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ORIGINAL PAPER

Perceptions of Pediatric Primary Care Among Mothers in Treatment for Opioid Use Disorder

Vanessa L. Short[1,5] · Neera K. Goyal[2,3] · Esther K. Chung[2,3] · Dennis J. Hand[1,4] · Diane J. Abatemarco[1]

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Abstract

To assess receipt of anticipatory guidance and family-centered care during well-child care (WCC) for children of mothers with opioid use disorder (OUD). Cross-sectional survey of 157 mothers receiving treatment for OUD who had a child < 3 years old and received primary care. Survey items evaluated (1) receipt of anticipatory guidance on 15 topics during WCC for the participant's child and (2) whether WCC was family-centered. The percentage of participants who reported guidance for each topic and the distribution of responses on family-centered items were calculated. A Pearson correlation was conducted to evaluate the association between the total number of topics for which anticipatory guidance was received and the family centeredness summary score. Receipt of anticipatory guidance varied by topic, ranging from 59% for guidance on childcare to 98% for guidance on safe sleep. Less than two-thirds of mothers reported that their child's provider "always" knew their child's medical history (56%), listened carefully (58%), clearly explained things (61%), and respected the mother (62%). Less than half reported that the provider spent enough time with them, and less than one-third reported that they were asked for their viewpoints. Anticipatory guidance and family-centeredness scores were positively correlated ($r = 0.22$, $P = 0.006$). Mothers with OUD report gaps in anticipatory guidance on important WCC topics, and limited family-centered care for their children. Further research may focus on refinements to the delivery of care for this population.

Keywords Anticipatory guidance · Family-centered care · Maternal opioid use disorder · Perceptions · Well-child care

Introduction

It is estimated that every 15 min in the United States an infant is born experiencing withdrawal from intrauterine opioid exposure, or neonatal abstinence syndrome [1]. While much of the research regarding maternal opioid use disorder (OUD) and its outcomes has focused on care during pregnancy and the newborn period, negative effects of maternal OUD and intrauterine opioid exposure may extend into later infancy and early childhood, including growth and nutrition challenges, increased risk of child abuse and neglect, and more frequent emergency department visits [2–8]. Routine well-child care (WCC) visits provide a critical opportunity for clinicians to address these issues, assess family dynamics, diagnose and prevent illness and injury, evaluate child growth and development, and provide anticipatory guidance to optimize child outcomes [9].

For mothers with OUD, however, numerous challenges and competing priorities, including stigmatization and discrimination, legal and child custody concerns, poverty, housing instability, mental health issues, and significant history of trauma, can limit their engagement in parenting and child preventive care [10–12]. Prior studies of this population demonstrate low responsiveness to child cues, heightened tendency towards physical provocation, low ability to promote child learning, limited understanding of basic child development, and limited adherence to recommended WCC [13–18]. Additionally, mothers in treatment for OUD have

✉ Vanessa L. Short
Vanessa.Short@jefferson.edu

1 Department of Obstetrics and Gynecology, Thomas Jefferson University, Philadelphia, PA, USA

2 Department of Pediatrics, Sidney Kimmel College of Medicine at Thomas Jefferson University, Philadelphia, PA, USA

3 Nemours/Alfred I. duPont Hospital for Children, Wilmington, DE, USA

4 Department of Psychiatry & Human Behavior, Thomas Jefferson University, Philadelphia, PA, USA

5 Thomas Jefferson University, 1233 Locust Street, Suite 401, Philadelphia, PA 19107, USA

reported feeling overwhelmed, guilty, judged, and removed from the care of their child [19, 20] and such negative feelings may create difficulties for a woman transitioning into motherhood and trying to establish a relationship with her child [19].

The American Academy of Pediatrics (AAP) provides guidelines for providing anticipatory guidance on a range of topics including feeding and nutrition, sleeping and physically caring for the child, safety and injury prevention, and child growth, development, communication, and behavior. For example, Practicing Safety is an AAP-sponsored toolkit that was developed to reduce the risk of child abuse and neglect by enhancing screening and anticipatory guidance among young children [21, 22]. Multiple prior studies have demonstrated that receipt of recommended anticipatory guidance is associated with improved satisfaction of care, improved child and family functioning, and preventive behavior changes [23–25]. Data from national surveys indicate that there is variation in the amount and type of anticipatory guidance received by parents during WCC visits [25], though this has not been explored in families affected by maternal OUD.

The AAP also recommends that WCC be family-centered. Care that is family-centered is collaborative between clinicians, patients and families, recognizes the family's role in promoting the health and well-being of a child, and identifies the family as the primary source of support and decision making for a child [26, 27]. Core aspects of family-centered care include partnership, respect, trust, information sharing, collaboration, and empowerment [27]; and similar to anticipatory guidance, it is recommended that pediatric providers incorporate these principles into their practice [27]. Family-centered care has been associated with improved costs, health outcomes, and satisfaction with providers [27]. Additionally, correlations between family and clinician relationships and provision of anticipatory guidance, adherence to clinician counseling, and behavior change have been reported in various populations [23, 28–30]. This may be due to visits and discussions being more collaborative, respectful and tailored towards individual family's needs. Consequently, parental sense of empowerment and trust in clinician's recommendations may increase, resulting in behavior change and subsequent improved child health.

To date, studies have not evaluated the attributes of anticipatory guidance and family-centeredness for WCC among children of mothers being treated for OUD. Moreover, within pediatric primary care, there is limited research on best practices for building trusting and meaningful relationships with mothers with OUD, addressing their unique parenting vulnerabilities, and increasing maternal empowerment and engagement in the child's care. An important first step to establish best practices is to identify the specific needs of families affected by maternal OUD and to identify opportunities for system-level improvements. The purpose of this study was to describe receipt of anticipatory guidance and family-centered care during WCC for children of mothers with OUD.

Methods

Study Design and Participants

This was a secondary analysis of data collected from "Practicing Safety Mindfulness Project for Mothers in Drug Treatment (PSMDT)," a large, multifaceted project which included a mindfulness-based parenting intervention, an enhanced case management component, and a pediatric practice quality improvement initiative (i.e., Practicing Safety [20, 21]). The Thomas Jefferson University and the City of Philadelphia Institutional Review Boards approved all study procedures and participants provided written informed consent. Additional details of PSMDT have been previously described [31].

PSMDT participants were English-speaking and at least 18 years of age, and had at least one child under 3 years old. All participants were receiving comprehensive behavioral and physical health support and care plus pharmacotherapy for OUD from a single treatment center. The participants' children, however, did not necessarily attend the same primary care clinic for their WCC. For this secondary analysis, only PSMDT participants with non-missing data related to anticipatory guidance and family-centered care were included. For participants who provided data more than one time (i.e., PSMDT repeaters), only data from the initial data collection period were included. Therefore, this analysis included data from 157 PSMDT participants (88% of all PSMDT participants).

Data Collection

Study participants completed several self-administered assessments shortly after enrollment into PSMDT. Data from all participants were aggregated into one analytic dataset void of personal identifiers.

Sociodemographic Characteristics

Sociodemographic characteristics, including age, race, ethnicity, marital status, highest level of education, employment status, number of children, and receipt of public assistance were obtained at study enrollment using a self-administered, sociodemographic survey.

Anticipatory Guidance

PSMDT investigators created a Quality of Care Questionnaire to assess the quality of routine WCC for the participant's youngest child (i.e., index child). Some of the questionnaire items were drawn from the Promoting Healthy Development Survey (PHDS), a validated parent questionnaire designed to measure the quality of health care for children 0–48 months [32]. Specifically, the PHDS measures parents' experience with pediatric care and the extent to which their children received preventive and developmental services in accordance with recommended guidelines put forth by the AAP [33]. For this analysis, the "Anticipatory Guidance and Parental Education" module of the PHDS was used to assess whether pediatric primary healthcare providers had discussed 15 anticipatory guidance topics with the study participants. Topics included: things to do to help a child grow and learn; expected child behaviors; breastfeeding; issues related to food and feeding; safe sleep practices; night waking and fussing; how a child communicates his or her needs; what a child is able to understand; how a child responds to parents, other adults, and caregivers; how to avoid burns; using a car seat; how to make a house safe; the importance of showing a picture book to or reading with a child; issues related to childcare; the Special Supplemental Nutrition Program for Women, Infants and Children (WIC); and safe sleep practices. Study participants were asked, "Has the infant's doctor ever talked to you about [topic (e.g., infant car seat use)]?" An affirmative response qualified as the topic having been discussed.

Family-Centered Care

A Satisfaction Questionnaire, created for PSMDT to assess maternal satisfaction with routine WCC, included items whereby participants reported on their experiences with primary WCC over the preceding 12 months. Several of the questionnaire items were derived from the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Clinician & Group Child 12-Month Survey, a publically-available standardized, evidence-based instrument developed with the support of the Agency for Healthcare Research and Quality [34]. Specifically, six items asked participants if their child's healthcare provider: (1) explained things clearly, (2) listened carefully, (3) showed respect, (4) knew important information about child's medical history, (5) spent enough time with the patient, and (6) asked about the mother's opinions and viewpoints as the parent of the child. Reponses were based on a 4-point Likert-like scale, ranging from 1 = Never to 4 = Always.

Statistical Analysis

Sociodemographic characteristics of study participants were described using mean and standard deviations for continuous variables and frequency counts and percentages for categorical variables. The percentage of participants who reported on the Quality of Care Questionnaire discussing each of the 15 anticipatory guidance topics with their child's healthcare provider was calculated. The total number of topics for which anticipatory guidance was received was determined, with a higher number indicating receipt of more guidance. The percentage of participants who reported that their healthcare provider met each of the six family-centered care items included on the Satisfaction Questionnaire was calculated, and a family centeredness summary score was created for each participant by summing the scores of the six items. Chi square tests were used to assess differences in receipt of anticipatory guidance by maternal sociodemographic characteristics and age of index child (dichotomized as ≥ 12 months or > 12 months). A Pearson correlation was conducted to evaluate the association between the total number of topics for which anticipatory guidance was received and the family centeredness summary score. All statistical analyses were performed using SAS version 9.4 (SAS Institute, Cary, NC, USA) and data were regarded as statistically significant at $P < 0.05$.

Results

The majority of participants were non-Hispanic white, with a high school education or less (Table 1). Nearly all received public assistance, including assistance with transportation, housing, or food, and were not employed. On average, participants had three children. The mean age of index children was 12 months.

Table 2 presents the percentage of mothers who reported that their child's primary healthcare provider had discussed each anticipatory guidance topic with them. For each topic, more than half of the mothers reported that their child's provider had ever discussed it with them. However, the receipt of anticipatory guidance varied by topic, ranging from 59% for guidance on childcare to 98% for guidance on safe sleep. About one-quarter reported that their child's healthcare provider had not discussed what a child is able to understand, and how a child responds to parents and other adults and communicates needs. The mean number of topics for which anticipatory guidance was received was 12 (range 2–15). Approximately two-thirds of mothers reported not receiving guidance on at least one topic (results not shown). In bivariate analysis, reported receipt of guidance was not significantly associated with the child's age or any maternal sociodemographic characteristic, including age, race, ethnicity,

Table 1 Sociodemographic characteristics of study participants

Characteristic	N = 157 n (%)
Maternal age in years, mean (range)	30 (18–41)
Race	
Non-white	37 (25)
White	109 (75)
Ethnicity	
Hispanic	19 (13)
Non-Hispanic	125 (87)
Relationship status	
Single	60 (41)
Married/partnered/other	87 (59)
Highest level of education	
Less than high school	43 (29)
High school	48 (33)
Greater than high school	55 (38)
Employment status	
Not employed[a]	128 (90)
Employed	14 (10)
Recipient of public assistance[b]	
Yes	141 (96)
No	6 (4)
Number of children	
1	33 (25)
2–3	64 (48)
4 or more	36 (27)

Missing observations: age, n = 9; race, n = 11; ethnicity, n = 13; relationship status, n = 10; education, n = 11; employment, n = 15; public assistance, n = 10; number of children, n = 24

[a]Unemployed/disabled/unable to work/student

[b]Assistance with transportation, housing, or nutrition

marital status, highest level of education, employment status, number of children, and receipt of public assistance (results not shown).

Top-box ("always" survey response) percentiles of the six family-centered care items are presented in Fig. 1. Less than two-thirds of participants reported that their provider always knew important information about the child's medical history (56%), listened carefully (58%), explained things in a way that was easy to understand (61%), and showed respect for what the mother said (62%). Less than half of mothers reported that their child's healthcare provider spent enough time with them, while less than one-third reported that their provider asked them for their viewpoint as a parent. The family-centeredness summary score had a mean of 13.9 (standard deviation 3.8) and an interquartile range of 12 to 17 (total range 0–18). Reported number of anticipatory guidance topics discussed and family-centeredness scores were significantly and positively correlated ($r = 0.22$, $P = 0.006$; results not shown). Greater anticipatory-guidance was correlated with higher ratings of family-centeredness.

Discussion

This is the first known study to describe maternal perceptions of anticipatory guidance and family-centered care during pediatric primary care visits for children of mothers in treatment for OUD. Findings from this study suggest that opportunities exist within the delivery of WCC for young children of these mothers to improve the provision of recommended anticipatory guidance. Specifically, mother-provider discussions about appropriate child development may be lacking. About one-quarter of mothers in

Table 2 Proportion of study participants who reported receiving recommended anticipatory guidance by topic

Topic	Received guidance %
Safe sleep	98
Using a car-seat	97
WIC	95
Breastfeeding	94
Things you can do to help your child grow and learn	93
The kinds of behaviors you can expect to see as your child gets older	85
Issues related to food and feeding of your child	81
How to make your house safe	80
How your child communicates his or her needs	78
The importance of showing a picture book to or reading with your child	78
Night waking and fussing	74
How your child responds to you, other adults, and caregivers	72
What your child is able to understand	69
How to avoid burns to your child	64
Issues related to childcare	59

WIC the Special Supplemental Nutrition Program for Women, Infants, and Children

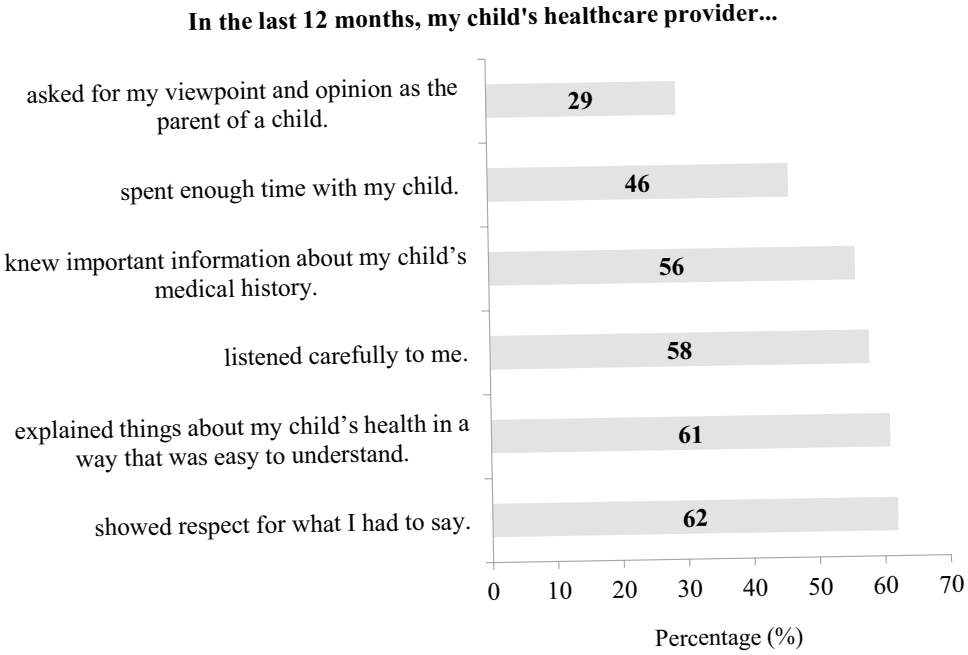

Fig. 1 Proportion of study participants who reported attributes of family-centered care

this study reported that their child's healthcare provider had not discussed what a child is able to understand and how a child responds to parents and other adults and communicates needs. This may be especially concerning as prior research has suggested that parental substance use is associated with parenting deficits, poor maternal responsiveness to child emotional cues, heightened tendency towards physical provocation, low ability to promote child learning and confidence, and lack of understanding regarding basic child development [13–15]. On the contrary, almost all study participants reported receiving information related to infant feeding and nutrition, safe-sleep practices, and car safety. This is positive and in line with and supported by national guidelines, such as the "Back-to-Sleep" campaign, and state and local regulations (e.g., seatbelt laws) targeting these preventive measures.

The deficiencies in anticipatory guidance reported here are similar to those found in the general population. A nationally representative study of parents of children aged 4 to 35 months found that there are inconsistencies in the provision of anticipatory guidance, with more medically-oriented WCC topics, such as immunizations, feeding and sleeping, generally receiving more coverage than psychosocial topics related to development and safety [35]. These findings underscore the need for integrating standardized approaches for psychosocial discussions within routine clinical practice [21]. In previous studies, gaps in anticipatory guidance were associated with parental characteristics including lower income, less education, lack of insurance, and membership in non-white racial/ethnic groups [25, 35]. These associations did not emerge in our analysis, likely due to the rather homogenous (e.g., white, non-Hispanic, receiving public assistance) study population.

There may also be significant room for improving the extent to which care for children with mothers in treatment for OUD is family-centered. Less than half of mothers in our study perceived that their child's healthcare provider spent sufficient time with their child and less than a third reported being asked for their viewpoints about their child. Approximately half of study participants reported that their child's healthcare provider knew important things about their child's medical history and listened carefully to them as mothers. These proportions are well below data reported elsewhere. Specifically, in comparison, among the of 12,488 respondents of AHRQ's 2016 CAHPS Clinician & Group Child Survey, from 81 practice sites across the U.S., 88–93% reported that their child's health care provider had always explained things clearly, listened carefully, showed respect, spent enough time with them, and knew important information about their child's medical history [36].

Care that is not particularly family-centered could have important consequences as family-centered care is positively correlated with reported provision of anticipatory guidance, as shown by results of our correlation analysis and previous studies [30] and perceptions of more complete anticipatory guidance is associated with subsequent positive preventive behavior changes [23, 24]. A healthcare model that is more collaborative in nature could have additional benefits for mothers in treatment for OUD who have unique vulnerabilities [10–12], including significant trauma histories [31]. Care that is family-centered may allow for a trauma-informed approach to care, increase trust with the healthcare

system, and provide mothers the opportunity for discussions of particularly relevant issues (e.g., management of infant withdrawal symptoms, normal child development and behavior, approaches to discipline).

There are potential limitations to consider when interpreting our results. In addition to the sociodemographic homogeneity of the study population, all study participants were recruited from a single urban OUD treatment clinic for pregnant and parenting women, which may limit the generalizability of our findings. Of note, the demographic profile of our study population is similar to that of pregnant women in treatment for OUD in the United States [37] increasing the likelihood that our findings are generalizable to a broader national population of mothers in treatment for OUD. It is possible that some mother–child dyads, as participants of PSMDT, were exposed to parts of the PSMDT project within their pediatric clinic aimed at addressing the specific needs of children affected by OUD. However, we did not ask participants to identify the clinic at which their child received care. As such, controlling for clinic site and comparing across different clinics was not possible. Similarly, the study design prevented us from ascertaining which clinicians interacted with parents. It is possible that the clinicians' level of experience and parents' interactions with other healthcare providers (e.g., non-pediatricians, nurses, medical assistants) influenced mothers' perceptions of care. Our study relied on self-reported data, without evidence from provider documentation of what anticipatory guidance was actually provided. It is possible that discussions were had between providers and mothers, yet mothers may not have recalled what was said. There may be other dimensions of family-centered care that were not measured. Our definition, however, covered items pertaining to healthcare provider communication, explaining things clearly, listening carefully, showing respect, providing easy to understand instructions, knowing patients' medical history, and patient-provider interaction time. The children of study participants were of varying ages, and likely attended varying number of WCC visits, which may have contributed to some of the variation in reported outcomes given providers may choose different ages to discuss different topics and attendance at more WCC visits will provide more opportunities for discussions around certain topics. Strengths of this study include the recent study cohort from a well-established, high volume OUD treatment program for pregnant and parenting women that is embedded within an academic research program, and the use of validated survey items whenever possible.

Findings from this study suggest the need for modifications to the WCC delivery for children of mothers in treatment for OUD to better address health and developmental concerns and to increase the family-centeredness of care. Given the complexity of the challenges mothers with OUD often face, traditional 15- or 20-min well child visits for this population may be insufficient for building maternal trust, addressing information needs, and engaging mothers as key participants in their child's health. Discontinuous healthcare in this population is common [3, 38] which can also make building trusting relationships challenging. Innovative approaches such as group-based WCC visits may address these challenges through increased time with the provider, peer-to-peer interaction, and more in-depth discussion of particularly relevant topics [39–41]. Integrating coordination of services across maternal OUD treatment and pediatric primary care providers may also be worth exploring. The provision of WCC at the site of maternal OUD treatment could potentially serve as a natural extension of the programmatic supports already offered to mothers in treatment, increase WCC convenience, reduce stigma, and provide a unique opportunity for coordination of other services for the family. Lastly, providing education and training to pediatric healthcare providers regarding caring for families affected by maternal OUD may be warranted given that pediatric trainees (i.e., students and residents) have reported discomfort with discussing mothers' substance use and trauma histories [42] and substance use disorders are generally stigmatized conditions.

Conclusion

Mothers in treatment for OUD report gaps in receipt of anticipatory guidance and limited family-centered care during WCC visits for their children. This raises questions on how refinements to the delivery of WCC for these families can improve engagement and better address child health and developmental risks.

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Compliance with Ethical Standards

Conflict of interest The authors declare that there is no conflict of interest.

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