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ORIGINAL RESEARCH



## Opioid use during pregnancy: An analysis of comment data from the 2016 Pregnancy Risk Assessment Monitoring System survey

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### ABSTRACT

**Background:** Opioid misuse during pregnancy has been associated with adverse infant outcomes including preterm birth, stillbirth, and neonatal opioid withdrawal syndrome. The Pregnancy Risk Assessment Monitoring System (PRAMS) is an on-going state-based surveillance system of maternal behaviors, attitudes, and experiences prior to, during, and after pregnancy. **Methods:** We analyzed qualitative comments related to opioid use during pregnancy collected in 2016 from an open-ended prompt at the end of the PRAMS survey in 35 states ( $N = 40,408$ ). Key word searches were conducted on the open-ended responses ( $n = 9,549$ ) to identify opioid-related content with an automated function using Microsoft Excel. All responses from the initial screening ( $n = 1,035$ ) were manually reviewed, and 69 responses were confirmed to relate to the respondent's personal experience with opioid use during pregnancy. Content analysis was conducted by 3 independent coders; key themes were compiled, discussed, and finalized by the coding team. **Results:** Five key themes related to opioid use during pregnancy were identified: (1) gratitude for treatment, recovery, and healthy infants; (2) pregnancy as motivation to seek treatment; (3) difficulty finding prenatal care providers with training in substance use disorders; (4) concern about the effects of treatment on the infant; and (5) experiences of discrimination and stigma in the hospital around the time of delivery. **Conclusions:** Women may be aware of the potential impact of opioid use during pregnancy on the health of their infants and motivated to seek treatment. Findings may help inform new and ongoing initiatives designed to improve care and reduce stigma for women needing or seeking treatment.

### KEYWORDS

PRAMS; qualitative data; opioids; pregnancy; stigma

### Introduction

The United States is facing an opioid crisis that affects individuals across the lifespan.<sup>1</sup> The effects range from the increased incidence of neonatal abstinence syndrome (NAS) among newborns<sup>2</sup> to an epidemic of opioid-involved overdose deaths.<sup>3</sup> Opioid use disorder among pregnant women, as documented at hospital delivery, increased significantly from 1.5 per 1,000 delivery hospitalizations in 1999 to 6.5 per 1,000 delivery hospitalizations in 2014.<sup>4</sup> The cost of treating infants diagnosed with NAS also increased from 1.6% of the hospital costs for all Medicaid births in 2004 to 6.7% in 2014.<sup>5</sup> In 2016, the total in-hospital cost for treating infants diagnosed with NAS was \$572.7 million with Medicaid shouldering the bulk (83%) of this cost.<sup>6</sup>

As national, state, and local leaders work to address the opioid crisis, the Centers for Disease Control and Prevention (CDC) has identified five strategies to guide the response to the opioid overdose epidemic. These strategies include conducting surveillance and research; building state, local, and tribal capacity; supporting providers, health systems, and payers; partnering with public safety; and empowering consumers to make safe choices.<sup>7</sup> The Pregnancy Risk

Assessment Monitoring System (PRAMS) survey data supports CDC's surveillance and research strategy and is important to help identify effective prevention activities and guide resource allocation. PRAMS quantitative data were recently analyzed to examine prescription opioid pain reliever use during pregnancy.<sup>8</sup> PRAMS also collects a limited amount of qualitative data which is also available for analysis and can complement quantitative findings.

Qualitative research offers a critical lens through which to view this issue as the methodology highlights beliefs, attitudes, and perspectives of those who have lived experiences and are most directly affected. Thus, qualitative studies are uniquely suited to improve understanding of the barriers and facilitators to treatment and recovery for opioid use during and around pregnancy. Qualitative research on opioid use among pregnant women has identified pregnancy as a change point and opportunity to develop self-efficacy and capacity for self-care,<sup>9</sup> and drivers of rising drug use during pregnancy in Kenya.<sup>10</sup>

The objective of this study was to further contribute to these findings by using qualitative data from PRAMS to gain a better understanding of women's experiences related

## PRAMS Sites Collecting Data in 2016

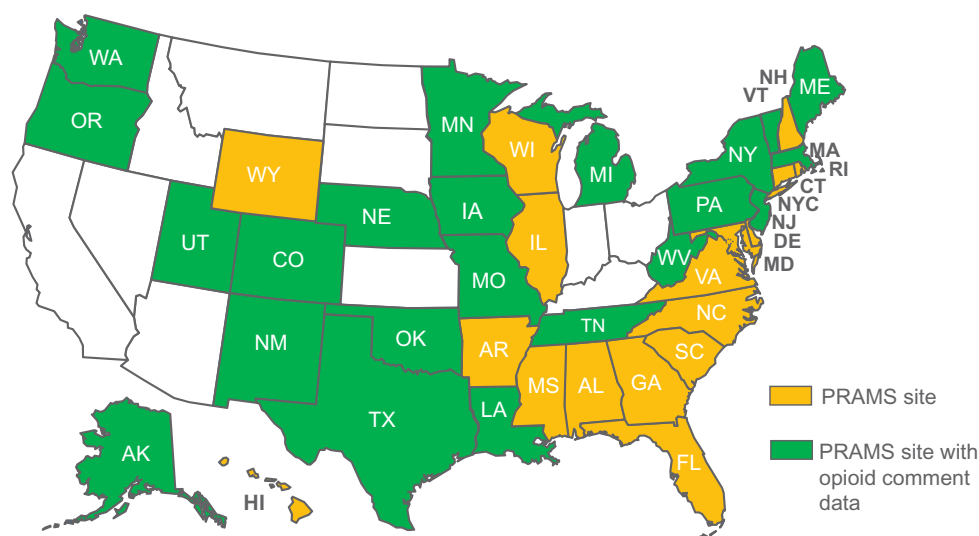


Figure 1. PRAMS sites collecting data, PRAMS 2016.

to opioid use during pregnancy. The information extracted from comments related to opioid use may help inform future research and programs that seek to improve care, reduce stigma, and mitigate factors that prevent pregnant women from seeking, receiving, and maintaining treatment.

### Methods

#### Data collection

We analyzed 2016 data from responses to an open-ended prompt collected on PRAMS. PRAMS is an ongoing, population-based surveillance system conducted by state, territorial, or city health departments in collaboration with the CDC. PRAMS collects information from women with a recent live birth about their behaviors and experiences before, during, and shortly after pregnancy. Women are randomly sampled from birth certificate records in each participating site between 2 to 6 months postpartum. PRAMS staff in each site send up to three mail questionnaires to each sampled woman and follow up to conduct a telephone interview with women who do not respond to mailings.<sup>11</sup> The PRAMS study protocol has been approved by the Institutional Review Boards of CDC and each participating site. Per the data sharing agreement and procedures for approval for release of de-identified data in the PRAMS protocol, all PRAMS sites had the opportunity to review and comment on the analytic plan for this study.

#### PRAMS qualitative data

At the end of the mail survey and telephone interview, respondents have the opportunity to provide additional information about their experiences. The following prompt is provided at the end of the mailed questionnaire: "Please use this space for any additional comments you would like

to make about the health of mothers and babies in <STATE>". At the end of the telephone interview, the following is read: "Is there anything you would like to say about your experiences around the time of your pregnancy or the health of mothers and babies in <STATE>?". Responses are captured verbatim in a free text field by data entry staff (mail surveys) and telephone interviewers. Responses collected through general open questions at the end of structured surveys and interviews can provide further depth to data already collected, particularly when data found in open-ended questions provides new insight not already captured.<sup>12</sup> This has been shown from previous research on postpartum experiences with PRAMS comment data.<sup>13</sup>

#### Analysis

All available comment data from 2016 were analyzed from 35 participating PRAMS sites that included the open-ended prompt on their survey (Figure 1). As the analysis was not focused on providing representative estimates, data were included for all available PRAMS sites who collected comment data, regardless of the annual weighted response rate in 2016 (range = 44.8% to 72.5%).

In total, there were 9,549 comments across all 35 sites. Initially, a list of keywords was compiled based on opioid use and treatment-related words identified through a literature review on opioid use and treatment as well as an internet search for "street names" of opioids and common misspellings (Figure 2). Using an automated function in Microsoft Excel, 1,035 comments containing keywords were identified. A three-person team (MC, DD, MO) read these comments and applied inclusion and exclusion criteria to identify comments related to substance use (Figure 3). The remaining 8,514 comments that did not include keywords were reviewed by the three-person team to confirm exclusion. A codebook was initially created using deductive codes,

or codes developed from previous literature searches, and hypothesized *a priori* to be of importance.<sup>14,15</sup> Inductive codes were created based on the themes identified during coding process and added to the codebook. After the codebook was developed, four randomly selected sites (Delaware, Georgia, Illinois, and Wisconsin) representing 10% of the comments were reviewed by 2 independent coders (MC, MO). Application of codes was then compared between the 2 coders and agreement was high (Inter-Rater Reliability [IRR] = 100% agreement between coders on 98% of codes); any discrepancies were resolved by consensus. Following this review, the codebook was finalized, and no further changes were made to the codes. The final analysis was conducted by dividing up the 35 states among three independent coders.

We identified 241 substance-use related comments, which included narratives around opioid use, tobacco use, marijuana use, alcohol use, partner substance use, polysubstance use, and “negative cases” (occurrences when women mentioned substances, only to say that she didn’t use them). From the substance-use related comments, the team eliminated non-opioid related comments and negative cases

resulting in 69 opioid-related comments for the final analysis. Polysubstance use comments were included if opioid use was mentioned. Comments ranged in length from 22 characters to 3,970 characters. The final 69 comments were analyzed for themes using a content analysis approach.<sup>16</sup> All coding and textual analysis was done using Microsoft Excel software.

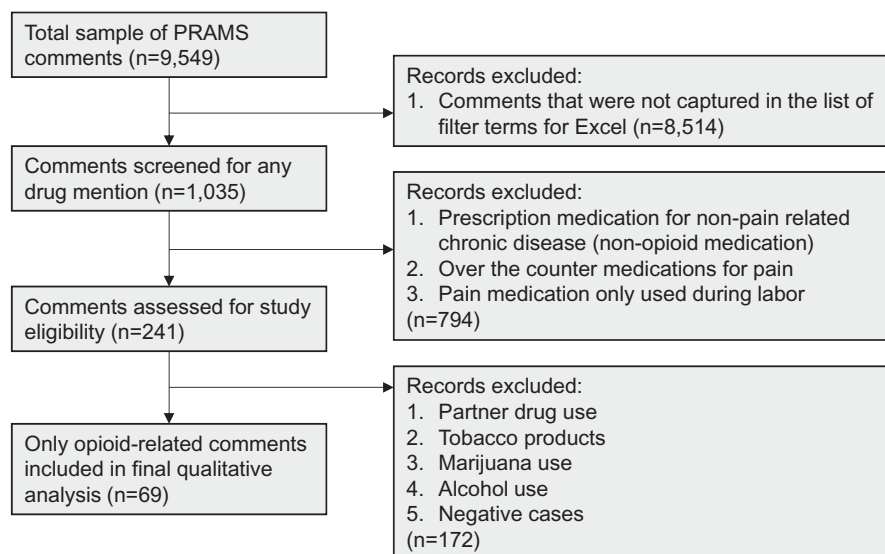
To examine characteristics of the population of women who had live births in the sample, we also analyzed quantitative data on demographic and other selected characteristics from the linked birth certificate file. Characteristics were examined to observe similarities and differences between the following 3 groups: all PRAMS respondents, PRAMS respondents who provided comments, and those who provided opioid-specific comments. Descriptive statistical analyses on the quantitative data were conducted using SAS v9.4 software.

## Results

Overall, there were 40,408 respondents to the PRAMS survey in the 35 sites in 2016 (Table 1). Among all respondents, 23.6% ( $N=9,549$ ) provided a comment (i.e. responded to the open-ended prompt) on any topic. Less than one percent of respondents who provided comments (0.7%,  $N=69$ ) included a comment specific to opioid use. About half of all respondents (47.2%) and respondents providing comments (48.2%) were white. Approximately 60% of all respondents and those providing comments were married (60.0 and 61.9%, respectively) and had private health insurance coverage for prenatal care (58.6 and 60.0%, respectively). Among women who provided a comment on opioid use, the majority were white (75.4%), were not married (66.2%), and reported their prenatal care was covered by Medicaid (73.4%). A larger proportion of opioid-related comments (87.0%) were provided via the mail questionnaire compared to the phone survey (13.0%). When coding the results, the codes most commonly applied related to experiences finding

Codeine	Oxy
Codine	OxyContin
detox	Oxycotton
Drug	pain
fentanyl	pain killer
heroin	relief
junkie	Percocet
medication	pill
medicine	prescription
Methadone	subutex
Narcan	treatment
Norco	used
Opioid	Vicodin
opiate	wean
overdose	withdrawal

**Figure 2.** List of common words and misspellings included in keyword search to identify opioid related open-ended comments from the Pregnancy Risk Assessment Monitoring System in 2016.



**Figure 3.** Selection of PRAMS records for inclusion in qualitative analysis of experiences with opioid use around the time of pregnancy.

**Table 1.** Characteristics of respondents by contribution of comments on the Pregnancy Risk Assessment Monitoring System (PRAMS) survey, 35 sites\*, 2016.

Characteristics	Percent		
	All respondents (n = 40,408)**	Respondents who provided any comment (n = 9,549)**	Respondents who provided opioid-related comments (n = 69)**
Age			
<20	5.2	5.1	1.4
20–24	19.1	19.4	18.8
25–34	58.0	56.4	68.1
>=35	17.8	19.2	11.6
Race/ethnicity			
White Non-Hispanic	47.2	48.2	75.4
Black Non-Hispanic	18.2	15.0	5.8
Other Non-Hispanic	15.4	12.9	13.0
Hispanic	19.3	24.0	5.8
Education			
Less than high school	13.7	14.3	11.9
High school	24.0	22.8	23.9
More than high school	62.3	62.9	64.2
Parity			
Nulliparous	39.4	40.5	29.0
Multiparous	60.6	59.5	71.0
Marital status			
Married	60.0	61.9	33.8
Not married	40.0	38.1	66.2
Insurance coverage for prenatal care			
Private	58.6	60.0	25.0
Medicaid	39.1	37.2	73.4
None	2.3	2.8	1.6
WIC during pregnancy			
Yes	41.1	40.5	47.8
No	58.9	59.5	52.2
Timing of PNC entry			
1st Trimester	85.8	84.6	78.3
After 1st trimester	14.2	15.4	21.7
Infant birth weight			
Normal birthweight (>=2500 grams)	76.5	73.3	58.0
Low birthweight (<2500 grams)	23.5	26.7	42.0

\*PRAMS sites that captured comment data and had a 2016 dataset available for analysis: AK, AL, AR, CO, CT, DE, IA, IL, LA, MA, MD, ME, MI, MN, MO, MS, NC, NE, NJ, NM, NY, NY, OK, OR, PA, RI, TN, TX, UT, VA, VT, WA, WI, WV, WY.

\*\*Unweighted sample size.

and using treatment and negative health care provider experiences (39 and 34 codes, respectively); least commonly applied were codes related to positive health care provider experiences and interaction with child protective services (11 codes each).

Women described experiences with opioid use that indicated use disorder as well as receipt of treatment for opioid use disorder around the time of pregnancy. Content analysis resulted in five overarching themes: (1) gratitude for treatment, recovery, and healthy infants; (2) pregnancy as a motivation to seek treatment; (3) difficulty finding appropriately trained prenatal care providers; (4) concerns about the effects of treatment on the infant; and (5) experiences of discrimination and stigma in the hospital around the time of delivery. Comments from each theme are provided as examples.

#### **Gratitude for treatment, recovery, and healthy infants**

One common theme was an expression of happiness, gratitude for treatment, and relief for healthy infant outcomes. Women talked about receiving treatment in a variety of settings including inpatient and outpatient facilities. These comments included an acknowledgement of the positive role

of healthcare providers, as well as encouragement to others about the benefits of getting help.

I was suffering from an opioid addiction during my pregnancy and went through a 26-day inpatient treatment with other pregnant woman and I want to say it's important to get the word out that there is help and resources out there if you have a problem, don't be afraid to ask for help. Don't think you're going to get in trouble or anything, people are there to help you. I've been able to maintain my sobriety and am happy I got help.

30 years old, West

My addiction caused me to use drugs during my pregnancy. If you're struggling please get help! ... By the grace of God, I'm clean and sober and my baby is now healthy after 4 months of help from doctors and nurses. Thank you for your help.

26 years old, Mid-Atlantic

#### **Pregnancy as motivation to seek treatment**

The timing in which women received help for their drug dependence ranged from right when they found out they were pregnant to throughout their pregnancy. During pregnancy, women sought treatment at methadone clinics, from their medical providers, and inpatient facilities. Women



most frequently cited their motivation to seek treatment was due to their pregnancy:

I was using pain pills when I found out I was pregnant so I got myself in a program to stop. They prescribed Subutex I used during pregnancy. My baby was born perfect... Now we are happy and healthy at home with her little sister who is 3-1/2 years old.

29 years old, Northeast

I was addicted to drugs before my pregnancy. Subutex helped me stay clean and have a healthy baby. Subutex should be encouraged if need be.

24 years old, Midwest

I am proof that having a baby on methadone doesn't make you a monster. My child truly changed me. There are no positive stories out there about this situation. I was scared my whole pregnancy about my baby having to stay in the NICU, and he came out perfect. Other women should know this, so they won't be scared like I was.

29 years old, South

### ***Difficulty finding prenatal care providers with training in substance use disorders***

Another common theme was frustration for women with experiences trying to find prenatal care providers willing to accept them as patients, providers who were able to appropriately advise them on treatment options, and providers who could connect them to other needed services.

When I got pregnant, I was addicted to opiate pain pills. I tried many places & services begging for help to get clean. Nobody was willing to help me at all because I was pregnant. There should be options available for mothers to access to be able to receive drug treatment if they seek it... At the very end of my pregnancy, I found a doctor willing to treat me with suboxone.

32 years old, South

I was on Methadone before, during, and after my pregnancy and I have been sober for 2 years now. It was extremely hard finding a doctor who would take me.

34 years old, Southwest

I feel there should be more programs available for addicted (opiate) mothers to be. My OB-GYN did very little to help me decide the best course of action for my situation...

30 years old, Northeast

### ***Concern about the effects of treatment on the infant***

Fear of witnessing their infants experience withdrawal symptoms was another recurrent theme. Although women mentioned different types of medication-assisted treatment (MAT), comments noted a desire to avoid methadone, in particular, because of fear that it would make withdrawal symptoms worse for the infant and lead to an extended infant hospital stay. There were also feelings of being uninformed about all treatment options and therefore being unable to select the option least likely to cause suffering in their infant.

I had twins so I was high risk! I never told my doctors that I was prescribed subutex 'cause I knew that my babies would be fine and they were when they was born. I didn't tell them 'cause I did NOT want my babies to be put on methadone!

23 years old, Mid-Atlantic

I told my OBGYN [about addiction] and he just gave me the # to the methadone clinic which I really wanted to avoid. Although I've never been on methadone maintenance I am aware that the withdrawal is 4x longer than any opiate withdrawal.

30 years old, Northeast

Before I got pregnant, I was dependent on drugs (heroin). I got on methadone 2 months before I got pregnant. At the clinic I attend there are a lot of women whom are pregnant, and we had tons of questions. I relied on other people who had babies on methadone, and I heard a lot of different things, some of which scared me, for instance my baby will have tremors, my baby will spend 1-2 months in the hospital for withdrawals, and the nurses will treat me terrible, and a lot more, which really scared me.

26 years old, Northeast

### ***Experiences of discrimination and stigma in the hospital and around the time of delivery***

Women also described experiences of discrimination based on their opioid use and treatment status during their delivery hospitalization. Comments in this theme focused on negative health care provider interactions, being misunderstood, being treated poorly, and being made to feel that they were a bad or negligent parent.

A nurse treated me very poorly at the hospital because of the Subutex. She made me think that my baby would go to the NICU if she had withdrawals. She scared me and made me feel like a bad mom. I was doing the right thing for my baby. I got off of heroin & got into treatment. Apparently, that woman has never walked in my shoes, and has lived a perfect life.

24 years old, Mid-Atlantic

I had some issues after my son was born at the hospital... I had narcotic medicines that I was told I had to take during my pregnancy by my doctor and it was in my medical records that I had to take them. When the baby was born... they treated me like a drug addict they wouldn't let my baby come home and they made me leave.

29 years old, Northeast

There is a lot of babies born addicted to illegal drugs in [STATE] ... and the way the staff at the hospital treats you when they find out ... is crazy. They treat you bad and judge you from the door.

30 years old, Mid-Atlantic

## **Discussion**

PRAMS qualitative data from the open-ended prompt provide a unique opportunity to examine some of the challenges of managing opioid misuse and opioid use disorder during pregnancy directly through the words of women who have lived through this experience. While women who



provided comments do not constitute a representative sample of women with opioid use or opioid use disorder, the demographic characteristics of these women, (most were White, unmarried, with Medicaid coverage for prenatal care) align with other studies that found the majority of pregnant women reporting opioid- and non-opioid illegal drug use were White,<sup>17</sup> and that White women were more likely to receive medication for opioid use disorder compared to Black and Hispanic women.<sup>18</sup> Although findings are not representative of any region, there were comments from across the United States. We did not observe differences in themes by region or by mode of participation (mail or phone).

Qualitative findings from other studies have identified sentiments of gratitude for empathetic and caring providers, medication treatment,<sup>19</sup> and group therapy for opioid use disorder<sup>20</sup> in the general population. However, there is scant research around sentiments of gratitude for healthcare providers and treatment for opioid use disorder around the time of pregnancy. Some women expressed relief and gratitude for healthy infants, their decision to seek and maintain treatment, and appreciation to facilities and providers who helped them. Other studies have demonstrated the positive effects of gratitude on mood, coping ability, reported quality of life, and the reduction of depressive symptoms in a variety of contexts.<sup>21–23</sup>

PRAMS participants who commented on opioid use during pregnancy also expressed concern for their infants. They discussed their awareness of the potential for poor outcomes for their infants and noted that pregnancy was the reason for starting treatment. When describing their experiences, some noted their infant was perfect and healthy while reflecting on their gratitude for providers and treatment programs. Women shared their desire to ensure the best possible outcome for their infant and some shared their frustration in finding relevant care. Barriers fell into several categories: difficulty finding a provider during pregnancy, feeling uninformed about the full range of options that might help their infants avoid withdrawal symptoms, and experiences or perceptions of being treated poorly or stigmatized for their opioid use in the hospital. Recognition that women are concerned about the possible effects of opioid use and treatment on the health of their infants may help inform public health efforts designed to make appropriate care more accessible, reduce negative stereotypes, and encourage women to seek help.

Difficulty finding care or prenatal care providers knowledgeable about their condition was a common theme mentioned among the opioid use related comments. Screening and referral for substance use disorder is a recommended routine part of prenatal care by the American College of Obstetricians and Gynecologists<sup>24</sup>. However, findings from some provider surveys align with the comments from our study, reporting a lack of training and confidence to screen, refer, and treat women with these conditions.<sup>25</sup> Efforts to improve training and resources for providers include the multidisciplinary work by the National Network of Perinatal Quality Collaboratives to improve maternal and child health

outcomes and health systems at the state level.<sup>26</sup> Another example is CDC's partnership with the Association of State and Territorial Health Officials (ASTHO) to develop the Opioid Use Disorder, Maternal Outcomes, and Neonatal Abstinence Syndrome Initiative Learning Community (OMNI LC) to build state and local capacity. OMNI LC members identified five focus areas including access to and coordination of quality services and provider awareness and training.<sup>27</sup>

Experiences of discrimination for opioid use and treatment for opioid use disorder during pregnancy was commonly reported by women and has been well-documented in other qualitative studies.<sup>28,29</sup> Negative provider interactions and fear of stigma are documented barriers to successful treatment for opioid use disorder during pregnancy.<sup>30,31</sup> The comments shared in this study reinforce the importance of addressing stigma and discrimination so that women are not reluctant to seek treatment and support findings suggesting that nonjudgmental and positive provider interactions may be key to successful treatment and recovery in this population.<sup>32,33</sup> Developing ethical, legal, and social considerations of strategies to address opioid use disorder among pregnant and postpartum women is another focus area of the OMNI LC. Specifically, supporting and training providers on the use of non-stigmatizing messaging and antidiscrimination and unconscious bias practices.<sup>27</sup>

Although many mothers who commented expressed a desire to find providers for treatment during pregnancy, an interesting finding of this study was the desire among some women to avoid methadone treatment, in particular, due to their perception that infants born to mothers who used methadone suffered worse withdrawal symptoms. These sentiments are supported by research suggesting infants exposed to methadone in utero are more likely to experience NAS than those exposed to buprenorphine.<sup>34</sup> Women talked about methadone in a variety of ways, including warning or being warned by others not to use it, hiding their opioid use to avoid methadone treatment for fear of their infants experiencing withdrawal symptoms, and feeling they had not been fully informed of the potential outcomes of or alternatives to methadone. Given that MAT for pregnant women with methadone or buprenorphine is a recommended clinical practice and that infant withdrawal symptoms are expected,<sup>35,36</sup> our findings support the work currently being done to improve provider awareness and training around caring for this population to ensure women receive accurate information regarding the recommended treatment options, including implications and plans for their infants at birth.<sup>27</sup>

Qualitative data collection methods may involve use of open-ended questions,<sup>12</sup> and the statement used to solicit responses for the PRAMS qualitative data analyzed in this study is one such example. Only a small proportion of all PRAMS respondents in our study (0.17%; 69 of 40,408) provided an opioid-related qualitative comment in response to the general prompt at the end of the survey. However, this is not surprising given the absence of a specific probe inquiring about opioid use, the location of the prompt at the end of the survey, the sensitive nature of the topic (87%

of opioid comments were from the mail survey rather than the telephone survey interview suggesting potential discomfort disclosing information to an interviewer), and the small proportion the population who uses opioids during pregnancy. PRAMS quantitative data from 2019 showed that 6.6% of respondents reported any prescription opioid pain reliever use during pregnancy,<sup>8</sup> and 2018 National Survey on Drug Use and Health found 3.6% of the U.S. population misused prescription pain relievers.<sup>37</sup> We were not able to assess whether comment data on opioid use correlated with opioid misuse or use disorder from quantitative data on PRAMS in 2016 because the PRAMS survey did not ask questions about this topic in detail until 2019.

The findings of this analysis are not generalizable to all women who used opioids or received treatment for opioid use disorder around the time of pregnancy, and are not intended to be interpreted as representative of the population of women with a live birth in the study sites. Our findings may lack the depth other qualitative research on this population are able to provide due to the brevity of the comments and inability to probe respondents.<sup>20,38</sup> Nevertheless, this study provides valuable insights on women's attitudes, perceptions, and experiences around opioid use during pregnancy that may inform prevention and treatment strategies designed to improve care and reduce stigma for women needing or seeking treatment, as well as future analyses of PRAMS data.

## Conclusion

The experiences described related to opioid use and treatment for opioid use disorder around the time of pregnancy are consistent with items addressed in CDC's recommended strategies to prevent opioid-related harms, including supporting providers and health systems, empowering consumers to make safe choices, and increasing provider awareness and training on ethical, legal and social considerations.<sup>7</sup> These data indicate a need for increased knowledge and capacity of providers to screen, refer, and provide appropriate, nonjudgmental prenatal care and support for women who use opioids around the time of pregnancy. This is especially critical for prenatal care providers as many women described pregnancy as a motivation to seek and maintain treatment and stigma and discrimination as a barrier to do so.

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## Author contributions

Megan O'Connor and Michaila Czarnik designed the study. Brian Morrow extracted data, performed all descriptive statistics and constructed the tables. Megan O'Connor, Michaila Czarnik, and Denise D'Angelo analyzed and coded all qualitative data, identified themes, interpreted findings, and drafted the manuscript. All authors have reviewed and approved the final manuscript.

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