2008) advancing an evidence-based approach to optimal care for women with opioid use is possible only when we know more about the needs of opioid-dependent pregnant women.

### **Transition to Motherhood: Care and Support for Women Who Use Opioids**

In the Transitions Framework, Meleis (2000) described pregnancy, childbirth, and parenthood as lifespan transition and emphasized that a healthy transition enables an individual to feel connected, to better interact with others, and develop confidence and coping strategies. While many women easily transition to motherhood, women who use opioids may be challenged in this transition by difficulty in developing the maternal-infant relationship, custody loss, or death of the infant. Prenatal opioid use was associated with insecurity in attachment to the infant, re-hospitalization, and child abuse and neglect (Foulkes, 2015; Friedman et al., 2009; Patrick & Wu, 2015; Terplan, Kennedy-Hendricks, & Chisolm, 2015; Worcel, Furrer, Green, Burrus, & Finigan, 2008). Mothers who use drugs may be less sensitive to infant cues and have inadequate infant care knowledge and skills. Removing an infant from a mother who uses opioids and placing the infant in a different family environment is often done to offer protection to the infant (Smith, Johnson, Pears, Fisher, & DeGarmo, 2007; Young, Boles, & Otero, 2007). However, this course of action could be viewed by the mother as punitive and can be detrimental to the mother’s recovery and treatment compliance (Krans & Patrick, 2016; Ordean, Kahan, Graves, Abrahams, & Kim, 2015; Stone, 2015; Worcel, 2008). Nevertheless, loss of parental rights or

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custody is common for mothers who use drugs and constitutes an involuntary loss which can cause a grief response with persistent anger, and could result in the need to blame others to minimize the consequences attributable to substance abuse and allow the mother to manage guilt and maintain her maternal identity (Sykes, 2011; Wells, 2011).

Another type of loss experienced by mothers who use opioids is perinatal or infant death. Women who abuse substances are 3-4 times more likely to experience fetal or infant death than the general population (King-Hele et al., 2009). Potential complications of opioid use that increase these risks are intrauterine growth restriction, premature labor, placental abruption, and sudden unexplained infant death (Jones, H. 2013a; Whiteman, 2014). Research on the perinatal or infant death experiences of mothers who use opioids is limited. Fetal and infant loss or death was described as a painful and traumatic experience for all mothers during their transitions to motherhood (Gaudet, 2010; Kersting, 2012; Rubin, 1985; Rubin & Malkinson, 2001). Mothers with such loss experience numbness, yearning, disorientation, and despair (Badenhorst, & Hughes, 2007; Bennett, 2005). Unresolved grief reactions may contribute to initial addiction or relapse of substance abuse, and addiction can also hinder the resolution of the grieving process in subsequent losses (Denny, 1984; Smith, 2009).

Substance use is a potential complication of the grief experience as bereaved mothers have as much as a two-fold increase in the need for hospitalization due to substance use over mothers who have not experienced a loss (Li, Laursen, Precht, Olsen, & Mortensen, 2005; Zuckoff et al., 2006). Some mothers seek to maintain relationships with their deceased children by carrying photographs and observing anniversaries; others may withhold emotional attachment in subsequent pregnancies until the perceived threat of loss is resolved (Lewis, 2006). Even though rates of perinatal loss are increased with maternal opioid use and the number of women

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who use opioids during pregnancy is increasing, there is little information in current literature about the unique aspects of these mothers' experiences. Our study, which was based on Fetal and Infant Mortality Review (FIMR) maternal interviews, was designed to explore the care experiences of women who used prescribed or illicit opioids during pregnancy and had fetal or infant loss.

## Methods

### Design

We conducted a thematic analysis (Sandelowski, 2000; Vaismoradi, 2013) of qualitative maternal interview data from a FIMR program in a Midwest County Department of Public Health in the United States. Our study was approved by the Institutional Review Board of Indiana University. Only de-identified FIMR data were used and were stored in a password protected drive used specifically for research data.

### Participants

Inclusion criteria required participants to be age 18 or older with known histories of prenatal opioid use and fetal or infant losses. Between the years 2007 and 2012, the local FIMR program reviewed a total of 381 infant mortality cases; 194 (51%) of the mothers participated in interviews. In the same period, 26 adult mothers experienced a fetal or infant losses and were also identified as opioid users (prescribed or illicit). Of the 26 women, 11 (42.3%) participated in a semi-structured telephone or in-person interview. Data from the 11 interviews were analyzed in this study. Interviews were conducted 3.5 – 10 months after the fetal/neonatal death (average = 5.2 months). Nine participants were interviewed by five months after infant death.

### Data Collection



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The 11 interviews were conducted by four FIMR program nurses who received the National FIMR Maternal Interview Training on how to conduct an interview, comply with public health and safety codes, and handle difficult encounters. Interview questions asked of each participant focused on their thoughts and perceptions of the care they and their infants received and their experiences throughout the pregnancy and loss (See Table 1). Interviewers took detailed written notes during the interviews. Audio or video recordings were not used in the interviews because of the sensitive nature of the subject. The interview notes were typed and saved in a FIMR database.

## Data Analysis

Coding and thematic analysis were conducted in three phases using the thematic analysis process described by Vaismoradi (2013). The first author is a neonatal nurse practitioner and a Ph.D. student with experience in treating infants with NAS. The second author is a prenatal health behavior researcher with experience in qualitative data analysis. In the first phase, to familiarize ourselves with the data, the first two authors read interview documents several times along with abstracted medical, obstetric, and infant data. The second phase of data analysis consisted of organizing data, including generating initial codes, searching for themes, and reviewing and naming themes. Interview data were initially organized based on the experience of pregnancy, birth, and postpartum periods (including care of the newborn), and infant care (up to 1 year). First, the two authors coded interviews independently; codes with similar meaning were grouped into themes within each perinatal stage. Then, we met in person to resolve coding and theme naming discrepancies. In the third phase of analysis, two additional authors reviewed codes and themes: a neonatologist with experience in qualitative research and the FIMR process and the coordinator of the local FIMR program. These two team members verified whether they

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could follow the analysis processes (dependability) and commented on whether the themes in each stage were meaningful to individuals in clinical and public health practice (transferability). Discrepancies in this phase were resolved by group discussion via email. Data saturation was reached in each theme.

## Results

### Participants

The sample consisted of 11 participants (Table 2). The participants ranged in age from 18 to 36 years. Most were White (n = 8), single (n = 9), and with less than high school educations (n = 7). Nine participants used opioids exclusively, and two reported or tested positive for polysubstance abuse. Four participants used prescription opioids for chronic pain, one participant was in a drug rehabilitation program using methadone, and five participants used opioids illicitly. Three deaths occurred before birth (intrauterine fetal demise), three during the neonatal period (first month after birth), and the remaining five in infancy (one month to one year after birth). Six deaths were related to prematurity or congenital/genetic abnormalities, and five were caused by sudden unexpected death, pneumonia, placental abruption, or unknown causes.

{Insert Callout #2}

### Themes

Five themes were identified that represented the experiences of participants. The themes were: 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, placing blame and guilt over death.

***Frustration and anger related to not being heard, feeling minimized***

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Many participants voiced their frustration that care providers did not listen to their concerns during pregnancy or the infant's illness. They wanted care providers to value their input and experiences. They also wanted care providers to "listen to" and "pay attention to" them: "My baby could have been saved if my prenatal doctor would've listened to me and paid attention to me." "I think if they looked more into what I was going through my loss could have been prevented."

"I took her to the clinic multiple times...and the doctors kept saying she was fine and not to worry about it. Then in May, I took her to get her shots and the next thing I know she's dead."

Some participants stated that providers did not ask what they wanted regarding their infant's care. Some participants felt they knew something was wrong, but care providers did not listen to their concerns: "I knew something was wrong. They never listened to me. They were all against me, and never asked what I wanted." "If my prenatal doctor would've listened to me and paid attention to my extremely high blood pressure; took my son... when I begged her to because I had pre-eclampsia and my son's heartbeat was only 118."

Some participants felt "upset" because they were not adequately informed about complications and medical treatment. They were not allowed to fully participate in care decisions. If explanations were offered, they did not facilitate the participant's understanding. The lack of information and communication frustrated the participants and contributed to their feelings of being ignored and marginalized in making care decisions:

"Everything was going okay, not great, but okay. Then one day they told me that they removed the breathing tube, without my permission. He didn't like it, and they had to put it back in. When they put it back in, they punctured a lung and

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messed everything up. We had no idea what was going on, and all of sudden they handed me my son and said he was dead. I called the father, he was driving home from work, and I told him I was holding our dead baby. We had no idea what happened. I was so upset. I needed to get out of there.”

### ***Being overwhelmed with attempts to process and understand medical complications and outcomes***

Some participants had preexisting medical problems (e.g., hypertension, obesity, sexually transmitted infection, hypothyroidism, sickle cell trait) and pregnancy complications, such as vaginal bleeding, placental insufficiency, or chorioamnionitis. Some participants also reported behavioral health issues such as bipolar disorder, anxiety, depression, and schizophrenia. These medical and behavioral comorbidities added complexity to their prenatal care and often required referrals. “I went from jail to the mental hospital, and they put me on a medication called Lurasidone that killed my baby. With my other children, I wasn’t taking no medication, and nothing like that happened.” “My OB saw me while I was in the hospital and decided to transfer me to another hospital because they didn’t know what else to do. I had two blood transfusions, and they stopped the magnesium.”

It was sometimes difficult for participants to identify physical signs of complications such as preterm labor. Some were seen and evaluated and sent home. As a result, they did not know whether they were actually in labor when the pain recurred. “I was having pains in my side and didn’t realize I was having contractions until I got to the hospital.” “I stayed home until the pain became unbearable and then went back to the hospital.”

Other complications during pregnancy were also common in the participants. Thoughts about hemorrhage, placental problems, and pregnancy-induced hypertension worried some

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mothers and increased their anxiety levels. The participants reported being anxious about their treatment, being transferred to another hospital, being told of the need for a cesarean birth, and uncertainty of the baby's survival. "She was born two weeks before that time she could live. Her heart and lungs were underdeveloped. They said she might make it and might not." "I went to the hospital and was bleeding everywhere. Pool of blood. They said my daughter swallowed it."

### *Profound sense of grief and coping with loss*

Participants struggled to deal with grief. They expressed "how lost I feel about losing him" and "this is a very hard thing to go through." Some participants wished "there was something you can do" to bring back their infants. Others thanked God for having other children who were alive. "Do you know how hard it is to deal with this after having him inside you all these months and then touching his hands and feet? This has been the worst 5 months of my life." "That is a very hard thing to go through, and you still wish there was something you could do." "...just how lost I feel about losing him and how lost I am without him! I just thank God for my other sons."

Participants talked about the support they received during the experience with grief. Some expressed appreciation for bereavement services, such as booklets on bereavement, molds of handprints and footprints, or photographs. Others experienced frustration and disappointment because they did not receive enough support or resources. Participants also expressed receiving various degrees of professional bereavement support. Some had begun counseling with a psychiatrist or were considering grief support groups. "Everyone at the hospital was excellent. They made molds [of my baby's hands and feet]. I was worried that I couldn't afford to bury her, so they let me talk to the trustee."

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“I am seeing [a] psychiatrist right now for my grief. I think it is helping. I am not ready to talk to people about it in a group or talk to other people. It’s just too hard, and I am not ready.”

Some participants had difficulty managing their grief and others actively made plans for closure through a “memorial service” for their baby, spirituality, and family support. They sought validation for their feelings of grief and loss but sometimes felt pushed by family and friends to move on. “We had a memorial service for him and buried him at the cemetery... We are doing okay with the loss; we have a lot of family.” “Can I ask you something? People tell me the more I talk about her, or keep wanting to celebrate her birthday; I will never get over her ...Do you think it is okay to celebrate her birthday?”

### *Need to understand why and make difficult decisions*

Participants expressed that they were adept at recognizing changes in their infant’s health status (e.g., coughing and throwing up or not breathing) particularly after hospital discharge. They sought medical attention and explanations. However, there were times some participants had to make difficult decision about care and treatment. “My baby did good at first. When he was 3 and half or 4 months old I noticed he couldn’t open his hand or sit up straight.” “I took her to the hospital and clinic multiple times because she was coughing and throwing up.” “I called out for someone to call 911 and started CPR, but it was already too late.” “His father and I decided to take him off the machine.”

Participants wanted to understand and make sense of their infant’s death. Knowing how and why their infant died seemed to offer them a “closure.” Knowing the cause of infant death was also important for them to understand implications for future children. They also wanted reassurance that their care, as a parent, and the health care provided was sufficient as “they did

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what they could for her [infant].” “Well, at least now we have closure. I wish someone had told us sooner; we have been going nuts not knowing.” “Now I know he did die because of sleep apnea.” “They said she had a tube defect and it was an encephalocele, and she couldn’t live.” “I don’t remember the name of the condition he had, but the doctors said it was genetic.”

### *Placing blame and guilt over death*

Participants responded to infant death with two reactions. Some blamed health care providers because “they are responsible for her [infant] death.” Others blamed themselves for the infant’s death and believed that if they had done something to help the baby, the death would not have occurred. “I believe the OB doctors should be checked out. My baby could have been saved ...” “I wanted to sue the hospital and clinic because they are responsible for her death.”

At times, pressure from family and friends precipitated feelings of self-blame and guilt. Occasionally, participants turned the blame to themselves and searched for how they might have prevented the death. “If we had used the monitor he might be alive. I wish we had kept on using the machine anyway.” “When I woke up, I knew something was wrong. I freaked out. So I told everyone she dies in her crib. But she was in bed with me. I tell everyone I know, see with a baby, everyone- not to sleep with their baby.” “All my friends and family thought I killed my baby. They kept saying I smothered her and stuff. My mom was real angry, but she was also crying.”

## **Discussion**

Our results indicate that women who used opioids and experienced infant/fetal loss had complex needs which were often unmet. Of note, participants in our study repeatedly voiced concerns about not being heard, being ignored, and being undervalued. These concerns may be related to the stigma of addiction; however, it is also likely that they may have been exacerbated

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by participants' anxiety about their high-risk conditions and frequent urgent medical treatments. The perception that their feelings were minimalized could also reflect their frustration and helplessness over the deaths of their infants. In previous studies on addiction, women expressed feelings of stigmatization from family, friends, society, and health care providers (Chandler et al., 2013; Earnshaw, Smith, & Copenhaver, 2013; McGinty, Goldman, Pescosolido, & Barry, 2015). If allowed to develop, these perceptions of stigma can create a lack of trust in individual health care providers and the health care system and serve as barriers to accessing care (Casper & Arbour, 2013; Winklbaaur et al., 2008).

Many participants in our study had difficulty understanding why devastating medical complications occurred for them and their infants and often felt the communication from health care providers was inadequate, incomplete, or difficult to understand. This problem of incomplete understanding may be caused partially by the stress and uncertainty of the situation itself, but also may reflect a lack of communication skills among health care providers (Pozzo, Brusati, & Cetin, 2010). Several previous studies conducted with patient populations facing high stress and complex medical situations, such as cancer or high-risk pregnancy, have indicated the need for standard protocols and practice in delivering bad news (Pozzo et al., 2010). In the context of maternal opioid users experiencing fetal and infant complications, providers could also be helped in their regular communication by training on how to deal with the mothers' emotional reactions and the mother's need to be well informed. Communication would be enhanced if health care providers created illustrations and provided information in clear and simple terms. Mothers who report satisfaction with the information they receive are better prepared to take action and make good decisions (Makary, 2015).



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Dealing with grief, guilt, and blame was an ongoing process for participants from the first time infant complications were identified through the infant's death and months later. Although every mother grieves in her own way, lack of support may prolong grief (Badenhorst, 2007; Cacciatore, Schnebly, & Froen, 2009; Kersting & Wagner, 2012). Moreover, the perinatal loss can be a trigger for addiction relapse (Smith, 2009). Bereavement support can help mothers with fetal/infant loss acknowledge their feelings of guilt over blame and the added burden of stigmatizing addiction (Bennett, Litz, Lee, & Maguen, 2005; Murphy, Shevlin, & Elklit, 2014).

Anger and blame towards others, or self is a typical reaction after a perinatal loss, particularly when mothers feel unsupported or uninformed (Badenhorst, 2007; McCright, 2008; Cacciatore, Frøen, & Killian, 2013). Providers need to recognize that grief may be expressed in many ways, including blaming others. Blame is a normal aspect of grief in perinatal loss and many mothers blame themselves for their loss which may be a barrier to resolution of grief (Cacciatore, 2013). However, our participants turned blame toward themselves with less frequency than in general perinatal grief studies (Badenhorst, 2007; Kersting, 2012)). Blaming others may represent an abnormal grief reaction related to the need to minimize implications of substance use. Regardless of the reason, providing support and counseling is essential.

### **Limitations**

The use of secondary data analysis provided only a narrow window into the care experience of the mothers. The FIMR interview was constructed for a specific purpose of identifying multiple maternal and infant healthcare, social, and community service issues. We were unable to clarify participants' care experience with additional interview questions. We were also unable to explore specific care experiences regarding methadone use or other drug treatment during pregnancy. The interviews were not recorded on audio or visual media. Although

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extensive written notes were completed based on the FIMR protocols, written notes might not have captured all information given by each interviewed mother. The range of time between the loss and the interview (3.5 to 10 months) is also a possible limitation. Grief is an individual experience and mothers interviewed soon after their infant's death may report a very different experience than those interviewed several months later. Unique perspectives related to opioid use and dependence may also affect the grief experience.

The secondary data analysis also prevented us from conducting member checks. Member checks reviewing the themes identified with the participants would have helped validate our findings. Our study was limited to a small number of women in one local FIMR program. Further study is needed to determine whether our findings are similar to those from other women with opioid use who experience a fetal/neonatal loss.

### **Implications for Practice**

Our findings indicated that health care providers need to partner with women who use opioids designing care and making treatment decisions that acknowledge their needs, perceptions, and satisfaction (Wolf, Lehman, Quinlin, Zullo, & Hoffman, 2008). Such a partnership fosters respect, shared decision making, and a caring environment where the concerns of mothers who use opioids can be addressed. This partnership focus also encourages care providers to be sensitive to the needs of these women to help reduce the perception of stigmatization and increase the perception of being valued.

The need for health care provider education and training in effective and sensitive communication is evident from this study. The participants' perception was that caregivers who did not listen to them, minimized their feelings, and were unsupportive, contributed to their pain, guilt, and bereavement experience. Projecting acceptance, accessibility, and readiness to

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listen is essential, as well as providing understandable medical information about the care provided and procedures performed (Fleischer, Berg, Zimmermann, Wüste, & Behrens, 2009). It is important to understand communication is bidirectional and the patient's interpretation of the message may be very different than the nurse's or other provider's intended message (Kourkouta & Papathanasiou, 2014). It is also necessary to continually assess the mother's knowledge and confirm understanding of health information given.

Comprehensive multidisciplinary care models may provide opportunities for care providers from different disciplines to develop coordinated care plans for opioid-using mothers and their infants, as well as to enhance communication among care providers. Continuing education programs or conferences could emphasize multidisciplinary aspects of care for the mothers with opioid use.

Bereavement support and counseling is particularly important for the mothers who use opioids and experience perinatal or infant death. Such support and counseling may need to be long-term in order to resolve the mothers' reactions of guilt, anger, and blame. There is a need to improve patient-provider communication and to address both individual and systems failures which may lead to poor outcomes through formal review processes such as FIMR and Child Death Review programs.

{Insert Callout #3}

### **Recommendations for Future Research**

Further exploration of this topic could best be accomplished with a phenomenology approach using open-ended interviews. This would provide a richer and more complete description of the participants' experience. More focused exploration divided by the timeframe

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of the loss (fetal, neonatal, or infant) may also aid in theory development, as well further defining guidelines for effective practice.

### **Conclusions**

The rapid increase in opioid use among pregnant women has led federal agencies to demand more research to determine best practice for caring for affected women and infants. We examined the care experiences of women who used opioids throughout pregnancy and experienced fetal or infant loss. Five themes were identified: not being heard, or feeling minimized, being overwhelmed with attempts to process and understand medical complications and outcomes, a profound sense of grief and coping with loss, a need to understand why and make difficult decisions, a need to place blame and assign guilt over death. The study findings suggest interdisciplinary team care, partnership in decisions, provider training for skillful communication, and emotional support for mothers with opioid use and pregnancy or infant loss.

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## FIMR Narcotic Users

Table 2: Demographics, Drug Use History, and Obstetric History for Study Participants (N = 11)

Variables	n (%)	Variables	n (%)
Age (years), Mean (SD) Range: 18 - 36	25 (7.27)	Number of Pregnancies, Mean (SD) Range: 1 - 6	3.45 (1.97)
Ethnicity		First Pregnancy	
African American	3 (18)	No	10 (77)
White	8 (72)	Yes	3 (23)
Education		Timing of Perinatal/Infant Death	
Less than high school	7 (64)	Fetal stage	3 (27)
High school	2 (18)	Neonatal stage	3 (27)
Master/PhD	2 (18)	Infant stage	5 (45)
Marital Status		This Pregnancy Planned	
Married	2 (18)	No	4(36)
Single	9 (82)	Yes	3 (27)
		Unknown	4 (36)
Tobacco Use		Health Insurance	
Yes	8 (73)	Medicaid	9 (82)
No	2 (18)	Private	1 (9)
Unknown	1 (9)	None	1 (9)
Maternal Opioid Use		Reasons for Fetal/Infant Death	
Prescription (1 methadone treatment)	6 (55)	Prematurity	4 (36)
Illicit	5 (45)	Congenital Anomalies	1 (9)
		SUIDS/ Suffocation/Apnea	2 (18)
		Genetic Syndrome	1 (9)
		Pneumonia	1 (9)
		IUFD (abruption)	1 (9)
		Unknown	1 (9)

*Note.* IUFD: intrauterine fetal demise; SUIDS: sudden unexpected infant death.