

# Contextual risk and psychosocial profiles of opioid-using mothers: A mixed-methods study

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## Abstract

**Introduction:** There is an increase in cases of mothers using opioids during pregnancy in the United States but research investigating mothers' psychosocial environments along with individual variability among this high-risk group of women is scarce.

**Methods:** This mixed-methods study aims to examine the complex interplay of contextual risks and experiences of opioid-using mothers. A sample of 50 opioid-using biological mothers of infants diagnosed with neonatal opioid withdrawal syndrome (NOWS) were studied using a set of standardized and open-ended questions, along with medical records extraction.

**Results:** A high-risk subgroup of 36 mothers was identified using cluster analysis, characterized by a distinct profile of psychosocial risk. Thematic content analysis revealed four themes: (1) barriers to communication and mistrust of health professionals, (2) limitations of access to health care and the amplification of disadvantages related to COVID-19, (3) lifelong consequences of adverse childhood experiences (ACEs), and (4) intimate partner violence and its influence on drug use.

**Conclusion:** Our findings highlight important information toward health services provision for opioid-using women of childbearing age. Efforts to reduce opioid usage in mothers need to consider psychosocial and contextual risks.

## Keywords

adverse experiences, contextual and psychosocial risk, in-utero opioid use, poverty

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## Psychosocial and contextual risk profiles of opioid-using mothers

### Opioid use

Within the past 10 years, the United States have seen a stark increase in rates of opioid use. As a result, the incidence of neonatal opioid withdrawal syndrome (NOWS) has risen drastically.<sup>1</sup> Between 2018 and 2019, an estimated 11.8 million Americans used opioids while 2.1 million Americans met criteria for opioid use disorder (OUD).<sup>2</sup> Opioids may be prescribed to manage pain; however, their use may quickly lead to dependency. Accordingly, when individuals attempt to discontinue the use of opioids, strong withdrawal symptoms can occur such as irritability,

anxiety, agitation, insomnia, severe pain, abdominal cramping, and nausea, leading to continual use.<sup>3,4</sup>

Opioids have profound effects on all users, yet mothers and infants are of a particular public health concern due to

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the dramatic increase in NOWS cases. NOWS is a significant problem in East Tennessee, with a rate of 1.35% of all live births.<sup>5</sup> Infants born with NOWS experience symptoms such as hypertonia, irritability, tremors, seizures, and respiratory distress.<sup>6</sup> NOWS (or neonatal abstinence syndrome, NAS) is a reportable condition in Tennessee and in the Appalachian region, and opioid-using mothers are at risk to lose custody for their infant, in particular if they are using opioids without prescription or along other illicit drugs.

### *Contextual factors*

General risk factors for opioid use include clinical depression, pain, and poly-drug use.<sup>7</sup> However, very few studies have investigated specific contextual factors that may explain the high opioid usage rates in certain regions, such as rural Appalachia. For instance, poverty and limited access to education have been found to contribute to the increased use of opioids.<sup>8</sup> Moreover, women who are living in rural areas are more vulnerable to certain stressors that can contribute to addiction such as lack of access to healthcare and transportation, increased loneliness, and socioeconomic insecurity.<sup>9</sup> As a consequence, areas with high poverty and unemployment rates tend to have higher rates of opioid use.<sup>10</sup>

### *Psychosocial factors*

Women who were exposed to adverse childhood experiences (ACEs) are at a high risk for developing mental health issues.<sup>11</sup> In addition, contextual factors such as poverty and lack of resources lead to increased psychosocial risks, including depression, anxiety, and violence, which in turn may lead to drug misuse.<sup>9</sup> It has been proposed that this is a vicious cycle where a composition of risk factors and drugs such as opioids may allow users to “escape” from their demoralizing daily lives.<sup>9</sup>

Studies have shown that individuals suffering from opioid dependence harbor feelings of shame and fear of others finding out about their dependence on opioids, further reinforcing the stigma around having a substance use disorder.<sup>12</sup> Frazer et al.<sup>13</sup> explored motivational factors and barriers in pregnant women with substance use disorders to seek care and treatment during pregnancy. Findings from this study revealed that most of the women were ready to discontinue using and were concerned for the well-being of their infants, but they feared losing custody of their children, were concerned about the stigma surrounding substance use disorders, and oftentimes did not have transportation to travel to places that offered the regular care they needed.<sup>13</sup> Similarly, Paris et al.<sup>14</sup> studied the process of disclosure to substance misuse in a population of pregnant women who were seeking prenatal care. The findings of this study showed that women with substance

use disorder felt shame and guilt regarding the disclosure of their disease.<sup>14</sup> Studies have also shown that, on average, women experience greater stigma for substance misuse than men.<sup>15</sup> As a direct consequence, following childbirth, opioid-using mothers in Tennessee are in a particularly vulnerable position, facing tremendous rates of stress and worry largely due to the reportable condition of NOWS and their infants' neonatal intensive care unit (NICU) treatment.

### *Opioid-using mothers in rural Appalachia*

Although the opioid epidemic is widespread throughout the country, rural Appalachia is struggling with a particularly high number of NOWS cases.<sup>16</sup> Appalachia extends to sections of Alabama, Georgia, Kentucky, Maryland, Mississippi, New York, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Virginia, and West Virginia. Those residing in this region have challenges that are unique to rural communities when compared with the rest of the country.<sup>17</sup> In line with the general factors related to use of opioids outlined above, four specific characteristics put women in Appalachia at increased risk of opioid use: poverty, distrust of outsiders, geographic isolation, and high rates of interpersonal violence.<sup>17</sup>

First, rural Appalachia has an extensive history of impoverishment due to its historical origin, exploitation of resources, and the unequal access to land within the region.<sup>17-21</sup> Accordingly, poverty rates in Tennessee are substantially higher among many eastern, rural Appalachian counties than they are for the rest of the state.<sup>16</sup> Research suggests that growing up in poverty and in neighborhoods low on resources has lifelong implications, including poorer physical and mental health, substance misuse, and depression in adulthood.<sup>22-24</sup> Not only do many residents of Appalachia experience poverty during their childhood, but there is also a lack of professional opportunities within the region.<sup>25,26</sup> Commonly, employment offers in the region are temporary, part-time, low-paying, and do not cater to those who have children.<sup>25,26</sup> Thus, women in rural Appalachia are at a structural disadvantage and are highly vulnerable.

Second, within Appalachian culture, there is an emphasis on the importance of kinship ties, self-sufficiency, and independence, which has been shown to create a culture in which outsiders are not easily allowed access.<sup>17-21</sup> Along with the frequent experience of ACEs, this creates barriers that make it difficult for Appalachians to trust outsiders, including medical professionals.<sup>24,27</sup> Furthermore, this cultural aspect of distrust of medical professionals may be attributed in part to a fear of stigma.<sup>15</sup> Distrust in medical professionals often leads to being less willing to seek help and follow medical guidelines.<sup>24</sup>

The third critical characteristic that puts women at increased risk of opioid use is that Appalachia is

geographically isolated and lacks critical infrastructure. Accordingly, accessing modes of transportation proves challenging and rehabilitation centers tend to be a long drive from where opioid-using women live, making it exceedingly difficult for them to make and keep medical appointments.<sup>17,28</sup> A study seeking to understand barriers for treatment among women from Appalachian Kentucky found that 49% of study participants were unable to receive treatment because treatment centers were not easily accessible.<sup>15</sup>

Finally, Appalachian women are at high risk for interpersonal violence.<sup>29</sup> More specifically, Shannon et al.<sup>29</sup> found that among a population of 114 pregnant women from rural Appalachian Kentucky, 75.3% had experienced intimate partner violence (IPV) within the past year and 71.4% had recently experienced psychological abuse.

Taken together, the characteristics of Appalachian culture and the minimal available literature do suggest that these barriers put Appalachian women at an increased risk of anxiety, depression, and other mental health issues that further exacerbate a general risk for opioid use.<sup>9</sup> However, there is a gap within the literature about the underlying mechanisms of this structural and potential transgenerational vulnerability. Ultimately, understanding the experiences of opioid-using mothers in rural Appalachia may help develop novel interventions that can disrupt the vicious cycle of opioid use.<sup>30</sup> Therefore, the purpose of this mixed-methods study is to contribute to the limited literature on opioid-using mothers by learning more about their experiences and examining the psychosocial and contextual risk profiles of opioid-using mothers in rural Appalachia.

## Theoretical framework

The present study is grounded in a biopsychosocial framework. The biopsychosocial framework suggests that behaviors, thoughts, and emotions may influence a person's physical state.<sup>31,32</sup> In this regard, we are including psychological and social factors and their dynamic relationships with biological functioning while also considering multilevel effects of different systems such as neurobiology, physiology, psychology, and social aspects on developmental pathways.<sup>33</sup> Biopsychosocial frameworks offer multidisciplinary explanatory mechanisms by integrating theories from the social and medical sciences.<sup>34</sup> Understanding the contributions of different biological and environmental factors such as genetics, in-utero exposures, and postnatal environmental experiences to individuals' life-course trajectories is critical in informing intervention efforts. For instance, biopsychosocial studies propose that *biological* compared with *environmental* adversities may affect development via different pathways,<sup>35–37</sup> and effects may be additive or interactive.<sup>38–40</sup> Importantly, very few studies examine the complex interplay of contextual risks

and how these affect the experiences of the study participants. We propose that a biopsychosocial framework applied to a mixed-methods design may help integrate multimodal and multidisciplinary theoretical aspects such as social adversity and maternal psychopathology.<sup>30</sup>

## The current study

The current mixed-methods study examined contextual and psychosocial characteristics of a high-risk sample of opioid-using mothers of young infants diagnosed with NOWS in East TN. Specifically, we answered the following research questions:

1. What are the contextual and psychosocial factors that characterize opioid-using mothers' specific risk profiles?
2. What are the experiences of opioid-using mothers with high-risk profiles?

## Method

### Procedures

As part of a prospective follow-up study of infants exposed to opioids in rural Appalachia, biological mothers of infants diagnosed with NOWS were initially recruited within 2 weeks of birth between December 2018 and March 2020. Study procedures were approved in 2018 by the Institutional Review Board of East Tennessee Children's Hospital (ETCH IRB #254). All participants provided written informed consent for participation in this study for themselves and for their infants' longitudinal medical records data, including follow-up clinic assessments to be extracted. Biological opioid-using mothers who had custody of their infants were recruited in person while their infants were treated in the neonatal intensive care unit (NICU) for NOWS. Exclusion criteria consisted of (1) infant gestational age below 32 weeks, (2) non-English-speaking caregivers, (3) infants diagnosed with HIV, (4) infants diagnosed with FAS (fetal alcohol syndrome), and (5) infants with severe congenital abnormality. These exclusion criteria were chosen due to documented confounding mechanisms with regard to long-term infant development.<sup>41</sup>

Due to the vulnerability with regard to contextual and psychosocial risk factors and uniqueness of this population, the research team participated in cultural sensitivity training and steps to recruit participants.<sup>41</sup> Our recruitment hours were adapted to best fit the schedules of this vulnerable population and were unconventional to what we see in traditional research. Our research team regularly went to the NICU from 9:00 to 11:00 p.m. because we learned that caregivers were more likely to visit their

infants at these times due to structural and geographical barriers such as lack of transportation. Our team of interviewers was composed of self-identifying female researchers who at the time were completing graduate programs and tenured faculty members in the fields of psychology and family studies. The two faculty researchers hold doctorate degrees, one of the interviewers holds a Master of Science degree, and two hold Bachelor of Science degrees. Additional undergraduate interviewers were supervised by the graduate students and one faculty member. Each interviewer had a minimum of 2 years of experience working in research. Because our participants did not have any previous relationships with our interviewers, an important step taken during data collection was to have each infant's designated neonatal nurse introduce our interviewers to caregivers who met criteria for our study.<sup>41</sup> The neonatal nurses explained the goals and tasks of the study to the participants and then asked whether our interviewer was allowed to talk with them. Once a prospective participant agreed to meet the interviewer, the interviewer would introduce herself and explain the study, goals, and their position within the study. The interviewer then asked the prospective participant whether they were interested in participating in the study. If the participant said yes, the interviewer handed them a consent form and read it out loud to them. Participants were then asked to look through the consent form themselves and ask any questions they may have. If participants did not have any questions or once all questions were answered, they were asked to sign the physical consent form and hand it back to the interviewer. The interviewer then handed the participant a copy of the consent form for them to keep. These steps allowed us to help build trust and rapport with the participants. Due to the vulnerability of the study population, we are not allowed to provide details about the few participants who refused nor their specific reasons for refusal.

For the purpose of the study, data collection consisted of a verbally administered questionnaire containing standardized instruments followed by six open-ended questions, which altogether lasted approximately 20–60 min. Those participants who decided to share more of their personal experiences took longer than 20 min to complete the open-ended questions. Participants were interviewed in their family's private room in the NICU or in a private area in the hospital patients' lounge, thus ensuring confidentiality of responses. Responses to the open-ended questions were recorded in writing by the researchers. Researchers also made separate notes regarding the interview process such as participants' tone of voice, body language, and movements. The individual standardized and open-ended questions that were read out loud to them served to capture the experiences of the participants to better understand their life experience with opioids. Open-ended responses were then transcribed, and field notes

were expanded once the researchers arrived at the research lab. In addition, we gathered written responses and data from extracting medical records. These records contained written notes from doctors, nurses, and from their assigned hospital social workers regarding their interactions with the mothers. The notes were used to further learn about the experiences of these mothers.

Interviewers provided participants with light refreshments approved for the NICU, such as their choice of soda or bottled water, and chewing gum, candy, or both. Participants received a \$10 gift card as compensation for answering a set of standardized and open-ended written questions, including items assessing demographic data as well as contextual and psychosocial risk factors (i.e. ACEs, depressive symptoms, and emotional/physical abuse). Detailed obstetric, perinatal, and postnatal characteristics, including NICU nurses' and social work reports, were obtained from infant medical records after discharge, and longitudinally throughout infants' first years of life.

All physical data were stored in a locked research lab and in a locked file cabinet where only members of the research team had access. The physical data were then transcribed, digitized, and stored in password-protected files within a password-protected drive only accessible to the research team. All data were de-identified and assigned a number to ensure confidentiality. Member checking was not possible for this study due to the challenges of communication with the participants such as them not having cell phones, changing their phone numbers often, not having cell phone service, not responding to postal mail, or not having an email address.

## Participants

The present study includes data from  $N=50$  biological opioid-using mothers of newborn infants who were formally diagnosed with NOWS. Of these,  $n=36$  who were identified via cluster analyses (described below) to have specifically high contextual and psychosocial risk profiles were included in the qualitative analysis.

## Measures

*Demographic and contextual factors.* The demographic background questions screened for age, race, education level, finances, family composition, living arrangements, and other contextual information such as previous imprisonment and loss of custody for older children. Example questions included "What is the highest level of education you have completed?" and "Who else is living with you and what is your relationship to them?"

*Psychosocial risk factors.* Mothers' psychosocial risks were assessed with a combination of different established

self-report instruments that measure depressive symptoms, abuse, and ACEs.

**Depression.** Depressive symptoms were assessed using the 20-item version of the CES-D WHO (Center for Epidemiologic Studies Depression Scale–World Health Organization) depression screening.<sup>42</sup> Mothers were asked to rate feelings over the past week from 1 (*rarely or none of the time*) to 4 (*most or all of the time*). Items included statements such as “I felt that I could not shake off the blues even with help from my family or friends” and “I felt hopeful about the future.” While CES-D scores > 15 indicate a clinically relevant risk for a depressive disorder, continuous sum scores were used for analyses.

**Emotional and physical abuse.** Mothers’ current experiences of emotional and physical abuse (i.e. experiences of IPV) were assessed using four items from the Abuse Assessment Screening.<sup>43</sup> Items included yes and no questions such as “Have you ever been emotionally or physically abused by your partner or someone important to you?” and “Within the last year, has anyone forced you to have sexual activities?”

**Adverse childhood experiences.** Mothers’ ACEs were assessed using 10 binary-coded items from the ACEs scale.<sup>44</sup> Items included statements such as “Were your parents ever separated or divorced?” and “Did you live with anyone who was a problem drinker or alcoholic or who used street drugs?” Responses were summed into a cumulative ACEs score.

### Analysis strategy

For the purpose of this study, interview-based self-report data and medical records were included as combined data sources to understand opioid-using mothers’ contextual risk profiles. The use of multivocal and multimodal data sources and methodologies ensured triangulation of the data and created rich descriptions.<sup>45</sup> This is a strategy that helps bridge narratives and contributes to the triangulation of research data.

SPSS 27 was used for the quantitative analysis. Multiple variables were entered into cluster analyses and evaluated as part of a stepwise model-fitting approach. The goal of cluster analysis was to identify relevant variables that help group participants who shared similar characteristics (e.g. high risk). We applied the principle of statistical parsimony to evaluate cluster fit, so that the final set of included variables would be as few as possible while explaining a large amount of variation in participants’ cluster membership. Mothers whose risk profiles identified them as most vulnerable were then selected for inclusion in qualitative analyses.

Qualitative data from open-ended interview responses to the question whether mothers wanted to share anything about themselves or their families along with detailed information from infants’ medical records were collected and placed into a de-identified file that was accessible to the research team. A codebook was created containing a list of a priori codes along with clear descriptions of the codes to be used in the subsequently following cycles of coding.<sup>46</sup> Data were coded by K.B.-A. and K.H. in agreement with the co-investigators using the constant comparative method. Similarities and differences were noted to document how codes were understood and represented.<sup>46</sup> Using an iterative cycle, codes were organized, revised, and repeatedly compared across the data to form categories until no further themes emerged. Data saturation was reached. Categories were analyzed through the frequent, precise, and continuous reading of the data. All possible meanings of the data were considered and categories were organized into themes. Thus, by reviewing and comparing categories in terms of their features and dimensions, they were reduced into more inclusive themes. Thematic analysis as an independent qualitative descriptive approach is mainly described as “a method for identifying, analyzing, and reporting patterns (themes) within data.”<sup>47</sup> As a final step, axial coding was conducted to explore interconnectedness among themes.<sup>48</sup>

### Trustworthiness

Trustworthiness in qualitative and mixed-methods research is the degree to which qualitative findings are supported by evidence and can be trusted.<sup>49</sup> This was achieved in five ways. First, qualitative study participants were nested in a larger sample and selected intentionally using an evidence-based stepwise cluster analysis that identified mothers with high psychosocial risk profiles. Second, several research team members were natives of the rural Appalachian region which helped increase the cultural sensitivity of the team. Third, all research team members were included throughout the development and analysis stages of this study which helped assure consistent interpretation of data. Specifically, all members of the research team were trained on coding methods until they achieved interrater reliability.<sup>46</sup> In addition, data were read and independently coded by each research team member, coding was reviewed and compared by K.B.-A. and K.H., and responses were counted and checked. Third, K.B.-A. thoroughly documented the data analysis process to record methodological decisions throughout the study and this process was monitored by J.J. Fourth, reflexivity and reflection are essential components of qualitative research<sup>50,51</sup> and were integrated into research activities and coding cycles, with the goal of acknowledging and reflecting on individual biases that may influence

interpretations of the data. Fifth, trustworthiness was established by utilizing participants' direct quotes in the findings.

### Subjectivity

As researchers, it was important to discuss previous experiences with the research topic and population as well as power dynamics within research to lay the foundation for illuminating our subjectivities and explore how those experiences had shaped the interest in the study. Steps were designed to minimize the biases in this study, such as holding weekly meetings, having open conversations with the research team regarding this ongoing experience, having time to reflect and write, and holding cultural sensitivity training sessions. There is not one simple solution to eliminate error and bias; however, the data collection and analysis were carefully thought through and conducted in a manner to ensure that any bias was limited. As such, the lead interviewer of the research team, K.B.-A., wrote the following positionality statement:

I am a Latinx doctoral student who has experienced micro-aggressions and racism as a member of our community. Through these experiences, I have developed a critical lens and a social justice approach in my research. My perspective and interest in this study builds upon my social justice lens for marginalized groups. I identify bias towards believing that power dynamics and systematic oppression create further barriers for marginalized communities; thus, hindering their progress and success. The data collection and analysis were carefully thought through and conducted in a manner to ensure that any bias is limited. Additional steps such as coding with my research team and having regular discussions regarding study design, and interpretations are designed to minimize the bias in the study. While research bias will always be present, these strategies were employed in an attempt to increase trustworthiness and demonstrate transparency.

## Findings

### Quantitative results

Table 1 shows descriptive characteristics of the  $N=50$  opioid-using mothers of newborn infants with Nows included in this study. Mothers in this study were on average 28.60 ( $SD=4.83$ ) years old and 94% self-identified as White. Monthly family net income was self-reported to range from \$200 to \$7500 ( $M=\$2387$ ,  $SD=\$2059$ ). The largest subgroup of mothers (34%) was "unemployed but not looking for work"; 68% were married or living together with their romantic partner. On average, the mothers in our sample had 2.42 ( $SD=1.25$ ) children, including the infant they had recently given birth to. A total of 30% reported to not have custody for one or more of their previously born children. With regard to contextual and psychosocial

stressors, 72% reported to have been emotionally or physically abused and 28% reported that they had been physically hurt by their husband or romantic partner. Mothers reported up to 10 ACEs, with an overall average ACEs score of 4.52 ( $SD=3.35$ ). Seventy-eight percent of mothers received a clinically relevant screening for depression (i.e. CES-D total score above 15) and the CES-D average score was 21.84 ( $SD=13.21$ ).

Multiple variables containing information on contextual and psychosocial risk factors were entered into cluster analyses and evaluated as part of a stepwise model-fitting approach. The final cluster analysis converged around a simple two-factor model of high versus low risk, including three indicator variables: ACEs, depressive feelings, and recent experiences of emotional or physical abuse, that is, IPV (Akaike information criterion (AIC)=101.685). The distribution of psychosocial risks was characteristically different between mothers in the high- versus low-risk clusters (i.e. *mean* ACEs=5.22 vs 2.41, *mean* CES-D=25.19 vs 12.63, abused=100% vs 0%). We explored external validity of the risk clusters using correlation and regression analyses. Results of these analyses indicated that mothers in the high-risk cluster had higher daily opioid prescription dosages than mothers in the low-risk cluster ( $r=0.54$ ,  $p=0.006$ ). With regard to Nows infants' perinatal outcomes, having a mother in the high-risk cluster was associated with lower 1-min APGAR scores ( $\beta=0.34$ ) and higher morphine treatment dosages ( $\beta=0.35$ ), after controlling for known confounders gestational age and sex.

### Qualitative findings

Table 1 shows descriptive characteristics of the  $n=36$  mothers with high-risk profiles who were subsequently included in the qualitative part of the analysis. Although their descriptive characteristics were very similarly distributed compared with the total sample, they had significantly higher rates of ACEs, CES-D scores, and IPV, as described in the cluster analysis above. Thus, they can be considered as a high-risk subgroup nested within the total sample that is likely representative for the population of opioid-using mothers in rural Appalachia. Their experiences are described in detail in the following section.

Four major themes were identified in relation to contextual and psychosocial risk factors: (1) barriers to communication and mistrust of health professionals, (2) limitations of access to health care and the amplification of disadvantages due to COVID-19, (3) lifelong consequences of ACEs, and (4) IPV and its influence on drug use.

### Barriers to communication and mistrust of health professionals

The first theme, *Barriers to communication and mistrust of health professionals*, describes participants' difficulties

**Table 1.** Opioid-using mothers' descriptive characteristics.

	Total sample of opioid-using mothers, N=50	High-risk subsample included in qualitative analysis, n=36
Age at interview	28.60 (4.83)	28.42 (4.49)
Age at first pregnancy (years)	21.32 (4.98)	21.56 (4.66)
Received no prenatal care for current infant	4%	3%
Race (non-White)	6%	8%
Education		
College degree	18%	5%
High school degree/general educational development	52%	56%
Some high school	22%	28%
Technical/vocational training	8%	11%
Household net income (\$/month)	2387 (2059)	2192 (1721)
Current employment status		
Employed for wages	18%	22%
Self-employed	6%	8%
Unemployed and looking for work	24%	19%
Unemployed but not looking for work	34%	28%
Homemaker	8%	11%
Student	2%	3%
Unable to work	8%	8%
Relationship status		
Married/living with partner	68%	69%
In a romantic relationship, not living with partner	20%	17%
Single, never married	10%	11%
Separated/divorced	2%	3%
Total number of children	2.42 (1.25)	2.31 (1.14)
Not having custody for children	30%	28%
Ever having been arrested	68%	69%
Child's father ever having been arrested	75%	79%
Having been emotionally or physically abused <sup>a</sup>	72%	100%
Physically hurt by husband/romantic partner	28%	39%
Total ACEs score <sup>a</sup>	4.52 (3.35)	5.22 (3.19)
CES-D Depression score <sup>a</sup>	21.84 (13.21)	25.19 (12.94)

ACE: adverse childhood experiences; CES-D: Center for Epidemiologic Studies Depression.

Values are reported as mean (standard deviation), if not stated otherwise.

<sup>a</sup>Variable included in risk cluster score.

with health professionals and issues they had related to communication. This theme is consistent with the literature on the cultural characteristics of rural Appalachia. As explained in the literature review, many individuals from Appalachia do not only have geographical barriers that create challenges for communication, but they are also mistrusting of outsiders. The combination of these two aspects, communication and mistrust, come together to emphasize the challenge for mothers to reach out to health professionals.

Strong and trusting relationships and rapport between healthcare providers and their patients are essential to help promote positive patient outcomes. Despite of this, the mothers in our study explained that they did not have these relationships with their medical providers. One of the mothers in our study spoke to us about her experience and explained that “getting treated as a recovering addict

makes me feel alone and increases my anxiety.” This was in reference to how medical professionals approached her and how they made her feel. During the interviews, several participants talked about having to work through their anxiety. The mothers shared that they had opioid prescriptions to lower their anxiety, but that the experienced stigmatization amplified their symptoms and made it more difficult to recover. This further increased their mistrust in health professionals.

Mothers continued to show clear signs of mistrust of medical practitioners as they shared their experiences. One mother shared with us, “doctors said the opioids they prescribed would not hurt the baby and that the baby would not have withdrawal symptoms.” As she shared her experience, the tone in her voice sounded frustrated and sad as she recounted the information she had received from her doctors. Specifically, this mother attributed the cause of

her infant's condition to the doctor who had prescribed her opioids. A different mother stated that there should be more awareness of the effects in-utero opioid exposure has on infants. In the following passage, she shares the reason for why she was taking opioids along with what her infant had experienced as a result of the opioid exposure:

People need to be educated on this. If I had ever seen a baby go through withdrawal, I would've never taken the medication. The medication was for my anxiety and the car crash. The doctors said it would not affect the baby, but they were wrong.

The mistrust of healthcare professionals is depicted in this quote while also highlighting the lack of awareness that some mothers have regarding the safety of opioid use. This mother's experience was one of many that the research team heard as participants were interviewed.

In addition to the stories mothers shared with us in-person, their medical records also contained documented experiences that showed the barriers unique to this population. Participant medical records frequently described that patients had not shown up for appointments and had not responded to contact attempts. Participants who had missed appointments had notes in their records such as "No visits recorded; missed appointment" and "No answer on caregiver phone number." This information supported the characteristics that put mothers at risk for not getting the help they needed in addition to showing that there was a lack of communication between mothers and their service providers. These events in our data, both the interview and medical record data, highlight the complex challenges these mothers experience along with the demonstration of the need to establish a sense of trust and bidirectionally maintaining good rapport. Due to financial challenges and geographical locations, the mothers in this study often-times did not have cell phones, some did not have cell phone service at times, others changed their phone numbers, lacked access to emails, and some did not have a permanent address to be reached at. This limited access to opioid-using mothers in Appalachia further widens the barriers to communication and reduces the likelihood that they remain able to receive care after their infants have been released from the hospital.

### *Limitations of access to health care and the amplification of disadvantages related to COVID-19*

The second theme, *Limitations of access to healthcare and the amplification of disadvantages related to COVID-19*, talks about how mothers in our study were from a difficult-to-reach population. As previous research has shown, mothers from rural Appalachia are at a disadvantage when it comes to accessing health professionals due to monetary restrictions and geographic isolation. The majority of

mothers in this study traveled long distances from different counties across East Tennessee as well as from different states (e.g. Kentucky) to visit their infants while they were treated in the NICU. They shared how challenging it was to attend medical appointments because oftentimes they did not have access to a vehicle, alternative transportation was costly or unavailable, or the length of the trip was too long. In addition, they did not have a stable income, nor the healthcare coverage needed to continue to receive care. One mother shared that she had been homeless for an extended period due to her drug misuse and stated that her current newborn had not been her first child, "once you lose your kids, there is no reason to try anymore." This mother was afraid that custody for her infant would be taken from her, and that, as a consequence, she would relapse. A report of another mother mentioned that the program coordinator had reached out to her after the infant's father had reported some concerns about the mother's mental health at their last appointment. The report continued to state that the mother was doing well but would like to see a doctor regarding her anxiety. In addition, the report stated, "[the] mother is currently uninsured because her Subutex clinic would not accept low-income insurance plans; so, she dropped it in order to receive her medications." This event demonstrates how the cycle of poverty and the effects of living in poverty are inescapable for these mothers such that medical care becomes unattainable due to systemic inequalities even when patients are taking the right steps to receive the necessary care. The report added that the coordinator encouraged the mother to re-apply for insurance and provided her further information of doctors that would prescribe her the medications she needed. In order to do this, the document reported that the "mother also reports that she needs her infant's birth certificate to do this, and coordinator encouraged her to get this at the Health Department." This mother's case is one of the many examples of a multitude of barriers that exist and prevent opioid-using mothers from getting care they need. In another case, it was documented that the "bio mother contacted coordinator stating that infant was now with grandparents (maternal) . . . and that they would not be attending the appointment due to distance." This example further shows the challenges and experiences of opioid-using mothers. Not only did this mother have to report that she no longer had custody of her infant but explained that her relatives were also not able to attend future appointments due to the barriers of distance and access to health care.

Importantly, the reported barriers to health care access were amplified due to the ongoing COVID-19 pandemic. One medical record stated, "patient has not attended any appointments since the beginning of the COVID-19 pandemic." On a different mother's medical record, it was documented that the mother and her family were losing sources of income and in the process of being evicted due

to missing rental payments. Furthermore, the COVID-19 pandemic was taking an emotional toll on participants. Medical record data showed that a mother had difficulties due to the lack of cellphone coverage in the area she lived in. A social/case worker documented,

[The] Mother stated that her father was hospitalized . . . on a ventilator with COVID-19 and the hospital called her today stating that he coded [died]. They performed CPR for 17 minutes and were able to regain a pulse, but they are unsure of whether or not he will survive. The mother was understandably very upset and thankful for the call and extra support.

Despite the tragic event that this mother was going through, a quick check-in with her case worker was well received, further showing that communication despite barriers is important to this population. This mother's experience with COVID-19 shows how detrimental a pandemic can become to an already vulnerable population.

### *Lifelong consequences of ACEs*

The third theme, *Lifelong consequences of adverse childhood experiences*, speaks to the impact ACEs have on this population. When recalling the events during their early life, mothers often spoke about negative experiences in childhood that affected the trajectories they took in life. A mother's record explained that her "dad was very strict; mom had no filter; feels that she has her father's anger issues and is unfiltered like her mother." She further added that growing up she was "closer with mom" since "dad wasn't really around." This mother shared a small glimpse of the family dynamics she grew up in and how this potentially affected her development into adulthood. A different mother shared, "my family made me try heroin and I fell in love with the relaxed feeling." When she began taking heroin, she was not aware that she would become addicted to the substance. The mother shared that during this time period, she also began taking opioids with her boyfriend, and it was only later on in life when her opioid prescription was discontinued that she realized she was addicted. Another mother explained,

My mom was addicted. I was a product of the environment I was raised [in]. My mom sold me to drug dealers for drugs. I started using drugs when I was a kid. It was the only way I knew to get close to my mom.

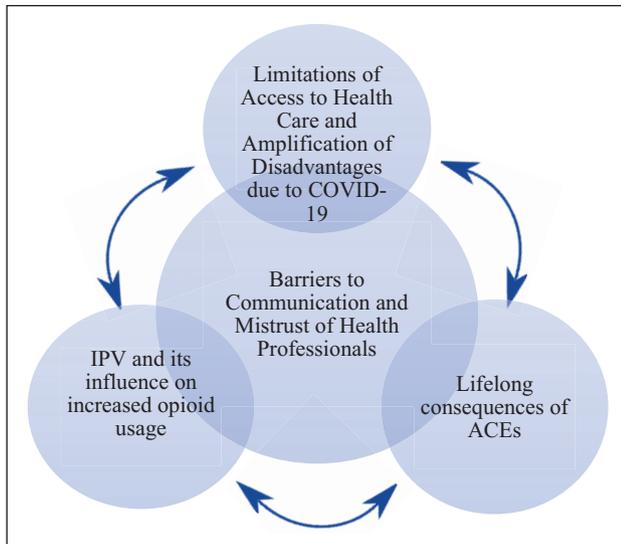
This mother's story highlights the complex lives of individuals who use opioids and the transgenerational challenges that exacerbate the current opioid crisis. A different mother talked about how she had a long history with drug usage and that she had begun doing drugs at the age of 14. These excerpts and stories give us a further look into events during early childhood and adolescence that influenced the trajectories of our participants. Another mother

shared that because of her own childhood experiences, she wanted to raise her children differently. She explained, "my childhood affected the way I raise my kids. Because of the way I was treated, I make sure I don't do that to my children." Despite the harsh environments these mothers were brought up in, they were able to recall and take a positive look into their past, reassessed their childhood, and attempted to adjust and recalibrate their present and future.

### *IPV and its influence on drug use*

The last theme, *IPV and its influence on drug use*, is used to explain the IPV the mothers reported which they related to leading to their dependency on substance use. In addition to experiencing ACEs, mothers also reported past and current experiences of IPV. When asked, "Is there anything else you would like to tell me about you, or your family?" the mothers would share how their drug and opioid use problems began due to the influence of an ex-partner. The conversations during the interviews included mothers describing their negative experiences in past relationships and often linked this with the start of drug misuse. Throughout the interviews, it was common for participants to associate their drug use with IPV. A mother explained she had "great parents" and that she had not used drugs until the age of 26 years, when she experienced abuse and infidelity from her partner. She did not go further into the details of their relationship but stated that she was now divorced and in a different relationship. Similarly, a different mother shared with us that she "got addicted through an ex-boyfriend who was addicted." Another mother shared, "[I] was severely physically abused by my ex-husband and I put him in prison for assault." She shared that this abuse led to a posttraumatic stress disorder (PTSD) diagnosis and explained that "the abuse was traumatizing, and I have since had EMDR (eye movement desensitization and reprocessing) for PTSD which was helpful." This reported pattern of abuse, being in unhealthy relationships, using drugs, and turning to opioids continued repeating as we talked and listened to the stories of our participants.

The levels of intensity and duration of IPV experienced by these mothers were different throughout the group but the effects of IPV greatly affected their pathways to use opioids. One mother stated that she had been physically abused from age 14 to 18 by her live-in boyfriend. Similarly, another mother shared that she had been abused by the infant's father. Her medical report stated, "bio father is currently incarcerated for abuse to bio mother." In this case, the biological mother and father remained in a relationship but had both lost custody of the infant. Overall, the majority of the familial and romantic relationships described by opioid-using mothers included a range of emotional and physical abuse, and IPV was inextricably linked to our participants' opioid usage.



**Figure 1.** Hypothetical model of connections between themes.

### Connections between themes

Finally, we informally explored the interconnectedness between themes in order to develop a graphical representation of our qualitative findings (see Figure 1). For instance, barriers to communication and mistrust of health professionals were present throughout the themes but were also represented across different aspects of participants' lives. These barriers continued to influence the way in which mothers approached health professionals. Limited access to health care and the amplification of disadvantages due to COVID-19 demonstrated the added challenges participants had by having to balance these barriers along with trying to attend doctors' appointments. Lifelong consequences of childhood adverse experiences continued to influence their life trajectories and showed up in their experiences with domestic abuse and its influence on drug usage.

### Discussion

Results of the current study advance our knowledge about the contextual and psychosocial risk factors faced by opioid-using mothers in rural Appalachia. The data revealed that the majority of mothers appeared to be at particularly high psychosocial risk and pointed to factors that influenced their health care experiences. Overall, this study found that 72% of all 50 participating mothers reported to have been emotionally or physically abused, and 28% reported that they were recently physically hurt by their husbands or romantic partners. Although such characteristics point to a moderate-high risk for all participants, 36 of the 50 mothers in this study were characterized as particularly high-risk based on the significant

accumulation of psychosocial adversities they experienced. Specifically, they exhibited significantly higher rates of ACEs, CES-D scores, and IPV than low-medium-risk opioid-using mothers.

Qualitative analysis of responses to open-ended questions revealed four major themes in high-risk mothers' experiences: (1) barriers to communication and mistrust of health professionals, (2) limitations of access to health care and the amplification of disadvantages related to COVID-19, (3) lifelong consequences of ACEs, and (4) IPV and its influence on drug use. The mothers in our study were more likely to report multiple barriers across their life span. Finally, an informal assessment of relationships between these themes suggested that Barriers to Communication and Mistrust of Health Professionals was substantially associated with the challenges described as part of the other themes. Findings from this study can be used to inform public health strategies to facilitate communication, build trust, and increase utilization of services to assist mothers from rural Appalachia with opioid addiction.

We found that low levels of communication between mothers and health service providers stemmed from geographical barriers (i.e. low cell phone coverage in the area or lack of transportation for their follow-up appointments), financial barriers (i.e. their cell phone service had been shut off), and/or mistrust of health professionals (i.e. mothers blamed their doctors for the infant's NOWS diagnosis). This list is likely incomplete as many reasons may remain unknown because some participants who may face even higher contextual and psychosocial risks did not participate in our study nor communicate with their social/case worker or medical providers. Mothers in our study showed mistrust toward doctors due to the lack of information provided to them regarding opioids and the risk of NOWS for their infants. The mothers then demonstrated mistrust by linking their infants' withdrawal symptoms to their prescribed opioids, furthering the distrust and barriers of understanding between mothers in rural Appalachia and their healthcare providers. This finding is aligned with other studies that have reported on barriers faced by women in this geographic location.<sup>15–17,27,28</sup>

Not only did the mothers in our high-risk group experience environmental, contextual, and monetary hardship, but the effects of the ongoing COVID-19 pandemic were intensified in this population. The COVID-19 pandemic presents new and unfamiliar territory regarding the ability to care for and support rural populations going through health crises of their own while access to already limited medical care has been reduced. The federal and state government response to the COVID-19 pandemic has not included vital support needed such as transportation services and information for additional resources in these areas to continue providing proper medical care and

assistance for vulnerable populations, thus leading to a wide range of missed opportunities in benefiting the health and wellness of rural populations.

Qualitative data further demonstrate that the origins of addiction can begin in childhood, and that it can be a vicious, intergenerational cycle running in families. Most of our participants shared stories from their childhood that demonstrated how adverse events led them to misuse drugs as a method of coping. This finding aligns with prior research that states a higher number of ACEs can have detrimental effects on individuals.<sup>11,27</sup> Along with a high number of ACEs, previous studies indicated a wide spectrum of mental health effects associated with opioid exposure such as major depression, anxiety, PTSD, and suicidal ideation.<sup>52,53</sup> However, we also found resilience among our participants. Despite the environments participants grew up in, some of the mothers were able to take a positive look into their past and attempted to adjust their present by seeking resources for both themselves and their infants. The resilience of these mothers was apparent throughout the interviews. Hearing more stories from these mothers would begin to help researchers, practitioners, and policymakers better understand why the usage of opioids is a nationwide epidemic and how certain groups are more vulnerable to misuse than others.

Consistent with elevated levels of IPV and emotional abuse that have been observed in previous studies of pregnant women in Appalachia,<sup>29</sup> the women in our study reported high levels of IPV. The women shared how their previous and current relationships were affected by abuse from their romantic partners and described how it further exacerbated their dependency on drug usage and isolation. This finding speaks to the potential importance of IPV screening and intervention for women of childbearing age and particularly during pregnancy.

This study suggests multilevel implications for research and practice. At the macro-level, there should be modifications on policies of how to screen and assess mothers who are at high risk for opioid usage and those who have a history of opioid misuse. By finding ways for practitioners to determine which patients are at high risk for opioid usage and by screening for opioid use without creating stigma, significant reductions in individuals addicted to opioids could be made as well as significantly improving the future outlooks of women and infants with NODS. Specific prevention efforts leading to a potential reduction in OUDs can decrease stress on the healthcare system and have immense economic benefits on productivity and associated healthcare costs on a societal level. At the micro-level, it should be required that institutions working with vulnerable populations incorporate cultural competency training for doctors, nurses, and other staff in order to build rapport with populations from marginalized groups. Cultural competency training for practitioners could help ameliorate some of the challenges with doctors

to carefully analyze all of the problems a marginalized group is going through, all of which should be analyzed to ensure that the best outcomes are possible for their patients. Indeed, there should be systematic efforts to address general needs such as transportation and education on prescribed medication for pregnant women and all women of childbearing age, especially in regions such as rural Appalachia with documented high opioid usage. With these systematic efforts, support systems that are already in place could run more efficiently and care could be offered to more patients who are not currently getting the care they need. In addition, more proactive intervention measures could also be set in place with greater access to healthcare and mitigation measures against the development of opioid addiction.

In addition, the findings have research implications not only for the literature that focuses on opioid usage and addiction but also for the medical field in general. Alternative medications other than opioids for pain management should be investigated, considered, and used in order to prevent a further exacerbation of the opioid epidemic and help lessen the chokehold that opioids have over the Appalachian region. Alternatives could help to dramatically decrease opioid medications in circulation and help ensure that patients who may be vulnerable to addiction (based on a variety of factors such as ACEs, IPV, etc.) are never introduced to opioids in the first place. Until a better alternative is available, the benefits of a powerful pain reliever must be evaluated alongside the risks of the formation of an opioid addiction, with decisions on prescribing made accordingly. Considering each individual's unique situation, patients should be made completely aware of the risks involved and all of the options available at their disposal for pain management. Opioid addiction is a complex issue that is impacted by personal, local, regional, national, and global events; therefore, more research should include strategies that focus on the experiences of the individuals who are affected by this epidemic. Supportive policies can help to ensure that women in these high-risk groups seek professional care without fear of retaliation and thereby improve the outcomes for the mother and infant in the long term. Moreover, studies on the experiences of mothers who use opioids should be used by institutions of medicine and of higher education to create policies that support these populations. Supportive practices could help increase this community's overall trust of medical professionals and thereby enhance patient health outcomes with honesty, trust, and compliance to positive health measures that were not common practice before. Ultimately, institutions of higher education such as universities and medical centers have a unique opportunity to transform their research and practice by incorporating supportive practices to create a positive healing environment for all of their patients.

### Strengths and limitations

This is a mixed-methods study reporting on a quantitative study sample of 50 opioid-using mothers from rural East Tennessee that includes a nested high-risk qualitative study subsample. We carried out our interviews in the form of written in-person questionnaires where researchers read the questions out loud for the participants in order to be considerate of individuals who may be illiterate, thereby increasing the validity and reliability of our data. In addition, our data set contains detailed and comprehensive information that was extracted from clinical medical records and follow-up visit information; these data originated from hospital staff entries, including nurses, doctors, and social workers.

Findings should be interpreted relative to several specific methodological parameters of our study. First, our sample was recruited from a pool of mothers who had the means to travel to the NICU while their infants were hospitalized, often from distant geographic locations. Our participants may therefore represent a somewhat more resourced sample than women who were not able to travel to visit their infants during the times of our recruitment. Second, our sample of women was racially homogeneous and predominantly self-identified as White. Although this mirrors the racial composition of people who use opioids in rural Appalachia, it does not reflect the broader population of opioid users in the United States.<sup>54</sup> Third, given the sensitive nature and stigma mothers experience for having a substance use problem, women may have underreported their experiences. However, we relied on carefully trained researchers and protocols designed to build trust with caregivers and community partners.<sup>41</sup> Another limitation to this study is the inability to conduct member checks due to the geographical and financial barriers of our participants. A strength of this study is that our interviewers self-identified as women, which may have increased trust and rapport, creating a more comfortable environment for our participants. Finally, our findings merit replication with a larger and more racially and ethnically diverse sample of women who use opioids. Notwithstanding these limitations, this study highlights key barriers within this population and underscores the need for additional research.

### Conclusion

There is substantial heterogeneity within samples of opioid-using mothers and particularly those at highest risk have been neglected by public health and social policies in the past. For women of childbearing age and mothers who use opioids during pregnancy, psychological screening may be helpful to identify those at high risk for developing opioid dependency. This could inform medical practitioners about additional programs or services this population will need to lead a healthy life. Support systems could be put in place in order to monitor and prevent OUDs and ensure that medications are taken as prescribed. Our study

demonstrates that there is substantial variability among mothers who use opioids during pregnancy, with a majority being at very high risk for accumulated contextual and psychosocial problems. When prescribing opioids, practitioners should always carefully evaluate whether certain risk factors are present and should make decisions on the prescription of opioids with the duration and need in mind in order to prevent an OUD, along with protecting unborn children from opioid exposure. In this respect, our findings fill an important gap in the available literature. Future studies and efforts to reduce opioid usage among mothers should take their psychosocial and contextual risks into account.

### Author Note

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### Authorship statement

K.B.-A. contributed to project administration, conceptualization, investigation, methodology, writing—original draft preparation, writing—reviewing and editing, data curation, formal analysis, validation, and visualization. K.H. contributed to investigation, formal analysis, writing—original draft preparation, writing—reviewing and editing, and validation. H.K.T. contributed to formal analysis, writing—original draft preparation, and validation. S.-A.H.B. contributed to formal analysis, writing—original draft preparation, and validation. H.C.R. contributed to formal analysis, writing—original draft preparation, and validation. M.M.A. contributed to formal analysis, writing—original draft preparation, and validation. E.J. contributed to conceptualization, funding acquisition, investigation, and writing—reviewing and editing. M.H. contributed to conceptualization, resources, and writing—reviewing and editing. J.J. contributed to funding acquisition, project administration, supervision, conceptualization, methodology, investigation, writing—original draft preparation, writing—reviewing and editing, data curation, formal analysis, and visualization.

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**Data accessibility**

The data reported in this article are from a highly sensitive opioid-using population. The institutional review board (IRB) protocol includes a Certificate of Confidentiality from the National Institutes of Health (NIH). For this reason, data points beyond the averaged values reported in Table 1 or quotes cannot be made publicly accessible.

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