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# Journal of Midwifery Women's Health





The Official Journal of the American College of Nurse-Midwives

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# Journal of Midwifery Women's Health

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The Journal of Midwifery & Women's Health (JMWH) is the official journal of the American College of Nurse-Midwives. Within a culture of inclusion and antiracism, JMWH advocates for health equity, access to quality care for all persons, and excellence in midwifery. Articles published in JMWH include new research and current knowledge across a broad range of clinical and interprofessional topics including perinatal care, sexual and reproductive health, gynecology, primary care, public health, health care policy, and global health. Implications for midwifery practice, policy, education, research, and workforce development in the United States are emphasized. International health articles with global perspectives and broad implications are welcomed. JMWH utilizes a double anonymous peer review process to ensure manuscripts meet the highest standards of scholarly work and welcomes submissions from midwives, collaborating health professionals, scientists, and others with an interest in the Journal's scope.



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# Are You Using fFN Testing Correctly?

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# Moving Midwifery: New Federal Documents Champion the Profession

The spotlight on poor perinatal health in the United States compared with similar countries is contributing to a national focus on midwifery. The causes for the escalating rates of maternal mortality and morbidity are complex but include a shortage of qualified and diverse health clinicians. Much has been written about the midwifery profession and the quality of care provided by midwives. Yet, unlike most other highincome countries, midwives provide only a fraction of similar care in the United States. However, in 2021, the proportion of births attended by certified nurse-midwives and certified midwives (CNMs/CMs) reached an all-time high of 10.6% of all US births after topping 10% in 2020.<sup>1</sup> The percentage of births attended by all midwives in 2021 was nearly 12%.<sup>2</sup> The number of American Midwifery Certification Board (AMCB)-certified midwives has also gone up alongside the increasing number of graduates. Over 800 new CNMs/CMs were certified in 2022,3 although the overall increase in practicing midwives is reduced by retirements or lack of AMCB certification renewal for other reasons. Eight new midwifery programs have been preaccredited by the Accreditation Commission for Midwifery Education (ACME) since 2020,<sup>4</sup> with 4 additional programs undergoing evaluation by ACME in 2023.

Two new federal policy documents addressing the value of midwifery were just published in April and May 2023. These documents from the US Government Accountability Office (GAO)<sup>2</sup> and the Medicaid and CHIP (Children's Health Insurance Program) Payment and Access Commission (MACPAC)<sup>5</sup> provide current summaries on midwifery education and workforce development as well as updates on US midwifery practice and payment for perinatal care. The 2 documents have different foci, but both are useful as advocacy tools to advance the profession.

The GAO document, Midwives: Information on Births, Workforce, and Midwifery Education, examines midwifery education and access to midwifery care in response to a request from Congress.<sup>2</sup> Data from federal agencies and midwifery organizations, including the American College of Nurse-Midwives (ACNM), as well as published midwifery research, were analyzed to produce the report. Interviews with knowledgeable individuals, including representatives from ACNM, the National Black Midwives Alliance (NBMA), and the National Association of Certified Professional Midwives (NACPM) were also included. The ACNM Workforce Study findings informed the GAO about many midwifery variables at the state level, including number of midwives, density of midwives per 1000 live births, number of births by state, independent practice, and the regulatory environment.<sup>6</sup> Increases in midwife-attended births in 2021 were documented along with the proportion of midwife-attended births by state

ranging from 1% to nearly 32%. The increase in the number of midwives educated and certified over the past several years is also reported.<sup>2</sup> The proportion of White midwives continues to be higher than US population estimates by race, and the proportion of midwives of color is less than those population estimates. However, the proportion of first-time AMCB-certified midwives of color increased from 15.1% to 21% from 2016 to 2020.<sup>7</sup> The document highlights challenges to accessing midwifery care as well as challenges to practicing midwifery.<sup>2</sup>

MACPAC advises Congress on policy related to Medicaid and CHIP. In May 2023, MACPAC released Access to Maternity Providers: Midwives and Birth Centers, a report summarizing midwifery practice and care provided in freestanding birth centers.<sup>5</sup> The report cites evidence supporting improved outcomes and lower cost when care is provided by midwives in birth centers. In addition, the report highlights the well-known barriers of the lack of payment parity for midwives and birth centers with other health care provider types and facilities, and the difficulty contracting with managed care organizations. The report also highlights state legislative and regulatory variations in midwifery recognition and scope of practice, and challenges educating an adequate number of midwives. Appendices document the variation in the proportion of midwife-attended births by state paid for by Medicaid ranging from less than 1% to 30% across the country.5

The documents add to previously identified tools midwives and others can use to overcome the ongoing barriers to full-scope midwifery practice and access to midwifery care in all settings and all US states.8 In addition the ACNM Workforce Study has generated publicly accessible state-level data available for use in advocacy. The data show that some states have a higher density of midwives than other states; arguments can be made to policymakers that increasing the number and density of midwives will have a positive effect on perinatal outcomes. Greater barriers in accessing hospital privileges exist in some states, and comparing neighboring states may be an incentive for hospital systems to open up to midwifery.<sup>6</sup> Having publications and data to support the profession is critical at a time of increased attention on maternal mortality and morbidity, particularly when midwives are providing more care in the United States than ever and the number of education programs and new midwives are on the rise.

All midwives can easily support legislation aimed at promoting perinatal health and midwifery education and practice. ACNM urges support for current congressional legislative efforts (eg, passage of the Midwives for MOMS Act of 2023, HR 3768/S 1851,<sup>9</sup> and the Perinatal Workforce Act, HR 3523/S 1710<sup>10</sup>) to increase the number of racially and ethnically diverse midwives, thereby diversifying the perinatal care workforce with individuals who represent the lived and cultural experiences of the patients they serve. Legislators track contact from their constituents on various bills. Requesting their support of legislation by their coauthorship or vote helps move these bills forward. Midwives can visit congressional legislative staff with ACNM state affiliate colleagues to provide current information and encouragement for the legislation. Approaching legislators with colleagues from partner stakeholder organizations, such as the American Association of Birth Centers, NACPM, NBMA, the American Association of Colleges of Nursing (where most ACME-accredited midwifery programs reside), and the American College of Obstetricians and Gynecologists, helps to move legislation forward and can be fun!

These new documents can be effectively used at the state level to support the growth of midwifery programs by promoting state funding and advocating for full practice authority in states where that is still needed. The MAC-PAC document can help midwives negotiate for state-level Medicaid payment parity and address practice barriers. Continuing to grow a robust and diverse workforce of midwives in the United States requires every midwife acting with intention. These federal publications help midwives promote what we already know—increasing access to midwifery care is a meaningful part of the strategy to improve perinatal outcomes. The work is not complicated; with nearly 14,000 CNMs/CMs, we can get the job done.

> Melissa D. Avery, CNM, PhD Editor-in-Chief Amy Kohl Director, Advocacy & Government Affairs, American College of Nurse-Midwives Karen Jefferson, CM, DM Director, Midwifery Practice & Education, American College of Nurse-Midwives

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**Research Article** 

### Continuing Education

## Breastfeeding Aversion Response (BAR): A Descriptive Study

Melissa A. Morns<sup>1</sup>, MPH <sup>(1)</sup>, Amie E. Steel<sup>1</sup>, PhD, Erica McIntyre<sup>1,2</sup>, PhD, Elaine Burns<sup>3</sup>, PhD, RM

**Introduction:** For many women, breastfeeding their infant is an enjoyable experience. Some, however, have reported negative sensations such as an overwhelming need to unlatch while breastfeeding. This phenomenon is known as breastfeeding aversion response (BAR). The incidence of BAR is unknown and literature on this experience is limited. This study therefore aimed to expand the understanding of BAR using an online survey targeting those who have experienced feelings of aversion while breastfeeding.

**Methods:** An online survey was distributed within Australia using purposive sampling to those who self-identified as experiencing BAR. This survey contained 5 sections: (1) demographics and health-related characteristics, (2) breastfeeding difficulties and onset of BAR, (3) the experience of BAR, (4) birth and breastfeeding experience, and (5) coping with BAR and support. Questions were included to test the generalizability of previous qualitative findings on BAR.

**Results:** Participants (N = 210) predominantly were aged between 25 and 35 years (69.2%), were in a relationship (96.2%), and had one child (80%). BAR was more commonly experienced when feeding the first-born child (44.8%), breastfeeding while pregnant (31%), or tandem feeding (10%). The feelings of aversion were experienced by most respondents throughout the feed while the child was latched (76.7%). More than half (52.4%) of participants reported that BAR had caused them to end breastfeeding sessions before their child was ready to stop feeding. Almost half of the participants (48.6%) reported receiving no support from a health care provider for BAR.

**Discussion:** This study contributes new information about the experience of BAR, including when it commonly happens and who may be at greater risk. More support is needed for women who want to breastfeed while experiencing BAR. New public health policies which promote breastfeeding are needed to help women achieve satisfying breastfeeding experiences and meet their own breastfeeding goals.

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*Keywords:* breastfeeding, breastfeeding experience, mother-child relations, maternal health, breastfeeding aversion response, nursing aversion, chest-feeding, tandem breastfeeding

### INTRODUCTION

The World Health Organization (WHO) recommends that infants are breastfeed a minimum of 12 months and children up to 2 years and beyond.<sup>1,2</sup> Breastfeeding has proven shortand long-term physical and mental health benefits for women, infants, children, and families<sup>3</sup> and offers protection against child infections, obesity, and diabetes.<sup>4</sup> However, less than half of women globally continue to breastfeed exclusively after 6 months.<sup>5,6</sup> Global rates of infants fed with any breastmilk at age 6 months have only increased slightly in recent years,<sup>6,7</sup> as many women who intend to breastfeed report a lack of adequate support to achieve their breastfeeding goals.<sup>8,9</sup> It is therefore vital to better understand breastfeeding complexities from the perspective of breastfeeding women.<sup>10</sup> Strategies

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ORCID Melissa A. Morns (D) https://orcid.org/0000-0002-4254-3690 and policies are needed to support women in achieving their personal breastfeeding goals<sup>11</sup> and enable national health services to achieve the WHO targets.<sup>12</sup>

Postpartum mental health difficulties have become more prevalent in recent years. Evidence has cited activating factors such as traumatic birth experiences,<sup>13</sup> lack of postpartum support,<sup>14</sup> and complex breastfeeding issues.<sup>15</sup> Previous research has also identified that postpartum infant feeding complications can trigger feelings of guilt and shame,<sup>16</sup> which can be associated with an increased risk of postpartum depression.<sup>17</sup> Breastfeeding can generate positive and negative experiences for women that range from feelings of connectedness and pride, to negative emotions such as frustration and disappointment.<sup>18</sup> Common breastfeeding challenges such as inadequate milk supply, poor latch, nipple trauma, and mastitis can cause physical and mental distress.<sup>14</sup> Less commonly, some women have described feelings of aversion while breastfeeding, with the overwhelming urge to unlatch their infant.<sup>18</sup> This negative phenomenon is referred to as breastfeeding aversion response.

Continuing education (CE) is available for this article. To obtain CE online, please visit http://www.jmwhce.org. A CE form that includes the test questions is available in the print edition of this issue.

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# Quick Points

- Breastfeeding aversion response is an overwhelming urge to unlatch in response to feelings of aversion while breastfeeding, which occur while the child is latched.
- Breastfeeding the first child, tandem breastfeeding, menstruation, and breastfeeding while pregnant can trigger breastfeeding aversion response.
- Breastfeeding aversion response can have a negative effect on maternal mental health such as higher levels of severe stress and anxiety.
- Most women who experience this complex breastfeeding challenge want to continue breastfeeding and need support from knowledgeable health care professionals and peers.

### **Breastfeeding Aversion Response**

Breastfeeding aversion response (BAR) is a complex breastfeeding experience that is poorly understood, and there is limited literature to guide diagnosis and management. BAR has been defined as a compulsion to unlatch in reaction to negative physical sensations while breastfeeding. This reaction can last throughout the entire feeding session and ranges from mild to repellent, conflicting with the desire to continue breastfeeding.<sup>15</sup> BAR was first reported in nonacademic breastfeeding literature in 2003,<sup>19</sup> which led to the creation of online support groups for BAR. Anecdotal findings from these online communities were then added to later editions of international breastfeeding resources.<sup>19</sup> Social media discourse and lay literature around breastfeeding aversion has further increased in recent years, with several blogs, books, and websites supporting this issue.<sup>20-22</sup> To date, however, empirical research on this phenomena remains sparce.

The experience of BAR differs from documented characteristics and sensations of other negative embodied experiences while breastfeeding such as dysphoric milk ejection reflex (D-MER). D-MER is defined as negative sensations that occur during the letdown reflex while breastfeeding or pumping breastmilk. D-MER was first described in a case report in 2011,23 and recent research on D-MER hypothesized that this experience may be associated with a disruption in neurotransmitter and hormone activity of prolactin and dopamine; however, more research is needed to confirm this.<sup>24</sup> Previous research has also explored the breastfeeding challenges of those with a history of childhood sexual assault such as increased risk of emotional distress and complications with breastfeeding.<sup>25,26</sup> Likewise, a history of assault can activate negative feelings while breastfeeding described as flashback traumatic memories and feelings of dissociation.26

In 2016, the earliest known empirical research to identify feelings of aversion while breastfeeding found that this experience can have a negative impact on maternal identity.<sup>27</sup> Likewise, a meta-ethnographic synthesis of the literature on BAR found that this experience may cause internal conflict and affect the mother-infant relationship; however, some of those who were able to continue breastfeeding had positive outcomes.<sup>18</sup> Morns et al conducted a focused qualitative investigation of BAR and found that empathy and practical support from others enabled some women to continue breastfeeding with BAR and to ultimately achieve their personal breastfeeding goals.<sup>15</sup> These results showed that BAR can be deleterious to maternal well-being for others without support and informed the survey development for this descriptive study. Thus, the aim of this study was to explore the experience of BAR by further describing this experience, demographics, and health characteristics of this population.

### **METHODS**

An anonymous online cross-sectional survey was used to describe features of BAR from those who self-identified as experiencing this phenomenon. The survey focused on the experience of BAR and the demographics and health characteristics of this population. This study also investigated coping strategies used by women who experienced BAR and which types of health care and community support facilitated their ability to continue to breastfeed. Ethics approval was obtained through the researcher's host institution ethics committee (University of Technology Sydney Human Research Ethics Committee no. ETH20-5341).

### **Participants and Data Collection**

Individuals who were 18 years of age and older, were living in Australia, and self-identified as experiencing BAR at the time of completing the survey were invited to take part in the study. Participants were recruited using purposive and snowball sampling from already established online support group communities for breastfeeding and a Facebook support group for breastfeeding aversion with a membership of approximately 6300 members. The first author was an insider and may have been known to participants, so an arm's length approach was used to distribute the survey whereby another member of the research team approached group facilitators to distribute the survey anonymously. The Australian Breastfeeding Association (ABA) approved and distributed the survey within their online social media networks. The survey was administered via Qualtrics and was available online for 4 months from mid-November 2020 until mid-March 2021. Participant information was provided prior to consent. There were no incentives offered to participants. Support contacts were provided on every page of the survey for participants to seek help if the survey triggered any negative emotions or previous trauma.

The term *child* is used throughout this article to encompass the feeding experience with newborns, infants, and children without age limits. The researchers also acknowledge that some who feed their infant human milk do not identify as female and will use the term *chestfeeding* rather than *breastfeeding* to describe the feeding experience. This study did not ask participants to provide their gender or pronouns, so for consistency, the words *breastfeed* and *women* are used throughout this article.

### **Survey Development**

The survey was developed by the researchers for the purposes of this study. Items were informed by previous qualitative research describing the experience of women who had feelings of aversion while breastfeeding.<sup>18</sup> These items used Likerttype scale responses and were reviewed by one independent certified nurse-midwife and 2 expert midwifery faculty researchers for construct validity. Five prevalidated scales were built in: (1) the Depression, Anxiety, and Stress Scale short form (DASS-21), (2) The EQ-5D-3L to measure health-related quality of life, (3) the Dimensions of Anger Scale (DAR-5), (4) the Brief Resilience Scale (BRS), and (5) the Short-Form McGill Pain Questionnaire (SFMPQ). An adaptive flow strategy was used to present follow-up questions to participants based on previous answers. Participants with at least one newborn or infant were presented with up to 87 questions, and participants with a second infant or child were presented with up to 116 questions. The final version of the survey was separated into 5 key sections that integrated items developed by the researchers and the previously validated scales

### Demographics and Health-Related Characteristics

This section collected information about participants, age, education, health history, current medications, general wellbeing, and current levels of stress, anxiety, and depression. Common neuroendocrinological conditions that could have an impact on maternal well-being28,29 were also included. The DASS-21 has been validated previously to assess depression, anxiety, and stress among Australian and New Zealand mothers with excellent internal consistency (Cronbach's alpha = .93.30 For this study the DASS-21 internal consistency was excellent (Cronbach's  $\alpha = .93$ ). The DASS-21 was scored by adding the items of each subscale for depression (D), anxiety (A), and stress (S) which were multiplied by 2 (for this short form scale 21 items, which is half the full scale 42 items), and then measured using the DASS severity ratings of normal, mild, moderate, severe, and very severe. The EQ-5D-3L was used to test the general well-being of this population by measuring self-reported difficulty with mobility, self-care, usual activities, pain/discomfort and anxiety/depression on a 3 point Likert scale from none or no problems (1), some problems (2), or extreme problems (3).<sup>31</sup> EQ-5D-3L internal consistency in this study was acceptable (McDonalds  $\omega = .57$ ), and the test-retest intraclass correlation coefficient was 0.54 (95% CI, 0.44-0.63; P < .0001).

### Describing the Experience of BAR

This section invited participants to describe their "in-themoment" experience of BAR and their thoughts about having had this experience. Participants were asked to rate statements describing thoughts and feelings associated with BAR<sup>15</sup> on a 5-point Likert scale rating from agree (1) to disagree (5). Respondents were also asked to score their pain associated with BAR on a 10-point scale (0 = no pain to 10 = the worst painpossible) and to rate their experience of pain associated with BAR on a 6-point Likert-type scale (1 = no pain to 6 = excruciating). Validated scales were included in this section to measure pain descriptors and participants' general levels of anger. The SFMPQ<sup>32</sup> was presented to respondents to determine if validated pain descriptors appropriately described their experience of BAR. The SFMPQ items are measured on an 11-point numeric rating scale (0-1 = none/very mild, 2-5 = mild, 6-8 =moderate, 9-10 =worst). Participants were asked to rate whether any of 22 pain words described their feelings of BAR (eg, throbbing, stabbing, pain caused by light touch, itching, sickening). SFMPQ internal consistency in this study sample was very good (Cronbach's  $\alpha = .87$ ). This section included the DAR-5, which measures anger frequency, intensity, duration, antagonism, social relations interference, and the impact on functioning over the previous 4 weeks. The DAR-5 has been validated in Australian populations to measure problematic anger.<sup>33</sup> DAR items are scored on a 5-point Likert scale (1 =none of the time to 5 =all the time); scores for all items are summed (total range = 5-25), with scores above 12 indicative of psychological distress and functional impairment because of anger. DAR internal consistency in this study was very good (Cronbach's  $\alpha = .84$ ).

### Onset of BAR and Breastfeeding Difficulties with Each Child

This section included multiple-choice questions with an open-text option about when participants first experienced BAR and if respondents had also experienced other breastfeeding difficulties such as nipple pain. Multiple-choice items with an open-text response option also inquired about the birth and individual breastfeeding experience for each infant who the participant had breastfed.

### Coping With BAR and Support from Others

Questions investigated participants' resilience and their experiences of receiving support from others (peers, family, and health care providers). This included multiple-choice questions and Likert-type items about coping strategies used when experiencing BAR. The BRS is a validated scale used to measure personal resilience and the ability to adapt and bounce back from stress and adversity.<sup>34</sup> Scoring categories for this scale are 1.00 to 2.99 = low resilience, 3.00 to 4.30 = normal resilience, and 4.31 to 5.00 = high resilience.

### **Data Analysis**

Data was cleaned and analyzed using SPSS statistical analysis software. Frequency tables were exported from SPSS to Excel to investigate the data. Variables were analyzed using descriptive frequencies, means, and SDs. All participants in this study self-identified as currently experiencing BAR at the time of completing the survey, so there was a preconfirmed correlation between respondent's experience of BAR and survey variables.

Table 1. Demographic Characteristics of Study Participants			
	Distribution of		
	Responses		
Demographics	n (%)		
Age range $(n = 208)$ , y			
18-24	11 (5.3)		
25-30	68 (32.7)		
31-35	76 (36.5)		
36-40	43 (20.7)		
41-50	10 (4.8)		
Relationship status ( $n = 209$ )			
Single	7 (3.3)		
De facto	46 (22.0)		
Married	155 (74.2)		
Other	1 (0.5)		
Level of education $(n = 208)$			
High school	24 (11.5)		
Trade certificate	17 (8.2)		
Diploma or advanced diploma	29 (13.9)		
Bachelor's degree	75 (36.1)		
Postgraduate qualification	63 (30.3)		
Number of children $(n = 210)$			
1	168 (80)		
2	42 (20)		
3+	0 (0)		
Place of birth for first child $(n = 210)$			
Public hospital	145 (69.0)		
Private hospital	37 (17.6)		
Home or another community location	11 (5.2)		
Birth center	17 (8.1)		

### RESULTS

In total, 533 participants clicked on the survey link. Participants who did not give consent were removed during data cleaning (n = 42). Screening questions removed an additional 108 responses from those who were not within Australia, and 173 responses were removed due to missing values and zero progress. This left a final sample of 210 with a response rate of 39.4%.

### **Descriptive Demographics**

Most respondents were aged between 25 and 40 years (89.9%), had education beyond high school (66.4%), were married or in a de facto relationship (96.2%), and had one child (80%). No participants reported having more than 2 children. The place of birth was most frequently reported as a public hospital (69%) and least frequently at home or other location (5.2%). (Table 1).

### **Health-Related Characteristics**

Table 2 details the health-related characteristics of respondents. The DASS-21 mean scores from this study showed that

Table 2. Health-Related Characteristics of ParticipantsCurrently Experiencing BAR			
Medical History and Sleep	Value		
(n = 208)	n (%)		
Current medications			
Oral contraceptive	25 (12.0)		
Anxiety medication	8 (3.8)		
Antipsychotic	2 (1.0)		
Antidepressant or SSRI	15 (7.2)		
Thyroid medication	17 (8.2)		
Regular pain medication	5 (2.4)		
Medication to increase milk supply	3 (1.4)		
CBD oil	1 (0.5)		
Blood pressure medication	3 (1.4)		
No medication	131 (63.0)		
Neurologic conditions			
Sensory processing disorder	3 (1.4)		
Autism or Asperger's	2 (1.0)		
Anxiety disorder	58 (27.9)		
Postnatal anxiety	3 (1.4)		
Depression	3 (1.4)		
Postnatal depression	37 (17.8)		
Posttraumatic stress disorder	15 (7.2)		
Bipolar disorder	2 (1.0)		
Dissociative disorder	1 (0.5)		
None of the above	123 (59.1)		
Endocrine conditions			
Cushing's syndrome	2 (1.0)		
Addison's disease	2 (1.0)		
Hyperthyroidism	3 (1.4)		
Hypothyroidism	18 (8.6)		
Hypopituitarism	2 (1.0)		
Lupus	1 (0.5)		
None of the above	185 (88.1)		
Menstrual conditions			
Premenstrual dysphoric disorder	6 (2.9)		
Amenorrhea	5 (2.4)		
Dysmenorrhea	12 (5.8)		
Polycystic ovary syndrome	18 (8.7)		
Menorrhagia	13 (6.3)		
Endometriosis	14 (6.7)		
Irregular periods	29 (13.9)		
Premenstrual tension syndrome	10 (4.8)		
"I have not had any menstrual problems"	79 (38.0)		
None of the above	53 (25.5)		

(Continued)

Table 2. (Continued)	
Medical History and Sleep	Value
(n = 208)	n (%)
Average h of sleep per night	
<5	23 (11.1)
5-7	141 (67.8)
7-9	43 (20.7)
>9	1 (0.5) <sup>a</sup>

Abbreviations: BAR, breastfeeding aversion response; CBD, cannabidiol; SSRI, selective serotonin reuptake inhibitor. <sup>a</sup>Some percentages total greater than 100 because respondents could choose

multiple answers.

those most who experienced BAR had normal levels of anxiety, depression, and stress, however a small proportion had slightly elevated levels of mild to very severe anxiety, mild and moderate depression, and moderate to severe stress. These results are similar to previous DASS-21 findings for Australian and New Zealand mothers (N=3601) who predominately scored in the normal range for levels of anxiety (80.8%), depression (71.1%), and stress (72.1%). Respondents' mean scores for the EQ-5D-3L were similar to previous validation research Australian age and sex population norms for mobility, self-care, pain and discomfort.<sup>31</sup> Respondents mean scores for the EQ-5D-3L were similar to Australian age and sex population norms for mobility, self-care, pain and discomfort.<sup>31</sup> This BAR population scored predominatly level 1 (no problems) for all EQ-5D-3L categories (Table 3 and 4).

### **Breastfeeding Difficulties and Onset of BAR**

Complications with breastfeeding were commonly reported by respondents. The most frequent breastfeeding difficulty with the first child was "feelings of aversion while breastfeeding" (80.7%), followed by "nipple pain" (69.6%), "engorgement" (49.7%), and "mastitis" (34.8%). The most reported breastfeeding difficulties for the second child were "too much milk" or "engorged breasts" (48.7%), followed by "tongue tie" (35.9%).

Respondents most often reported the onset of BAR when breastfeeding their first child (44.8%) or when pregnant and breastfeeding a toddler (31%). For those who experienced BAR while breastfeeding during pregnancy, most reported that BAR began in the first 2 trimesters (41.5% and 47.7%, respectively) and that the feeling of BAR lasted throughout the entire breastfeeding session while the child was latched. Some respondents experienced BAR during and around the time of menstruation, with most reporting that BAR felt the strongest in the days leading up to their period (53.3%). Respondents who reported tandem breastfeeding predominately experienced BAR only with their oldest child (95.2%) (Table 5A, 5B).

### Describing the Experience of BAR

Participants responding to items describing the experience of BAR largely agreed with each statement, most strongly agreeing with "I feel guilty for feeling like that" (84.2%). When describing the in-the-moment feelings of BAR, respondents most often agreed with the statement "as soon as I stop breastfeeding that feeling stops" (87%). Statements women

Table 3. DASS-21 Results <sup>51</sup>			
DASS-21	Depression	Anxiety	Stress
n=186	n (%)	n (%)	n (%)
Normal	125 (67.2)	126 (67.7)	113 (60.1)
Mild	25 (13.4)	18 (9.7)	19 (10.1)
Moderate	26 (14.0)	22 (11.8)	28 (14.9)
Severe	2 (1.1)	11 (5.9)	22 (11.7)
Very severe	8 (4.3)	9 (4.8)	6 (3.2)
Total	186 (100)	186 (100)	188 (100)

Abbreviation: DASS-21, Depression, Anxiety, and Stress Scale short form.

Table 4. EQ-5D-3L Results					
	Mobility	Self-Care	Usual Activity	Pain/Discomfort	Anxiety/Depression
EQ-5D-3L	n (%)	n(%)	n (%)	n (%)	n (%)
Level 1	192 (93.2)	202 (98.5)	161 (78.5)	148 (72.2)	111 (54.4)
No problems					
Level 2	14 (6.8)	3 (1.5)	42 (20.5)	54 (26.3)	82 (40.2)
Some problems					
Level 3	-	-	2 (1.0)	3 (1.5)	11 (5.4)
Extreme problems					
Total	206 (100)	205 (100)	205 (100)	205 (100)	204 (100)

Table 5A. Breastfeeding Difficulties With Each Child and Onset and Duration of BAR (Part 1)

Have You Had Any of the	Distribution of Responses		
Following Problems When	Eldest Child 1	Child 2	
Breastfeeding This Child?	n = 161	n = 39	
(Choose All That Apply)	n (%)	n (%)	
I had sore nipple pain	112 (69.6)	11 (28.2)	
Felt embarrassed around others	49 (30.4)	1 (2.6)	
I experienced mastitis/infection	56 (34.8)	11 (28.2)	
Too much milk/engorged breasts	80 (49.7)	19 (48.7)	
Infant had colic/irritable/crying	52 (32.3)	5 (12.8)	
Not enough milk	25 (15.5)	3 (7.7)	
Infant had lactose intolerance	11 (6.8)	2 (5.1)	
Infant had tongue tie	42 (26.1)	14 (35.9)	
Feelings of aversion (BAR)	130 (80.7)	8 (20.5)	
None of the above	1 (1.9)	1 (2.6)	

identified that were specifically assessing emotional aspects of BAR were sadness (81.3%), anger (79%), worry (71.6%), and anxiety (63.7%) (Table 6A, 6B).

### **BAR** and Types of Pain

Most respondents described mild discomfort (44.8%) when experiencing BAR. The mean (SD) score participants attributed to their pain during BAR was 3.6 out of 10 (2.69) (Table 6A,6B). The majority (18/22) of pain descriptors in the SFMPQ were rated with mean scores under 0.2 (no pain to very mild). Those who experienced BAR did not rate most pain descriptors in the SFMPQ as suitable for describing their experience; only "tiring" and "sickening" rated as somewhat explanatory of the sensation of BAR. The mean (SD) BRS for this population was 2.91 (1.03), consistent with the lower resilience group (<2.99). Likewise, the mean (SD) score on the DAR was 9.55 (3.49), indicating participants did not experience problematic levels of anger (<12).

### **BAR Personal Management and Support from Others**

Respondents were asked about practices they used to manage BAR in the moment while breastfeeding. "Distracting self" was the most common personal technique used to continue breastfeeding (83.8%). Other self-identified strategies were stopping the child from "twiddling" the other nipple while feeding (59.5%), breathing techniques (55.8%), reducing the length of each feeding session (53.3%), and reducing the number of feeds per day (45.2%). The strategies that users reported as most helpful to manage BAR was distracting self (53.8%), followed by taking or using magnesium (36.7%) and helpful company (36.4%) (Table 7A, 7B).

### Support From Others for the Experience of BAR

Most participants reported receiving some support from friends, family, or people in the community, with only 13.9%

Table 5B. Breastfeeding Difficulties With Each Chil           and Duration of BAR (Part 2)	d and Onset
When Does BAR Happen?	n (%)
When did the BAR feelings first start? $(n = 210)$	
When I was breastfeeding my first child	94 (44.8)
When I was pregnant and breastfeeding my	65 (31.0)
toddler	
When my period returned	15 (7.1)
When tandem breastfeeding both my toddler and	21 (10.0)
newborn	
Other	15 (7.1)
When during the breastfeeding session?	
(n = 210)	
Throughout the entire breastfeeding session	161 (76.7)
while latched	
Only the first few minutes of the breastfeeding	28 (13.3)
session	
Only during the letdown reflex or when latching	11 (5.2)
None of these describe my experience	7 (3.3)
Other, please describe	3 (1.4)
When during the menstrual cycle?	
(n = 15)	
It feels strongest in the days before my period	8 (53.3)
It feels strongest during my period	2 (13.3)
It feels strongest when I'm ovulating	2 (13.3)
I'm not sure	3 (20.0)
With which child when tandem feeding?	
(n = 21)	
Both tandem feeding children	1 (4.8)
Only the oldest child	20 (95.2)
When during pregnancy did BAR begin?	
(n = 65)	
In the first trimester (first 12 wk)	27 (41.5)
In the second trimester (13-26 wk)	31 (47.7)
End of the pregnancy in the third trimester	7 (10.8)

Milk supply decreased during pregnancy when 42 (64.6) BAR increased

Abbreviation: BAR, breastfeeding aversion response.

(27-40 wk)

indicating they received no support from others. Respondents' partners were most frequently reported (61%) to provide specific support for BAR. Online, phone, and group support services were commonly used by participants, including online breastfeeding support groups (43.8%), ABA phone counseling (21.2%), and in-person ABA or an inperson breastfeeding support group (13%). Some respondents reported that family members had discouraged them from breastfeeding (11.6%), whereas online peer/community support groups were considered the most encouraging (69.7%). Midwives (25.5%) and certified lactation consultants (24.5%)

Table 6A. Describing the Experience of BAR (Part 1)			
When You Think About Your Experience of Feelings of Aversion		Neither Agree nor	
While Breastfeeding, Do You Agree or Disagree With the Following	Agree	Disagree	Disagree
Statements?	n (%)	n (%)	n (%)
As soon as I stop breastfeeding, that feeling stops (n = 209)	181 (87)	8 (3.8)	19 (9.2)
I feel touched out $(n = 174)$	143 (82.1)	15 (8.6)	16 (9.2)
It is as if my body is telling me that I've got to stop $(n = 169)$	103 (60.9)	28 (16.6)	38 (22.4)
It almost feels like I am being violated ( $n = 167$ )	106 (63.4)	15 (9)	46 (27.6)
I just start feeling angry ( $n = 167$ )	132 (79)	13 (7.8)	22 (13.2)
When my child twiddles the other nipple, it gives me BAR (n = 167)	120 (71.9)	35 (21)	12 (7.2)
It's a sudden homesick feeling of dread and despair (n = 168)	80 (47.6)	21 (12.5)	67 (39.9)
It gives me a sense of anxiety about breast feeding $(n = 209)$	133 (63.7)	27 (12.9)	49 (23.5)
I feel guilty for feeling like that $(n = 190)$	165 (84.2)	8 (4.1)	23 (11.7)
It makes me feel sad $(n = 190)$	154 (81.3)	16 (8.4)	20 (10.5)
I don't feel ready for breastfeeding to end $(n = 190)$	152 (80)	13 (6.8)	25 (13.2)
I'm worried that I will have to wean before my child is ready (n = 190)	136 (71.6)	23 (12.1)	31 (16.3)
I enjoyed breastfeeding up until I was pregnant/tandem (n = 187)	85 (45.5)	73 (39)	29 (15.5)
People talk about enjoying breastfeeding, I never understood what	42 (22.3)	14 (7.4)	133 (70.3)
they meant $(n = 189)$			
It's a disconnect between wanting to breastfeed but having negative	153 (81.4)	23 (12.2)	12 (6.4)
feelings (n = 188)			
Does BAR Affect Your Time Spent Breastfeeding? (n = 210)	Most of the Time	About Half of the Time	Rarely
	n (%)	n (%)	n (%)
Do you end breastfeeding session early because of BAR?	110 (52.4)	61 (29)	39 (18.6)
Do you need to take breaks during breastfeeding because of BAR?	114 (54.5)	60 (28.7)	35 (16.7)

Table 6B. Describing the Experience of BAR (Part 2)	
Pain From BAR	n (%)
To what degree would you describe BAR as	
physically painful? $(n = 210)$	
No pain/mild rating 0-2	84 (40)
Discomforting rating 3-5	69 (32.9)
Distressing rating 6-8	36 (17.1)
Excruciating rating 9-10	21 (10)
The worst time of the day for BAR $(n = 210)$	
Morning and daytime	21 (10)
Evening and nighttime	122 (58.1)
All day	51 (24.3)
Unsure	16 (7.6)

Abbreviation: BAR, breastfeeding aversion response.

had the highest reported frequency of providing support for BAR. Many respondents however reported they received no support from health care providers (46%) when experiencing BAR. (Table 8A, 8B).

### DISCUSSION

This is the first study to specifically explore predisposing, precipitating, and perpetuating factors of BAR and the de-

mographics and health characteristics of those who have had this experience. This article describes the onset of BAR and investigates this phenomenon within the context of other breastfeeding challenges that may be experienced concomitantly. This research uncovered participants' personal management strategies for BAR and examined support systems women had in place that were helpful. The findings highlight that BAR is a complex phenomenon, and these results contribute to a greater understanding of describing the feelings and physical sensations of BAR: how BAR differs from other negative breastfeeding sensations such as D-MER; what is BAR and how it is different from D-MER; when BAR happens and why; who is more likely to experience BAR; and what support can be helpful.

### Describing the Feeling of BAR

This study identified new language to describe the experience of BAR. Previous available research on BAR has found that those who experienced this challenge had difficulty finding the right words to describe their experience.<sup>15</sup> To support women who experience BAR, midwives and perinatal health care providers need appropriate communication strategies to ask about complex breastfeeding challenges including BAR. Pain descriptors identified in this study included affective pain words, such as "tiring," "exhausting," and "sickening." Sensations of BAR were described as "touched out"; "feeling

Table 7A.	Descriptive Statistics for the Personal Management of
BAR and Se	elf-Identified Coping Strategies (Part 1)

Personal Approaches Used to Manage	Frequency
BAR $(n = 210)$	n (%)
Distracting self, thinking about	176 (83.8)
something else	
Self-harming: biting, pinching,	5 (2.5)
scratching self	
Using phone to distract self	23 (11.5)
Reducing the length of each feeding	112 (53.3)
session	
Reducing the number of feeds per day	95 (45.2)
Night weaning	57 (27.1)
Stopping child "twiddling" other	125 (59.5)
nipple while feeding	
Not feeding 2 infants at once	34 (16.2)
Breathing technique	116 (55.8)
Meditation technique	28 (13.5)
Other relaxation technique	22 (10.6)
Eating or drinking	49 (23.6)
Taking or using a form of magnesium	49 (23.6)
Taking another nutritional supplement	18 (8.7)
Having another person with you,	44 (21.2)
company	
"I didn't use anything to manage my	12 (5.7)
feelings of BAR"	

violated"; feeling angry, sad, dread, anxiety, guilt, or worry; and feeling a disconnect between wanting to breastfeed and having negative feelings. These findings are consistent with previous studies that have described similar participant sensations such as feeling violated,<sup>15</sup> touched out, and exhausted.<sup>15,35</sup> This study validates that these descriptors accurately describe the experience of BAR.

### Pain and BAR

Many women in this study who experience BAR also experienced other breastfeeding difficulties such as nipple trauma and tongue tie in their newborn. These are common breastfeeding complications related to latch difficulties which are associated with nociceptive breastfeeding pain.<sup>36</sup> Previous research<sup>36</sup> exploring pain and breastfeeding with the SFMPQ found that most pain was experienced with initial breastfeeding-associated nipple trauma and was described using different pain descriptions than those used to describe BAR. When specifically asked to rate the experience of physical pain with BAR, participants reported that BAR was associated with low levels of physical pain. Also, participants did not choose nociceptive descriptors when describing BAR and instead chose affective pain descriptors, which refer to the suffering quality of pain and feelings of being unpleasant or aversive.<sup>37</sup> The affective descriptor "tiring" was shared by those who experience BAR or early breastfeeding pain. However, unlike BAR, breastfeeding pain associated with nipple trauma and tongue tie was predominantly described using continuous and intermittent pain descriptor words such as "sharp," "stabbing," "burning," and "shooting." This study has shown that the experience of BAR is not one predominantly of nociceptive pain and is instead an experience arising from feelings and emotions of affective sensations of aversion.

### Comparison of BAR and D-MER

Women in this study experienced BAR throughout the feeding session while their child was latched, which contrasts with the experience of D-MER. Previous descriptive research on D-MER found that participants were more likely to experience D-MER during the letdown reflex within the first 1 to 5 minutes of the feeding session.<sup>38</sup> However, if there are multiple letdown reflexes during a feeding session, the feeling of D-MER may occur on and off throughout the feed.<sup>24</sup> When describing the sensation of BAR in this study, participants least agreed with the descriptors "dread" and "despair," which were taken from previous research describing the feelings of D-MER.<sup>38</sup> Although BAR and D-MER are both negative embodied sensations that are felt while breastfeeding, this study has identified that they are distinct breastfeeding difficulties.

Table 7B. Descriptive Statistics for the Personal Management of BAR and Self-Identified Coping Strategies (Part 2)				
	Somewhat			
Please Rate How Helpful the Following	Not Helpful	Helpful	Very Helpful	Unsure
Measures Were in Managing BAR	n (%) <sup>a</sup>	n (%) <sup>a</sup>	n (%) <sup>a</sup>	n (%) <sup>a</sup>
Breathing (n $=$ 116)	7 (6.0)	89 (76.7)	18 (15.5)	2 (1.7)
Mediation $(n = 27)$	5 (18.5)	18 (66.7)	4 (14.8)	
Relaxation method $(n = 22)$	8 (36.4)	13 (59.1)		1 (4.5)
Eating or drinking $(n = 48)$	6 (12.5)	38 (79.2)	3 (6.3)	1 (2.1)
Magnesium $(n = 49)$	6 (12.2)	16 (32.7)	18 (36.7)	9 (18.4)
Other nutritional $(n = 18)$	4 (22.2)	11 (61.1)	1 (5.6)	2 (11.1)
Helpful company ( $n = 44$ )	4 (9.1)	24 (54.5)	16 (36.4)	
Distracting self (39)	1 (2.6)	16 (41.0)	21 (53.8)	1 (2.6)

Abbreviation: BAR, breastfeeding aversion response.

<sup>a</sup>Some percentages total greater than 100 because respondents could choose multiple answers.

Table 8A. Support from Others (Part 1)	
Please Choose Any of the Following People	
Who Have Helped or Supported You Specifically	Frequency
With Your Experience of BAR? $(n = 187)$	n (%)
Partner	114 (61.0)
Parent	43 (23.0)
Other family members	28 (15)
Friend	69 (36.9)
Neighbor	2 (1.1)
People in your community, group, or club	22 (11.8)
Online friends or online community	74 (39.6)
None of the above	26 (13.9)
Health care providers $(n = 208)$	
Midwife	53 (25.5)
Certified lactation consultant	51 (24.5)
Counselor or other mental health care worker	17 (8.2)
Doula	5 (2.4)
Acupuncturist	1 (0.5)
GP	25 (12.0)
Maternal and child health nurse	36 (17.3)
Naturopath or herbalist	1 (0.5)
Obstetrician	3 (1.4)
None of the above	101 (48.6)
Phone, online or group support $(n = 208)$	
ABA phone support	44 (21.2)
13 Health phone support	2 (1.0)
In-person ABA, or in-person breastfeeding	27 (13.0)
support group	
Online breastfeeding support group	91 (43.8)
Phone counseling: Lifeline, Beyond Blue, or other	1 (0.5)
Online counseling: Lifeline, Beyond Blue, or	1 (0.5)
other	
None of these	11 (5.3)

Abbreviations: ABA, Australian Breastfeeding Association; BAR, breastfeeding aversion response; GP, general practitioner; N/A, not applicable.

### When Does BAR Happen and Why?

Most participants in this study who experienced BAR had this response to breastfeeding throughout the entire feeding session while the child was latched. This research has validated findings from previous qualitative research on BAR,<sup>15</sup> which identified that as soon as the breastfeeding session ends, the negative sensations of BAR may cease. Some participants who were menstruating reported that breastfeeding in the days leading up to their period was a trigger for BAR, which may imply neuroendocrinal contributing factors.<sup>39</sup>

### Who Is More Likely to Experience BAR?

Almost all participants in this study had also experienced other breastfeeding challenges when breastfeeding their first child. However, recent research suggests that breastfeeding challenges (ie, painful latch) may be ubiquitously common among breastfeeding women.<sup>40</sup> This study revealed that almost half of those who experienced BAR had this experience when breastfeeding their first child, and a further 41% of participants experienced BAR when breastfeeding while pregnant or tandem breastfeeding. These findings coupled with previous research on BAR may indicate that those who breastfeed while pregnant or tandem breastfeeding may have a heightened risk for experiencing BAR.<sup>15</sup>

At the time of this survey, those who experienced BAR were in otherwise good health and did not frequently take any medication. This population scored low resilience (<2.99) on the resilience scale included in this survey,<sup>41</sup> which may indicate that those who experience BAR may be less able to "bounce back" from hardship.42,43 However, it is unclear if this outcome indicates an independent (cause) or dependent (effect) result. Previous research has shown that a sample of women with constant pain scored lower resilience than those who were not suffering with constant pain<sup>43</sup> and that resilience can be affected by lack of social support and feelings of loneliness.<sup>43</sup> This population scored low to average mean scores of anger on the DAR-5, indicating that although participants described feeling angry while breastfeeding with BAR, they did not have ongoing functionally problematic anger.44 This population did not have any notable or defining demographic or health-related characteristics other than almost half were breastfeeding while pregnant or tandem breastfeeding.

### Strategies for Maintaining the Breastfeeding Relationship

This study found that one of the main ways women coped with BAR was by seeking support from others, primarily their partner and online peer support groups. Women used selfcare strategies to minimize the feelings of BAR such as taking supplements (eg, magnesium), staying well hydrated, and using breathing or meditation techniques to calm themselves during difficult feeding sessions. Some women set gentle breastfeeding boundaries with older children and used personal distraction as a coping tool when breastfeeding with BAR; however, the clinical effect of these strategies has not yet been tested. These recommendations must be considered in alignment with the individual needs, culture, and goals of those who breastfeed with BAR before being suggested for implementation.

### Maternal Mental Health and BAR

This study substantiates findings from previous research that found those who experienced BAR felt guilty, sad, and worried about their breastfeeding relationship.<sup>18</sup> Our study found that participants who experienced BAR claimed to have a sense of anxiety about breastfeeding; however, this population did not show levels of functional anxiety higher than the population normal.<sup>47</sup> This result may indicate that although those who experience BAR have higher levels of in-the-moment anxiety while breastfeeding, they did not have higher levels of ongoing anxiety throughout the day. For anxiety, depression, and stress, this population scored higher than Australian normative data for age and sex,<sup>31</sup> however when compared

Table 8B. Support from Others (Part 2)				
Did the Following People Encourage or Discourage	N/A	Encouraged	Neither	Discouraged
You With Breastfeeding?	n (%)	n (%)	n (%)	n (%)
Online peer support/online community $(n = 208)$	27 (13.0)	145 (69.7)	31 (14.9)	5 (2.4)
Partner (n $= 207$ )	5 (2.4)	160 (77.3)	38 (18.4)	4 (1.9)
Parent (n $= 208$ )	11 (5.30)	110 (52.9)	71 (34.1)	16 (7.7)
Other family members $(n = 207)$	15 (7.2)	86 (41.5)	82 (39.6)	24 (11.6)
Friend/s (n = $208$ )	4 (1.9)	100 (48.1)	94 (45.2)	10 (4.8)
Neighbor (n $= 207$ )	124 (59.9)	19 (9.2)	60 (29.0)	4 (1.9)
In person community, group, or club ( $n = 206$ )	72 (35.0)	63 (30.6)	63 (30.6)	8 (3.9)

with previous research on Australian mothers experiencing adversity, this cohort scored lower for depression, anxiety, and stress.<sup>45</sup> These findings show that previous research on anxiety and breastfeeding that reports breastfeeding mothers are less anxious may not reflect the full scope of the breastfeeding experience.<sup>46</sup>

### Support for Women Who Experience BAR

Women in this study confirmed previous findings on BAR reporting that those who experience this phenomena found it comforting to share their difficult breastfeeding journey with others and that being heard without judgment had encouraged participants to continue breastfeeding.<sup>15,18</sup> Our research supports previous research findings that women who are able to talk through difficult issues associated with shame, and find empathic connection with others, were more likely to have a more positive experience.48 Many in this study reported receiving the most useful support from their partners. It is unclear, however, if this finding was because those with supportive partners are more likely to breastfeed for longer.<sup>49</sup> Those who experience BAR need more support from health professionals and friends and family to continue breastfeeding, if that is their goal. Women experiencing BAR may want to continue to breastfeed, and many in this study felt worried that they may need to wean their child earlier than planned and did not feel ready for breastfeeding to end. Previous research identified that health care providers must approach breastfeeding support from a holistic perspective considering not just the physical aspects of breastfeeding but also the psychological and sociocultural processes involved.27

### Limitations

This study was a small exploratory study without a comparison group; therefore, we were unable to make comparisons to the general population. This sample may not be representative of all who experience BAR, and it is unknown if BAR is experienced in other geographic areas. This breastfeeding difficulty is likely underreported in some populations, such as those experiencing sensory processing disorder. Some item responses may have been affected by self-reporting or recall bias; however, the instruments used in this study were validated for self-reporting, and study items were aimed to specifically capture participant experience. Therefore, self-report was appropriate. The first author had a personal experience with BAR and was known to social media groups approached to participate in this study. This could represent insider bias; however, this limitation also has benefits in that as an insider the first author had greater knowledge of the target population, <sup>50</sup> and the first author recused herself from distribution of the study.

### Implications for Practice and Further Research

Midwives and other health care professionals working to support breastfeeding should be mindful that those who are breastfeeding while pregnant or tandem breastfeeding may have an increased risk for experiencing BAR. Women who experience negative sensations while breastfeeding without an obvious cause, such as nipple trauma, should be assessed for the symptoms and feelings described in this study and provided with additional support. Further research on the triggers for BAR could allow those working in lactation to consider preventive measures for this breastfeeding difficulty that may inform possible treatment options. Prevalence data on this phenomenon would be useful to target public health breastfeeding strategies aimed at increasing breastfeeding rates. Further research on the experience of BAR would be of benefit for this population and all stakeholders supporting positive breastfeeding outcomes.

### CONCLUSION

This is the first descriptive study to investigate the unique experience of BAR. This phenomenon is likely underreported, and these results add to the literature to provide evidence for midwives to help raise awareness and offer helpful support.

This study explored the experience, health characteristics, and risk factors of those who experience BAR and found that women who experienced BAR had higher levels of severe stress and anxiety. This study found that those who were able to breastfeed while experiencing BAR used strategies such as distracting self while feeding, taking a magnesium supplement, and helpful company. Participants also reported a lack of adequate support from health care professionals. More support and understanding for BAR is therefore needed to support women who have this experience to meet their own personal breastfeeding goals.

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### **CONFLICT OF INTEREST**

The authors declare no conflict of interest.

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### Journal of Midwifery & Women's Health

### **Research Article**

## Examining Enhanced Implementation of Routine Antenatal Care Practices to Support Healthy Pregnancy Weight Gain

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Introduction: Current antenatal guidelines advocate for regular weighing of women during their pregnancy, with supportive conversations to assist healthy gestational weight gain (GWG). To facilitate overcoming weight monitoring barriers, a pregnancy weight gain chart (PWGC), coupled with brief intervention advice, was implemented in 2016 to guide provider and woman-led routine weight monitoring. This study aimed to examine the extent to which the use of PWGCs and routine advice provision were normalized into routine antenatal care following enhanced implementation strategies and whether this led to a change in GWG.

Methods: This pre-post study included data from 2010 (preimplementation), 2016, and 2019 (postimplementation). A retrospective audit of health records and PWGCs was undertaken to assess adherence to chart use and evaluate GWG outcomes. A survey was sent to women in 2010 and repeated in 2019 to understand the advice women received from health care professionals.

Results: Compared with the preimplementation cohort (2010), more women achieved a healthy GWG in 2019 (42% vs 31%, P = .04). In 2019, having 3 or more weights recorded was associated with a reduction in excess GWG (P = .028). More women reported receiving helpful advice about healthy GWG in 2019 compared with 2010, although minimal changes to advice received about nutrition and physical activity were observed.

Discussion: Enhanced implementation strategies and ongoing efforts to optimize supportive antenatal care practices are required to effect positive change in GWG. Further evaluation of the perspectives of pregnant women and counseling practices of health professionals is needed. J Midwifery Womens Health 2023;68:449-457 © 2023 The Authors. Journal of Midwifery & Women's Health published by Wiley Periodicals LLC on behalf of American College of Nurse Midwives (ACNM).

> Keywords: pregnancy weight gain, weight monitoring, pregnancy weight gain chart, implementation, antenatal care, obesity, brief intervention advice

### INTRODUCTION

Excessive or inadequate gestational weight gain (GWG) is a growing public health issue that presents significant risks and poor health outcomes for women and their fetus.<sup>1,2</sup> It has been estimated that approximately two-thirds of Australian women gain an unhealthy amount of weight during their pregnancy, with the majority exceeding weight gain recommendations.<sup>3,4</sup> There are a growing number of women who enter pregnancy in the overweight or obese body mass index (BMI) category who are more likely to gain excess gestational weight compared with women who are in a healthy weight range.<sup>4</sup> Gaining more weight than the Institute of Medicine (IOM) guidelines recommend increases risk of pregnancy and birthrelated complications and chronic disease later in life.<sup>2,5</sup>

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Established guidelines<sup>2,6,7</sup> advocate for regular weighing of women during their pregnancy with a conversation about progress and influencing health behaviors to support healthy GWG, although this is not always practiced in the delivery of routine antenatal care.8,9 Barriers to providing best-practice care have been reported<sup>10</sup> and include lack of confidence in providing weight advice,<sup>11</sup> lack of awareness and education,<sup>12</sup> and a desire to have appropriate tools and resources to support weight monitoring and supportive conversations.<sup>10,13</sup> Pregnancy weight gain charts (PWGCs) are a tool that can facilitate provider and patient-led routine weight monitoring.<sup>14</sup> PWGCs are a means to track weight gain throughout pregnancy, providing an objective tool to place a weight measurement in the context of a woman's gestation to initiate discussions about GWG.14

Previous published work highlighted that the implementation of PWCGs and brief intervention advice at a large metropolitan birthing hospital in Queensland was feasible and well received by women<sup>9</sup> and, in the context of suboptimal implementation,<sup>15</sup> resulted in a reduction in excess GWG in women classified as a healthy weight prior to pregnancy.<sup>16</sup> However, sustained use of interventions such as PWGCs and brief intervention advice can be limited beyond the initial implementation phase. Very few studies have directly examined the implementation of PWGCs into routine antenatal care. From the literature available, key findings have demonstrated health care professional education as an important strategy

# Quick Points

- To support healthy gestational weight gain, implementation of pregnancy weight gain charts (PWCGs) and brief intervention advice have been shown to be feasible and well received by women.
- However, sustained use of such interventions can be limited beyond the initial implementation phase.
- This study reports on the fidelity of using PWGCs within routine antenatal care and provides an evaluation of improvements in care standards and clinical outcomes.
- This study also used enhanced implementation strategies to inform ongoing interventions and provide direction for future service improvements for sustainable PWGC use in routine antenatal care.

to support implementation.<sup>14,15,17</sup> Furthermore, it has been emphasized that targeted training content should consider identified barriers and enablers, implementation science literature, and perspectives of pregnant women and perinatal staff.<sup>17,18</sup> A gap in research continues to exist around how to normalize a change in health service delivery and embed these changes into routine practice beyond the initial implementation. The limited evidence in this area suggests that sustaining a change in practice requires ongoing action, the generation of evidence, and performance monitoring, through a theory-led analysis as well as an evaluation of participant responsiveness and uptake of the intervention.<sup>19,20</sup> The aim of this study was to examine the extent to which the use of PWGCs and brief intervention advice were normalized into routine antenatal care following enhanced implementation efforts and whether this has led to a change in GWG.

### METHODS

### Study Design

A pre-post study design was used to evaluate the provision of pregnancy weight gain advice and monitoring between 2010 (preimplementation) and 2019 (postimplementation). Comparisons include GWG and survey data from pregnant women in 2010 and 2019 to highlight the changes to antenatal advice provision and overall changes to GWG, following almost a decade of implementation and improvement activities. Additionally, comparisons between 2016 and 2019 are provided to demonstrate the changes to the use of PWGCs since their implementation in 2015. The study site was a large metropolitan birthing facility, where approximately 4500 women birth annually.

### Antenatal Care Service Context

A program of work spanning more than a decade involved the incremental implementation of interventions designed to improve pregnancy weight gain outcomes. Figure 1 summarizes the main time points for pre- and ongoing implementation and include research activities, implementation strategies, and antenatal health care worker activities that form the low-intensity antenatal interventions. The PRECEDE-PROCEED model of Health Program Planning was used to guide the entire process from preimplementation through to intervention development, implementation, and evaluation. The PRECEDE phases are summarized in the New Beginnings Healthy Mothers and Babies Study (New Beginnings), a

prospective observational study examining influences on weight gain and lifestyle behaviors during pregnancy and the postpartum period. New Beginnings describes the preimplementation work designed to understand practice related to supporting healthy pregnancy weight gain within the antenatal service and demonstrated a significant evidence practice gap.<sup>3,21</sup> New Beginnings identified the need to support women to achieve recommended pregnancy weight gain within antenatal care. Health care professionals and pregnant women formed the target populations of the antenatal interventions that followed, including the interventions reported in the Healthy Pregnancy Healthy Baby study.<sup>14,16</sup> Healthy Pregnancy Healthy Baby used a facilitated implementation approach to build capacity of health care professionals to change practice to support healthy pregnancy weight. Changes included service-wide health care professional training, the introduction of PWGCs, and the provision of scales and clear guidelines on the expectations of weight-related care and documentation. Two PWGCs were implemented in 2015 to guide women and health care professionals on the upper and lower range of healthy GWG for each prepregnancy BMI category; one was for women with a prepregnancy BMI <25kg/m<sup>2</sup>,<sup>22</sup> and one was for women with a prepregnancy BMI ≥25kg/m<sup>2</sup>.<sup>23</sup> A PWGC was to be established for all women during their first booking-in appointment at the birthing hospital and attached to their Pregnancy Health Record.

An initial audit of practice was undertaken in 2016 that identified high error rates in the PWGC dissemination to women, with inconsistent use.<sup>14</sup> After the 2016 audit, modifications were made to the charts in response to health care professional and consumer feedback to improve the usability. A tick box for the recommended GWG range based on prepregnancy BMI was added, the graph was made larger, and chart labeling was altered to make it easier to select the correct chart. Additional implementation strategies were used to normalize the use of the charts, improve errors, and address issues identified in the delivery of antenatal care. Implementation strategies were mapped to the Expert Recommendations for Implementing Change,<sup>24</sup> with an additional 12 strategies implemented between 2017 and 2019 (See Supporting Information: Appendix S1). This included greater saturation of education, further training to all health care professionals rotating through outpatient areas, addressing clarity of who completes the PWGC and when, and environmental changes, whereby a coordinating midwife completed the chart in specialist doctor clinics.

2010			201
	PRE	CEDE	PROCEED
New Begin 2010 - 20	nings )11	2014 - 2015	HPHB 2016 and HPHB follow-up audit 2019
A gradient constraints of the second	is 1 to 3 ssessment ness and and ent practice actice gap n and ubtain and umers	<ul> <li>PRECEDE Phases 4 to 5 Intervention alignment and implementation</li> <li>Stakeholder workshops and focus groups (inform local opinion leaders, build a coalition)</li> <li>Agreement on intervention activities (conduct local consensus discussions)</li> <li>Develop and implement tools for quality monitoring</li> </ul>	<ul> <li>Audit 1 (2016) and audit 2 (2019)</li> <li>Women's surveys (obtain and use patient feedback)</li> <li>Ongoing quality monitoring</li> <li>Provide ongoing consultation</li> <li>Remind clinicians</li> </ul>
lai Re		Facilitation, conduct ongoing train tec	ing, mandate changes, tailor strategies, provic hnical assistance
	Antenatal staff activities	<ul> <li>Attend mandatory training (40 minute session, annually)</li> <li>Include routine weighing into all antenatal appointments</li> <li>Use of pregnancy weight gain charts (PWGCs)</li> <li>Brief intervention advice</li> </ul>	<ul> <li>Mandatory training (40 minutes)</li> <li>Provide feedback on use of PWGCs and improvements</li> <li>Continue to include routine weighing/ weight tracking and brief intervention advice (implementing practice changes based on audit and feedback)</li> </ul>

Implementation, and Evaluation

Abbreviation: HPHB, Healthy Pregnancy Healthy Baby study, <sup>a</sup>Key implementation activities based on Expert Recommendations for Implementing Change taxonomy, See Supporting Information: Appendix S1 for full list of strategies including explanations.

### Participants and Data Collection

Preimplementation participants were from the New Beginnings study (preimplementation), described in detail elsewhere.<sup>3,21</sup> The postimplementation data were collected in 2019 as a follow-up audit. To show changes in PWGC provision and accuracy since their implementation in 2015, comparisons of a 2016 and the 2019 audits were made. Women in 2010 and 2016 provided written informed consent. For women in 2019, consent was implied through completion of the survey, and a waiver of consent for chart audit was granted for the purpose of quality improvement from the hospital Human Research Ethics Committee.

### Gestational Weight Gain

To understand the impact of implementing PWGC into routine antenatal care on GWG outcomes, anthropometric data obtained from women in the 2010 New Beginnings study were compared with the chart audits conducted in 2019. At the time of this study, the hospital did not have electronic health records, and therefore, all calculations were performed manually and handwritten. Self-reported prepregnancy weight and measured height recorded in the Pregnancy Health Records were used to calculate prepregnancy BMI. World Health Organization (WHO) classifications were used to categorize BMI in kilograms per square meter: underweight <18.5; healthy weight 18.5 to 24.9; and overweight  $\geq$  25.0 (comprising preobese 25.0-29.9 and obese  $\geq$  30.0).<sup>25</sup> Total GWG was calculated based on the difference between weight measured at 36 to 40 weeks' gestation and prepregnancy weight recorded in the Pregnancy Health Record. Women who did not have a prepregnancy weight recorded or a weight taken at 36 weeks'

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gestation or later were not included in the GWG analysis. Total GWG was evaluated against the IOM Guidelines<sup>2</sup> for each prepregnancy BMI category to determine the proportion of women with inadequate, healthy, and excess GWG.

### Pregnancy Weight Gain Charts

In 2016 an audit was undertaken of PWGCs of women participating in the Healthy Pregnancy Health Baby Study, which has been previously described.<sup>14</sup> In 2019, Pregnancy Health Records were accessed for a sample of women who gave birth between January and August that year. Data obtained from the Pregnancy Health Record included prepregnancy weight, height, booking-in weight, calculated BMI, last weight recorded before birth and gestation, antenatal model of care, and whether a PWGC was provided. A copy of the PWGC was taken for women at 36 weeks' gestation or later for auditing purposes. If available, information recorded from the PWGC included calculated prepregnancy BMI, accuracy of prepregnancy BMI calculation, correct chart provided, gestation at first weight recorded (weeks), frequency of weight monitoring during pregnancy, and specific errors identified. PWGC use, including the proportion with 3 or more weights recorded, and accuracy were compared using the 2016 and 2019 chart audit data. Three or more weights recorded was recommended, as this aligned with the minimum number of visits to the midwife at the hospital.

Age, parity, and country of birth information was also obtained from the Pregnancy Health Record. Country of birth was used as opposed to ethnicity because it is more consistently reported in the Pregnancy Health Record.

### Advice Received by Health Care Professionals

In both 2010 and 2019, surveys were sent to women (>35 weeks' gestation) receiving antenatal care at the study site. The surveys were designed to understand what advice women received from their antenatal team regarding GWG, healthy eating, and physical activity. The survey questions were altered in 2019 from asking women about advice from all health care professionals (relating to antenatal care) to specifically asking about the advice provided from their doctor and midwives, as the nature and intensity of implementation strategies was different for each discipline.

### **Ethical Considerations**

This study was conducted in accordance with all necessary ethical principles and approved by the Human Research Ethics Committee of the birthing hospital (HREC/14/ QRBW/491).

### **Statistical Analysis**

Analyses were performed using SPSS (Version 25). Continuous variables were examined for normality using descriptive statistics and histograms. Mean and SD are reported for normally distributed data; median and interquartile range are reported for skewed data. Descriptive statistics were used to examine population characteristics and outcomes. Difference between groups used *t* tests or  $\chi^2$  for continuous and categorical variables, respectively. Logistic regression, stratified for WHO prepregnancy BMI classification, examined the association between the 2010 and 2019 GWG according to the IOM GWG recommendations (adequate, inadequate or excessive) and controlling for prepregnancy BMI, age, gestation at final weight measurement, and parity.

The criterion for statistical significance was set at the conventional level of P < .05 (2 tailed) for all analyses. All available data were used in analysis; no data were imputed.

The sample size was calculated based on categorical variables, as these are known to have higher sample size requirements than continuous variables. All calculations were established using a 95% CI with a 0.05 significance level. The prevalence of excess weight gain has previously been estimated to be approximately 40%; therefore, it was determined that a sample size of 354 women was necessary to detect this difference in excess GWG.<sup>3</sup>

### RESULTS

Total participant numbers and characteristics for each time point are shown in Table 1. A detailed description of the New Beginnings study cohort (2010)<sup>3,21</sup> and Healthy Pregnancy (2016) study<sup>14</sup> cohort have been described elsewhere. Briefly, the New Beginnings (preimplementation) cohort totaled 715 from 1059 eligible women (67%),<sup>3,21</sup> whereas in the Healthy Baby Healthy Pregnancy 2016 cohort (postimplementation), 478 women consented to participated from 590 women approached (81%).<sup>18</sup> In 2019, 472 Pregnancy Health Records were accessed, and 187 women responded to the survey. Women in the 2010 cohort tended to be younger than in

# Table 1. Characteristics of Women With Complete DataParticipating in the Preimplementation (2010) andPostimplementation (2019) Cohort Examining Routine AntenatalCare for Supporting Healthy Pregnancy Weight Gain

	<b>2010</b> <sup>a</sup>	<b>2019</b> <sup>b</sup>
Characteristics	(n = 417)	(n = 354)
Age, mean (SD), <sup>c</sup> y	30.0 (5.0)	31.5 (5.0)
Nulliparous, n (%) <sup>c</sup>	248 (60)	159 (49)
Prepregnancy BMI, mean (SD)	24.1 (4.8)	24.1 (4.8)
Underweight, n (%)	18 (4)	24 (7)
Normal weight, n (%)	257 (62)	223 (63)
Overweight, n (%)	97 (23)	67 (19)
Obese, n (%)	45 (11)	40 (11)

Abbreviations: BMI, body mass index; GWG, gestational weight gain. <sup>a</sup>Recruited participants, 2010, n = 715.

<sup>b</sup>Audited records, 2019, n = 417.

<sup>c</sup>P < .05.

2016 and 2019 (Table 1, P < .01). There was a greater number of women in the 2010 cohort who were nulliparous compared with the other 2 years (Table 1, P < .01). There were no statistically significant differences in prepregnancy BMI among the 3 groups.

### **Gestational Weight Gain**

Complete GWG data were available for 58% (n = 417) of women in 2010 and 75% (n = 354) of women in 2019. Table 2 outlines GWG outcomes for each prepregnancy BMI category. The use of logistic regression to adjust for BMI, age, parity, and gestation at final weight did not change the statistically significant differences detected using a  $\chi^2$  analysis. Overall, more women in 2019 achieved a healthy GWG compared with women in 2010 (42% vs 31%, P = .04, Table 2). Women in 2019 who commenced their pregnancy with a BMI in the obese category were more likely to achieve a healthy GWG and less likely to gain inadequate weight, compared with women in the same BMI category in 2010 (Table 2). Similarly, more women in the underweight BMI category appeared to gain a healthy GWG in 2019, although the number of participants in this BMI category was too small to demonstrate a statistically significant difference.

### Implementation of the PWGCs

In 2019, 312 PWGCs were available in the Pregnancy Health Records accessed, reflecting a chart dissemination rate of 66%. Of the 458 charts that had BMI calculations available, 6% (n = 29) of BMI calculations recorded in the Pregnancy Health Record were incorrect, and this affected the appropriate weight gain recommendation in 45% (13/29) of these cases. Since 2016, there was an improvement in the provision of the correct PWGC based on prepregnancy BMI (93% in 2016 vs 98% in 2019; P = .003), and there was an increase in the proportion of PWGCs that were established correctly (accurate prepregnancy weight, height BMI calculation, and correct GWG recommendation; 74% in 2016 vs 82% in 2019; P = .016), demonstrating a reduction in error rates (Table 2).

			ð		Healthy	Healthy				
			Underweight	Underweight	Weight	Weight	Preobese	Preobese	Obese	Obese
	All Women	All Women	2010	2019	2010	2019	2010	2019	2010	2019
Weight Gain	2010	2019	n = 18	n = 24	n = 257	n = 223	n = 97	n = 67	n = 45	n = 40
Measure	n = 417	n = 354	(4%)	(2%)	(28%)	(63%)	(21%)	(19%)	(10%)	(11%)
Total GWG at	13.5 (6.6)	13.4 (4.9)	14.1 (3.9)	14.1 (2.1)	14.4(5.4)	13.8 (4.7)	13.6 (6.2)	13.5 (5.5)	7.7 (8.1)	10.3 (5.2)
$\sim 36$ weeks'										
gestation, mean										
(SD), kg										
Inadequate	113 (27)	79 (22)	7 (39)	6 (25)	78 (30)	62 (28)	6 (6)	5 (7)	19 (42) <sup>c</sup>	6 (15) <sup>c</sup>
$GWG^{b}$ , n (%)										
Healthy GWG <sup>b</sup> ,	139 (33) <sup>c</sup>	150 (42) <sup>c</sup>	9 (50)	17 (71)	97 (38)	100(45)	26 (27)	19 (28)	7 (16) <sup>d</sup>	14 (35) <sup>d</sup>
n (%)										
Excess GWG <sup>b</sup> ,	165 (40)	125 (35)	2 (11)	1(4)	82 (31)	61 (27)	62 (64)	43 (64)	19 (42)	20 (50)
n (%)										

 $^{b}$ GWG defined by inadequate, healthy, and excess according to the Institute of Medicine guidelines for each weight category (underweight 12.5-18 kg, healthy weight 11.5-16 kg, preobese 7-11.5 kg, and obese 5-9 kg).  $^{c}P < .01$  for difference between 2010 and 2019.  $^{d}P < .05$  for difference between 2010 and 2019.

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Table 3. Comparison of Pregnancy Weight Gain Chart Use and Accuracy in 2019 to 2016					
	2016	2019			
Outcome	n = 275	n = 312	P Value		
PWGC established correctly, n (%)	204 (74)	257(82)	.016		
3 or more weights plotted	125 (45)	192 (62)	<.001		
PWGC with specific errors, n (%)	71	55			
Incorrect or no weight recorded on chart axis	42 (60)	4 (7)	<.001		
Incorrect weight, height, or BMI on calculation	11 (15)	16 (29)	<.001		

Abbreviations: BMI, body mass index; PWGC, pregnancy weight gain chart.

### **Table 4.** Women Reporting Sometimes, Usually, or Always Being Provided With Advice From Health Care Professionals (2010) and Doctorsand Midwives (2019) Relating to Supporting Healthy Pregnancy Weight Gain at 36 Weeks' Gestation

		2010		
		Health Care	2019	2019
		Professional	Doctor	Midwife
		Sometimes,	Sometimes, Usually,	Sometimes, Usually,
	Supportive Advice Item: "The health care	Usually, Always	Always	Always
	professionals who have cared for me since I	(n = 495)	(n = 187)	(n = 187)
Domain	became pregnant"	n (%)	n (%)	n (%)
Healthy eating	Ask me about the foods I eat	190 (39)	67 (36)	79 (42)
	Encourage me to eat healthy foods	286 (58)	115 (62)	117 (63)
	Criticize the foods I eat	14 (3)	6 (3)	10 (5)
	Give advice about the amount of food to eat	103 (21)	59 (32)	59 (32)
	Give advice about how to plan and prepare	65 (13)	24 (13)	31 (17)
Physical activity	Ask me about the physical activity I do	206 (42)	76 (41)	90 (48)
	Encourage me to be physically active	245 (50)	111 (59) <sup>a</sup>	103 (55)
	Advise me to limit the amount of activity I do	89 (18)	41 (21)	25 (13)
	Criticize me for not doing enough physical activity	14 (3)	5 (3)	5 (3)
	Offer advice about how to include physical activity in my day	100 (20)	49 (26)	64 (34) <sup>b</sup>
Healthy pregnancy	Encourage me to weigh myself regularly	53 (11)	39 (21) <sup>b</sup>	65 (35) <sup>b</sup>
weight gain	Check how much weight I have gained	173 (35)	102 (55) <sup>b</sup>	152 (81) <sup>b</sup>
	Offer advice about how much weight I should	127 (26)	85 (46) <sup>b</sup>	125 (67) <sup>b</sup>
	Offer me advice about how to gain the right amount of weight in my pregnancy	81 (16)	57 (31) <sup>b</sup>	87 (47) <sup>b</sup>

 $^{a}P < .05$  for difference between 2010 and 2019.

 ${}^{\rm b}P < .001$  for difference between 2010 and 2019.

Improvements in specific errors identified in 2019 (compared with 2016) are summarized in Table 3. Compared with 2016, there was a significant increase in the proportion of PWGCs with 3 or more weights plotted (45% in 2016 vs 62% in 2019; P < .001). Having 3 or more weights plotted in 2019 was associated with a reduction in excess GWG (50% excess GWG with <3 weights recorded vs 33% excess GWG with >3 weights recorded; P = .028). However, this was not seen with the 2016 cohort, potentially due to the smaller numbers (36% vs 29%; P = .429).

### Healthy Pregnancy Weight Gain Advice

The women's survey was answered by 495 of the 715 participants in the New Beginnings study (69% response rate). In 2019, there were 187 respondents to the survey (denominator unknown, Table 4). All survey items asking about weight gain advice from both doctors and midwives had significantly improved from 2010, whereas advice about physical activity and healthy eating largely remained unchanged (Table 4).

### DISCUSSION

The results of this study have shown promising developments in the implementation of PWGCs and brief intervention advice, with improved chart usage since the initial audit of practice in 2016. Incremental implementation efforts to improve pregnancy weight gain outcomes have resulted in small but clinically and statistically significant changes to healthy GWG since 2010. Since the introduction of PWGCs in 2016 and targeted implementation strategies to address key barriers for their use,<sup>14</sup> there have been improvements in the provision of the correct chart and the number of weights recorded and a greater accuracy in establishment. More women in 2019 had 3 or more weights plotted on the PWGC than in 2016, and as a result, these women were less likely to gain weight above the recommendations.

Improved distribution of the appropriate chart demonstrates the benefit and importance of gaining health care professional feedback to refine implementation approaches. Greater frequency of weight monitoring may be reflective of changes within health professional training and local practice guidelines to stipulate clear expectations in their responsibility to complete the chart at hospital appointments and provide adequate education for women to self-monitor between appointments. Common errors and strategies to overcome them were also incorporated into ongoing health care professional training, and this is likely to have supported the improved accuracy of chart establishment. It is reassuring to see these changes following sustained implementation efforts within the antenatal service, which further highlights the unique benefits of targeted strategies to address the local barriers in place.14,20

There is considerable debate in the literature as to what defines a *sustained* innovation or change in practice. Some argue that it must be measured in terms of fidelity, routinization, or continued use for a particular timeframe.<sup>19,26</sup> Four years since implementation, PWGCs are still in use, and ongoing improvements in utilization have been achieved. However, sustainability is a continuing process, requiring ongoing efforts.<sup>19,27</sup> Although progress toward routine practice may be achieved, sustainability is not an outcome but rather an enduring progression.<sup>19,27</sup>

There remain further opportunities to increase the uptake of PWGCs and several areas that should be addressed to enhance accurate utilization. Overall error rates have reduced since 2016; however, inaccurate recording of weight, height, and BMI calculations continue to affect chart establishment, with implications for providing the appropriate weight gain recommendation. Additionally, in more than one-third of the charts audited, GWG recommendation based on prepregnancy BMI was incorrectly or not identified on the PWGC. Misclassification of BMI and the subsequent misclassification of GWG recommendations is likely to impact on GWG as an outcome.<sup>28,29</sup>

Two studies have reported on the use of a weight gain chart and its impact on GWG,<sup>8,15</sup> although both were conducted under trial conditions and did not report on the fidelity of the intervention. Findings from Daley et al demonstrated small improvements in GWG between those in the intervention compared to the control group, whereas Aguilera et al reported no significant difference.8,15 Promising outcomes from this research was the association between frequency of weight monitoring and reduced excess GWG. PWGCs encourage regular weight monitoring, and although the benefit of this practice has been demonstrated in the present study, it remains controversial in existing literature. Fealy et al previously highlighted that routine weighing alone does not reduce excessive GWG,<sup>30</sup> whereas others have shown that weight monitoring, in conjunction with diet and physical activity interventions, appear to provide the most positive outcomes.<sup>31,32</sup> To this effect, the significance of using a PWGC extends beyond its role to track and identify patterns of weight gain outside of recommendations. Its value stems from providing positive reinforcement for those who are gaining within the recommended target, as well as supporting the opportunity to act and counsel women to achieve healthy GWG.<sup>2</sup> Several studies have evaluated GWG counseling from the perspectives of both pregnant women and perinatal health care professionals.<sup>33,34</sup> There is a consensus that a gap exists between health care professionals reported behaviors and pregnant women's perceptions of these discussions, suggesting that GWG counseling was lacking.8,14,33 The conversations and advice from health care professionals are likely to have a greater impact on GWG outcomes than the PWGC as a stand-alone intervention.<sup>32</sup> However, it is to be acknowledged that many women report experiencing weight stigma in perinatal care and that weight monitoring can be sensitive.<sup>35</sup> This highlights the importance of supporting health care professionals to deliver person-centered, individualized care, a key focus of the training within this study.

Recognizing patterns of excessive or inadequate GWG is a key role for health care professionals, guided by the use of a PWGC, but having the capacity to help women alter this trajectory is another matter in itself, arguably a greater priority for supporting healthy GWG.<sup>36</sup> Health care professionals are well placed to provide counseling and explore the weight management, nutrition, and physical activity concerns of pregnant women.<sup>32,37,38</sup> However, research suggests that perinatal professionals lack confidence in their knowledge and skills to support the management of healthy pregnancy weight gain,<sup>12,38</sup> highlighting that future opportunities lie within developing and improving the capacity of health care professionals to deliver GWG counseling. A component of the implementation strategies as part of this study included health care professional training focusing on brief intervention advice and communication skills, with midwives demonstrating improved knowledge and confidence to deliver care that supports healthy pregnancy weight gain.<sup>18</sup> Although it is encouraging to see a significant improvement in healthy weight gain advice provided to women between 2010 and 2019, the provision of nutrition and physical activity advice by health care professionals requires further work.

The findings of this study need to be considered in the context of several limitations and strengths. First, due to the practicalities of health services research, the data collection methods differed between the 2016 and 2019 audits. In 2016, pregnant women were recruited at their first antenatal visit and followed up at their 36- to 38-week appointment, where a

copy of their PWGC was taken to assess its use. This methodology provided a PWGC dissemination rate based on women reporting whether they received a chart. In 2019, Pregnancy Health Records and PWGCs were accessed independently by the research team. Consequently, the provision of PWGCs in the 2019 audit is likely to be a slight underestimate of the true dissemination rate and improvements in chart dissemination. Furthermore, the present study does not consider the perspectives of health care professionals delivering antenatal care, limiting identification of ongoing barriers to PWGC use, advice, and conversations surrounding GWG and the potential for feedback on using the charts. However, a strength of this research is that it reports on the fidelity of the intervention, regarding the use of the charts within routine antenatal care, and, by comparison to a previous audit undertaken at the site, it provides an evaluation of improvements in care standards. Continuing to enhance the implementation of PWGCs and embed their use in routine antenatal care is fundamental in the provision of best practice to support healthy pregnancy weight gain and management. The results of this study have assisted in evaluating the success of previous implementation strategies and will inform ongoing interventions and provide direction for future service improvements to ensure long-term sustainability of PWGCs in routine antenatal care.

### CONCLUSION

Four years since the introduction of PWGCs within the antenatal service and almost a decade since formative work commenced to improve healthy pregnancy weight gain, the use of PWGCs has become more frequent and accurate, resulting in statistically and clinically relevant improvements in GWG. There are opportunities to further improve the uptake and accurate utilization of PWGCs in routine antenatal care through ongoing implementation efforts, and future research must continue to consider the perspectives of pregnant women and the counseling practices of perinatal health care professionals.

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### **CONFLICT OF INTEREST**

The authors have no conflicts of interest to declare

### SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

**Appendix S1**. Expert Recommendations for Implementing Change (ERIC) strategies used to facilitate changes to routine care to support healthy pregnancy weight gain.

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**Research Article** 

# The Experiences of Black Community-Based Doulas as They Mitigate Systems of Racism: A Qualitative Study

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Introduction: Black pregnant individuals endure a disproportionate burden of preventable morbidity and mortality due to persistent, racially mediated social and systemic inequities. As patient advocates, Black community-based doulas help address these disparities via unique services not provided by conventional doulas. However, Black doulas themselves may encounter obstacles when providing care to Black perinatal clients. We characterized the barriers encountered by Black community-based doulas in Los Angeles, California.

Methods: We partnered with a Black community-based doula program to conduct semistructured interviews with its community doulas and program directors, covering the following topics: motivations for becoming a doula, services provided, and challenges faced as a Black doula in perinatal settings. Interview transcripts were reviewed via directed content analysis, with attention to the influence of systemic racism on service provision. Additionally, our research team used Camara Jones' Levels of Racism, which describes race-associated differences in health outcomes to code data.

Results: We interviewed 5 Black community-based doulas and 2 program directors, who all shared experiences of inequitable care and bias against Black clients that could be addressed with the support and advocacy of culturally congruent doulas. The community doulas shared experiences of stigma as Black doulas, compounded by racial prejudice. Interviewees noted sources of structural racism affecting program development, instances of interpersonal racism as they interacted with the health care system, and internalized racism that was revealed during culturally based doula trainings. Additionally, the doulas emphasized the importance of cultural concordance, or a shared identity with clients, which they considered integral to providing equitable care.

Conclusion: Despite facing institutionalized, interpersonal, and internalized forms of racism, Black community-based doulas provide avenues for Black birthing individuals to navigate systemic racism experienced during the perinatal process. However, these forms of racism need to be addressed for Black community doulas to flourish.

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### INTRODUCTION

Disparities in Black American health outcomes are rooted in racism and its attendant social and structural inequities.<sup>1,2</sup> For Black birthing individuals, these disparities are associated with severe perinatal morbidities (eg, postpartum hemorrhage, severe hypertension, venous thromboembolism, and stroke),<sup>3,4</sup> such that individuals are at greatest risk of

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ORCID Kimeshia Thomas iD https://orcid.org/0000-0001-6811-3683 pregnancy-related mortality, regardless of their socioeconomic status.<sup>2,5,6</sup> These disparities can be attributed to the weathering of chronic exposure to racism and provider prejudice across all levels of the health care system.

The mounting evidence linking systemic racism and Black maternal mortality represents a public health crisis that warrants innovative mitigation strategies. Checklists and racial bias trainings are suggested solutions to promote and ensure the provision of equitable pregnancy care.<sup>7,8</sup> However, hospital-level interventions are inadequate to solve a multifaceted problem that needs to incorporate patient-level protections, such as those afforded by the inclusion of doulas. Doulas provide continuous support during labor and advocate for their birthing clients; to effectively do so, doulas must identify and mitigate conscious and unconscious variations in perinatal care, which can subsequently decrease rates of preterm, operative, and cesarean births.9,10

Community-based doulas are trained, nonmedical personnel who provide support during labor and childbirth; however, unlike conventional or white doulas, they reflect the community they serve and provide prenatal and postpartum support to historically excluded populations (eg, those in the carceral system or recovering from substance use, the lesbian, gay, bisexual, transgender, and queer community) at low or no cost.<sup>11,12</sup> Community-based doula programs are gaining momentum for their potential to reduce perinatal adverse outcomes within the Black community.13 However, these

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# Quick Points

- Community-based doulas are uniquely positioned to reduce disparities in health care for Black pregnant individuals as they confront bias and systemic racism.
- ◆ Black community-based doulas and programs are themselves forced to mitigate various manifestations of racism.
- The impact of community-based doulas on Black communities may be limited by the instability and challenges to sustainability of these programs.

programs struggle with funding and sustainability.<sup>13–15</sup> The implementation and propagation of community-based doula programs requires characterizing and describing the barriers that they face. Our objective was to identify what unique services Black community-based doulas provide, and specifically what barriers are faced by Black community doulas in supporting Black communities.

### METHODS

We conducted a focused qualitative study consisting of indepth interviews with Black community-based doulas and program directors between January 2020 and May 2020. Participants were selected from the Frontline Doulas Centering the Community Program, a pilot program sponsored by Diversity Uplifts, Inc., and funded by a grant from Health-Net, a Medicaid managed care organization. Frontline was approached specifically because they provide Black communitybased doulas for Medicaid-insured Black patients in Los Angeles County. The program consists of 2 program directors with experience as doulas and 8 birth doulas, some who completed certification programs and others who completed professional training programs. We solicited participation from all the members of Frontline at their doula orientation and through emails to each member. All participants provided informed consent and received a \$50 gift card as compensation provided by HealthNet. This study was approved by the Institutional Review Board of the Health Sciences Campus of the University of Southern California.

We used a video conference platform, Zoom 4.0, for all interviews. Each interview was audio recorded and then transcribed verbatim. We asked each participant 10 open-ended questions (see Supporting Information: Appendix S1) with probes to delve into salient topics exploring the following themes in relation to race and the experience of racism: limitations to the growth of Black community-based doula programs, motivations for becoming a doula, and challenges faced in becoming one. In particular, we asked participants about the unique services the Black community-based doulas provide, the importance of having a Black doula providing care for Black clients, and obstacles within the health care system specifically affecting Black community-based doulas. These questions were based on preconceived themes; however, themes were further defined and coded based on the data. For example, a preidentified theme was based on the premise that Black community-based doulas provide unique services for Black clients. An example of an inductive code that emerged from the review of the transcripts was how Black community-based doulas face the same forms of racism as their clients.  $^{\rm 16}$ 

Our research team consisted of the primary investigator (K.T.), as well as 2 expert consultants (P.M. and B.T.N.). K.T. is a female-identifying Black obstetrics and gynecology resident and former doula; P.M. is a female-identifying South Asian family medicine physician; B.T.N. is a male-identifying Asian American obstetrics and gynecology researcher. In addition to analyzing qualitative project data, P.M. supported the development of the doula program's infrastructure and health care system's relationships with the community-based doulas. K.T. performed all semistructured interviews and conducted all initial coding. B.T.N. and P.M., as experienced qualitative researchers, assisted in the initial development of themes to be examined in the structured interview guide. B.T.N. and P.M. reviewed the transcripts and independently assisted with coding and interpretation of quotes taken from the transcripts. We used a layered approach to our analysis, recategorizing codes into the overarching themes: racial concordance and the dimensions of racism framework by Camara Jones. Jones' framework provided a clear and concise description of racism and its impact on health care outcomes (Supporting Information: Appendix S2).1 Additional emergent themes were discussed with 2 of the participants (F and G) to ensure their correct interpretation.

Of note, we use *individual* or *clients* as a gender-inclusive term to refer to people with the capacity for pregnancy and childbirth and use *mother* and *maternal* when discussing the results of studies that used these terms.

### RESULTS

We invited every member of Frontline to participate in the study, leading to interviews with 2 program directors and 5 community doulas. Three doulas were unable to be reached or declined to participate. The interviews lasted 40 minutes on average. The doulas were 25 to 60 years old, and their experience ranged from 6 months to 20 years. Additionally, doulas identified several external roles/occupations, including asthma/nutrition specialist, childbirth educator, reiki practitioner, lactation counselor, social worker, aromatherapy/acupressure specialist, and midwife in training. All interviewees self-identified as Black/African American women.

Review of the transcripts revealed 2 overarching themes: (1) the essential role of racial concordance in how Black community-based doulas cared for Black pregnant individuals, and (2) the challenges of being a Black community-based doula as well as the obstacles faced in sustaining and expanding programs that support them. Within the larger theme of the importance of racial concordance, defined in this case as the shared identity between a doula and a client, we uncovered its role in overcoming the Black community's mistrust of the health care system and health care providers, as well as the unique skills and services rendered by racially concordant Black doulas. The challenges faced by Black community-based doula programs included both stigma and racism that acted as barriers to providing in-hospital care, which we systematically discuss according to the following strata: internalized, interpersonal, and institutional levels of racism.<sup>1</sup>

### Importance of Racial Concordance

Reflecting on the unique role of the community-based doulas in supporting their clients, the doulas noted the importance of acknowledging the role of race in their clients' pregnancy experiences.

### **Racial Concordance and Mitigating Medical Mistrust**

With the publicization of Black maternal mortality rates in the United States, some doulas lamented that their clients sometimes attributed their pregnancy risk to their race alone rather than how their race might affect how they were treated during their pregnancy.

They were afraid they were going to die, that it was their Blackness that was going to make them die [...] I was able to explain to them it wasn't about their race. It was about how they'd been treated because of implied biases and prejudice.—Participant C

Most of their clients however, had already experienced such prejudicial treatment and attributed it to systemic racism within the health care system. In the most apparent case, Participant A recounted the story of one of her clients who would not have engaged with her had she been any other race, stating, "one of my clients, [... when] I showed up at her house [...] wouldn't come out. [Then her dad] went back, and he said, 'She's Black. Come out the room,' and then she came out of the room."

Three participants revealed experiences of mistreatment during their birth experience that allowed them to connect with their Black clients' fears and advocate for them: an experience that set them apart from white doulas. Participant C noted that "as a white doula, there's things that you don't understand. [A white doula] wouldn't necessarily pick up on the social things, because we have to be in a way hypervigilant to."

Additionally, the doulas acknowledged that their shared cultural identity, as well as their shared experience of racism, were assets that helped their clients overcome fears about how they might be treated or mistreated within the medical system. This was especially profound for another participant:

I think there's a lot of historical traumas that we carry in our bodies. I've definitely had women say that there's white doulas that won't take Black clients [..] There's still this racial component about servicing a Black woman in such an intimate space. When you have a Black doula a lot of times that's removed, so you don't even have that barrier to overcome. You just have an opportunity for a woman to show up with you that already identifies with you, that understands that this white doctor, these nurses that are not from your race, have these possible thoughts going through their mind and [the Black doula] has her back, almost a synergetic support, because she already knows that these thoughts can be going through these people's mind.—Participant E

She further emphasized pregnancy and the transition to parenthood as being universally vulnerable moments for clients that should not be tainted by any racial selfconsciousness. By identifying with their clients and acknowledging their experiences, Black doulas can alleviate such selfconsciousness as well as the hypervigilance experienced by members of the Black community and create a space of trustworthiness. Furthermore, the participants explained that their personal experiences of racism allow them to advocate for their clients' care in the medical setting when they encounter biased or racist treatment. "It's up to us to just be a safeguard in certain ways and inform our clients," noted Participant B. Black community-based doulas do this by asking clarify questions about medications, encouraging discussions of care, and calling out inequitable treatment. Participate B detailed a specific situation where she did this. A "nurse asked my client about being drug tested, I said, 'Hey, so she's declined your offer 3 times now, and I think it would be best if you just resigned from trying to pursue this."

Additionally, doulas recognized that their individual encounters with clients could have ripple effects beyond their interaction during birth, empowering them toward general resilience against racism.

I'm a Black doula, and I have a Black client, and I'm trying to help empower you, your birth, just by me being there, that's empowerment. And then I can tell you about my experience of how I've overcome things, or how I know other people who have overcome things similar to what you're going through, that's empowerment. And then I can give you tools to help become those things that also empower me. So now, not only have I related to you, but I've also empowered you and then I'm giving you tools to manifest what you want.—Participant E

## Racial Concordance and Connection With the Community

The community-based doulas specifically pointed out their ability to connect to and advocate for their clients as part of the Black community. This shared lived experience and identity were a unique quality that could not be replicated by a white doula. They subsequently contrasted the care they provided against the care that they sometimes did not observe among their white counterparts.

When I worked with those other communities, [white doulas] would just be very cut and dry about what they were offering. [...] They just did not have a clue about the kinds of issues that the Black community is really dealing with in order to provide the full scope. It's like being a doula for Black women, it's not just being a labor support assistant. It's not just doing 3 prenatals and 3 postpartums, and you just sit down and educate them about pregnancy. It's like really, you're building a relationship with them. You're building a bond with them. You're teaching

them how to step out of womanhood into motherhood and giving them the confidence and empowerment to do that. And also, to release these ideas about fear pertaining to birth and painful birth and a stereotypical birth.—Participant B

One doula attributed the unique sensitivity and commitment of the community-based doulas to their having come from the same community:

If you've never been in a hood, and you have to go in and deal with Black women who live [there, white doulas] may not feel comfortable going there [...] We have these experiences because either we see them in our community or have a relative or friend experiencing them.—Participant B

Black community-based doulas recognized that the experience of their communities and the sensitivities developed from that background are unique. Additionally, Participant C recognized that lack of concordance with clients is a factor that needs to be taken into consideration, stating, "if I'm an African American woman working with a Latina woman, I need to understand what the dynamics are for her culturally that may be different." It is when these aspects are ignored or underplayed that adverse health outcomes are liable to occur.

Black community-based doulas recognized that their work was not just about pregnancy or birth but additionally included the community into which these events take place. They distinguished themselves as caretakers for their community, with the provision of emotional and spiritual support. Essentially, they viewed their role as one part of dismantling systemic racism.

Representation matters, and it makes things a lot easier, it helps people to relax and put their guards down. So as a Black woman who's providing care for Black birthing people, Black women, we're able to relate to them. First of all, being relatable is really important. Secondly, when you understand the causes of these birth outcomes, you're also able to advocate for them differently. And then when you experience both causes, you're able to advocate for them differently. You can hold space deeper. That's really important [...] because basically we're talking about dismantling systems of racism, but we're starting with the babies.— Participant E

### **Challenges for Black Community-Based Doulas**

### Levels of Racism: Internalized Racism

The Black community-based doulas revealed that their own experiences with racism often primed them for their roles advocating for Black pregnant individuals. As stated by one doula, their experience gave them the ability to recognize racism at multiple levels. Yet, she acknowledged that had someone not trained her to identify and label the racism that she experienced, she would have viewed negative experiences as her fault.

I'd never saw when people talk about infant mortality and all the issues with African American women being higher than any other group. I didn't understand that because I saw it as almost like a flaw for us, but then it was explained that the issue really is racism. When I found that out, it was like a bell went off because

### *I've seen it. I just thought it was providers being rude. I thought it was providers being insensitive.—Participant C*

Black doulas who obtain traditional doula training from the national accrediting organization may internalize and accept the status quo, never becoming aware of the importance of their identity in addressing the role of racism in the Black maternal birth experience at its multiple levels. One doula acknowledged these limitations and remarked on how fortunate she felt to be aware of the inadequacy of national training, which led her to seek alternative training opportunities.

I ended up going to a Latina organization so I could get my doula training. Because [the organization Doulas of North America (DONA)...] was predominantly white. It wasn't very culturally competent. It wasn't really addressing the needs of the women that I have a heart to serve.—Participant E

### Levels of Racism: Interpersonal Racism

Doulas often face challenges being accepted as part of the care team in hospital settings. Community-based doulas face the additional challenge of performing the role of a doula while also being Black. As a part of their role, Black communitybased doulas worked to mediate relationships to support their clients. Yet in advocating for their patients, Black communitybased doulas faced racialized microaggressions from hospital staff, with participant A recounting, "the nurse just turned to me and was like, 'You know what? I don't like your attitude and you're being very aggressive with me.'"

By referencing the known stereotype of the "angry Black woman," whether knowingly or unknowingly, the nurse used a social control mechanism that prevented the Black community-based doula from advocating, and instead pushed her to be passive.<sup>17</sup>

Upon recognizing their experiences and their clients' experiences of racism, the Black community-based doulas noted its insidious presence within the medical system and recounted several episodes ranging from racial insensitivity to differences in the provision of treatment with regard to adequate consent. They noted that some providers may have not recognized their inappropriate biases about Black pregnancy, as noted by participant C, saying such snide statements as, "How many more kids are you going to have?" She further recounted another insensitive interaction where:

A young lady was delivering, and she had to have an emergency C-section [...] so, she's meeting with the anesthesiologist and [the anesthesiologist] asked her, 'Where's the baby's father?' And did it in a real rude way [...] That wasn't the appropriate question to ask somebody who's just found out they're going to have a C-section. – Participant C

Other Black community-based doulas, such as Participant D, recounted seeing their clients' bodily autonomy discounted with staff not fully informing their clients of interventions: "I've been in [the hospital] with some of the nursing staff where you don't know that they're putting medicine in your IV. They will just do it." For Black community-based doulas having to balance their role as patient advocates and health care allies, witnessing microaggressions and bias created significant challenges to supporting pregnancy and birth, as well as supporting their clients. Fortunately, Frontline developed a system of internal mentorship whereby the doulas could check-in with supervisors who could debrief situations and help them discuss racially charged situations and navigate their roles.

### Levels of Racism: Institutional Racism

Being a Black community-based doula means providing care for marginalized communities. These communities often cannot compensate community-based doulas for the care they provide at the same rate as conventional/white doulas. Thus, Black community-based doulas often work for organizations that can supplement wages. These programs face racism on an institutional level because of lack of advocacy, funding, and organizational support. Although the participants remarked on the value of their supervisors, mentors, and program, the directors highlighted the lack of support that warranted systemic interventions. In regard to advocacy, one director, Participant G, stated, "Our program has a lot of strong mentoring support in how to appropriately advocate [...] but we can't be the only resource. There must be legal and medical support, and even higher-level advocacy support for doulas."

One of the program directors additionally explained the importance of a having protection as a community-based program, which can allow doulas to advocate for their clients in ways unavailable to a hospital-based doula program:

The problem is when unethical things happen. And for our community this is what we are trying to protect people from. So, this is not just about helping a mom push her baby out without intervention. It's about preventing harm that is done by medical people. People are disrespectful to clients, and me needing to be free to handle that with my client, and needing to be able to talk directly to you if I need to, because I don't work for you. Who's the supervisor for doulas [in a hospital-based program]? [...] If she has a problem with the nurses, how will she be protected from retaliation?—Participant F

Additionally, the program directors explained the impact of their group's services becoming linked to an insurance provider and the role of funding in the effectiveness of a Black community-based doula program. Participant G remarked, "There's something to be said by not having [to worry about] the socioeconomic problem of supporting Black mothers." She noted that when Black community-based programs and Black doulas are adequately compensated it allows them to "reinstate the power that we have to give our sisters support during birth."

Ultimately, both directors emphasized that inadequate training, insufficient funding, and lack of structural support are barriers that Black community-based doulas face in providing adequate support for members from the Black community.

### DISCUSSION

We sought to ascertain and characterize the barriers that Black community-based doulas face. Our interviews with the community doulas revealed that as culturally and racially concordant providers, they focus on combating systemic racism

that Black birthing individuals face and attempt to prevent negative health outcomes. Often their goal is to help their clients' combat bias, alleviate concerns about their personal risk of becoming a Black maternal mortality statistic, protect the sanctity of their clients' pregnancy and birth experience, and empower them to become advocates for themselves. Multiple studies demonstrate improved perinatal outcomes, particularly within the Black community, because of these interventions.<sup>13,15,18-21</sup> However, our data also highlighted that community-based doulas face and attempt to navigate bias and racism within the health care system themselves. Our interviews with community-based doulas and program directors provide greater insight into the nature and mechanisms behind these challenges on an individual and organizational basis, and we categorized these experiences according to Levels of Racism, a framework described by Dr Camara Jones.<sup>1</sup>

The causal relationship between racism and increased morbidity and mortality in perinatal care is underpublicized/unknown in the Black community. A survey of Black women in California observed that the Black community at large was unaware of the link between poor birth outcomes and racism.<sup>22</sup> Our interviews echoed this concept and highlighted how Black community-based doulas help to combat this misinformation when they receive cultural-based training as part of their certification.

As Black community-based doulas, they also encountered bias from health care providers and attempted to intervene on behalf of their clients. Specifically, when prejudicial treatment or assumptions occurred, Black communitybased doulas were able to identify the situation and advocate for their patients; however, our interviews revealed instances where they also needed advocates of their own. This support may or may not be provided by the programs they work for.

Black community-based doulas may be at risk of taking on a greater emotional toll from their advocacy and selfidentification with their clients that merits a deeper support network, thereby warranting the strengthening of networks of mentors and peers who can understand their experience. From a practical perspective, this requires funding to develop structured mentorship and support programs. Additionally, greater financial and infrastructural support for Black community-based doula programs ensures programmatic sustainability and provides the opportunity to further support their staff. Of note, Black community-based doulas often provide birthing individuals with support and resources beyond birth; providing care for marginalized communities requires more resources that are often uncompensated.<sup>14</sup> As a result, financial limitations play a direct role in the number of Black doulas community-based doula programs can hire, the type of education and training they provide, and the level of mentorship they can offer for their community doulas.

For example, the Frontline Doulas Centering Community Doula Program was funded by a Medicaid insurer in California that recognized Black pregnant patients' need for community-based doulas. Without their funding, the doula program would be unable to train the doulas to provide the services described in this research. The need for supporting and expanding community-based doula programs is recognized broadly, and a bill to provide a Medicaid-funded pilot program for community-based doulas throughout California, AB 2258, was in process but halted by the COVID-19 pandemic.<sup>23</sup>

### Implications

Access to Black community-based doula support improves Black maternal and child health, yet the impact of these community doulas remain limited by the stability and sustainability of these programs, which suffer from rapid turnover and unstable financial support.9,10 Our interviews with Black community-based doulas revealed that their racial concordance and efforts to develop community with their clients can help to overcome bias and encourage empowerment. Yet in order for community-based programs to thrive, Black community-based doulas need, at the individual level, to be trained to identify and address racism that both they and their clients experience. Additionally, they need to be taught to link such racism to poor perinatal outcomes among minority groups, receive assistance with certification (when certification status exists as a barrier to competitive compensation or access to work in certain hospitals), and be provided ongoing mentorship and a network of health care referral resources. At the programmatic level, the positive contributions of Black community-based doulas need to be discussed and their impact disseminated to dispel stigma and garner greater morale and financial support, which are both necessary for sustaining and expanding community-based doula programs. Ways to address these limitations include better wages or Medicaid and insurance reimbursement for community-based doula services. These recommendations will synergize with the efforts of organizations, such as Ancient Song Doula Services, Village Birth International, and Every Mother Counts, who are all working to affect disproportionate rates of Black maternal mortality in the United States.<sup>12</sup>

It is important to recognize how the pandemic has exacerbated racial inequities in the health care system, contributing to Black maternal mortality. Although Black communitybased doulas can help to ensure that Black client's concerns are taken seriously and that they are treated with equity in the hospital setting, the pandemic has limited the number of people who can provide support to laboring individuals.<sup>24</sup> By considering doulas as an essential component of the care team, hospitals can help ensure optimal, equitable birth outcomes.

### **Strengths and Limitations**

To our knowledge, this is one of the few studies to investigate the perspective of Black community-based doulas, identifying systemic racism as a barrier to providing care for the Black community. However, we are unable to estimate the prevalence and quantify the impact of this barrier. We acknowledge that our interview sample of providers was from a single organization in Los Angeles. Consequently, our findings on racial concordance and medical mistrust may not be generalizable to the experiences of other groups that may vary by race or region, among other demographics. Additionally, findings may differ among a population with both racial and gender diversity. Nevertheless, the representation of our participants' experiences across all 3 of Jones' levels of racism framework suggested that their experience may not differ significantly from that experienced by racial minorities more generally.<sup>1</sup> Lastly, our data do not reflect the opinions/experiences of the clients themselves; therefore, conclusions about the community doulas effectiveness are limited and warrant further investigation via studies that incorporate patient experiences.

### CONCLUSION

Community-based doula programs are uniquely positioned to support Black pregnant individuals as they confront bias and systemic racism that increase their risk of poor outcomes. Yet in order to grow, or even sustain themselves, Black community-based doulas and programs are forced to mitigate the various manifestations of racism themselves. By investing in community-based doula programs for Black pregnant individuals, and ensuring that they are financially, logistically, structurally, and sustainably supported, we can build on their success and the movement toward equity in birth outcomes for Black birthing families.

### **CONFLICT OF INTEREST**

In the spirit of community-based participatory research, both S.P. and K.R. acted as participants in the research and authors on this article.

Each author has confirmed compliance with the journal's requirements for authorship.

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### SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Appendix S1.

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# Are You Using fFN Testing Correctly?

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**Research Article** 

# A Randomized Controlled Clinical Trial of Prenatal Oral Hygiene Education in Pregnancy-Associated Gingivitis

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**Introduction:** Research shows there is a significant increase in gingival inflammation during pregnancy. This study was conducted to determine if an oral health intervention (OHI), including oral hygiene education delivered by nurse-led staff and an advanced over-the-counter (OTC) oral home care regimen, improved gingival inflammation in pregnant women with moderate-to-severe gingivitis compared with a standard oral hygiene control group.

**Methods:** This was a multicenter, randomized, controlled, single-masked, parallel group clinical trial conducted in obstetrics clinics of 2 medical centers. A total of 750 pregnant women between 8 and 24 weeks of pregnancy with at least 20 natural teeth and moderate-to-severe gingivitis (>30 intraoral bleeding sites) were enrolled. Participants were randomized to either the OHI group, which included oral hygiene instructions supplemented with an educational video and advanced OTC antibacterial/mechanical oral hygiene products, or the control group receiving oral hygiene instructions and standard products. Both groups received oral hygiene instructions from nurse-led staff. Experienced, masked examiners measured whole mouth gingival index (GI) and periodontal probing depths (PDs) at baseline and months 1, 2, and 3.

**Results:** Participants enrolled in this study presented with moderate-to-severe gingivitis at baseline. Both the OHI and control groups exhibited significant reductions in GI (P < .001) and PD (P < .03) from baseline that persisted throughout the study period. The OHI group exhibited modest, yet statistically greater, reductions in GI ( $P \leq .044$ ) compared with the control at all time points. The reduction in PD directionally favored the OHI group, but between-group differences were small (< 0.03 mm) and not statistically significant (P > .18).

**Discussion:** Significant gingivitis was prevalent among participants in this study and identifies an opportunity to improve gingival health during pregnancy by providing oral health education during the course of prenatal care when coupled with an advanced OTC oral hygiene regimen. J Midwifery Womens Health 2023;68:507–516 © 2023 The Authors. *Journal of Midwifery & Women's Health* published by Wiley Periodicals LLC on behalf of American College of Nurse Midwives (ACNM).

Keywords: pregnancy, oral health, gingivitis, inflammation, education, prenatal care

### INTRODUCTION

Gingivitis is the most prevalent oral disease, affecting a majority of dentate adults.<sup>1</sup> Dental plaque is the primary etiologic factor in the development of gingivitis, and hormonal

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and other factors can influence the onset or severity of gingival inflammation.<sup>2,3</sup> There is a reported increase in the extent and severity of gingival inflammation during pregnancy<sup>3–6</sup> affecting 36% to 100% of pregnant women.<sup>6,7</sup> Inadequate oral hygiene contributes to plaque accumulation and subsequent gingival inflammation,<sup>8</sup> but significant qualitative differences in the composition of the biofilm are not uniformly associated with the increased inflammation seen in pregnancy.<sup>9–12</sup> The hormonal changes during pregnancy alter and increase the inflammatory response to the dental plaque biofilm, resulting in an increase in gingival inflammation without changes in oral hygiene habits.<sup>13–15</sup>

According to the 2017 World Workshop on the classification of periodontal disease,<sup>2</sup> pregnancy-associated gingivitis is diagnosed as dental plaque-induced gingivitis modified by systemic factors and associated with sex steroid hormones. The increase in severity and extent of pregnancy-associated gingivitis is self-limiting and transient. As the hormonal changes of pregnancy decline during the postpartum period, gingival inflammation levels return to prepregnancy levels, if oral hygiene is unaltered.<sup>5,16</sup> After a systematic review of studies of women with gingival inflammation during pregnancy, we found that a significant increase in gingival inflammation occurs throughout pregnancy when compared

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Birmingham, Birmingham, Alabama

## Quick Points

- Pregnancy-related hormonal changes elicit an inflammatory response to dental plaque biofilm, leading to gingival inflammation without any changes to the dental hygiene routine.
- Moderate-to-severe gingivitis during pregnancy was prevalent among participants in this clinical trial, across study sites, and in population subgroups.
- Advanced oral hygiene education regimens delivered by nurse-led staff in conjunction with perinatal pregnancy counseling is an effective new strategy to improve the oral health of pregnant women.

with nonpregnant women. The increase in gingivitis is not associated with an increase in differences in plaque accumulation between pregnant and nonpregnant groups and appears to be proportional to systemic hormone levels and inflammatory biomarkers.<sup>11</sup>

Gingivitis is optimally treated by the daily meticulous removal of biofilm from the gingival sulcus.<sup>17</sup> Although hormonal and inflammatory changes during pregnancy influence the development of clinical gingivitis, Geisinger et al have shown that pregnancy gingivitis is rare in instances of exceptional plaque control and, moreover, that the condition can be reversed through an intensive oral home care regimen, despite the influence of sex steroid hormones.<sup>18,19</sup> Furthermore, it has been established that pregnancy offers a distinctive opportunity in which women are more likely to adopt and continue positive health behaviors.<sup>20–22</sup> Given the low prevalence of optimal oral health behaviors in the general population, intervention during pregnancy may represent a particularly effective time for midwives and other prenatal providers to deliver health education and to improve oral home care habits.<sup>23,24</sup>

Periodontal disease in pregnancy has also been reported to be associated with adverse pregnancy outcomes, including low birth weight and preterm birth.<sup>25–29</sup> The hypothesized underlying mechanisms for these relationships include systemic microbial exposure and subsequent inflammatory burden from periodontal diseases. However, the efficacy of periodontal treatment on pregnancy outcomes has been inconsistent.<sup>25,30,31</sup> Furthermore, improved maternal oral hygiene during pregnancy and beyond as well as attendance of prenatal care visits has also been linked to improved oral health status in offspring, including lower rates of early childhood caries.<sup>32,33</sup> A further advantage of the approach we describe here is the accessibility of its implementation as an integral part of perinatal health care.

Given the potential effect of optimizing oral health habits and dental plaque biofilm removal during pregnancy on oral and overall health, the investigation of alternative mechanisms to enhance oral home care at this critical time was assessed in 2 pilot studies.<sup>18,19,34</sup> The first study showed that a nonalcohol cetylpyridinium chloride (CPC) oral rinse was associated with decreased incidence of preterm birth among women with periodontal disease who declined dental care.<sup>34</sup> The second pilot study expanded the intervention to include education and a combination of advanced oral hygiene products in pregnant women with moderate-to-severe gingivitis.<sup>18,19</sup> Findings showed the intervention improved the women's periodontal health. Based on these collective findings, and those from related research on the effects of oral hygiene combination therapy on oral health,<sup>35</sup> this randomized controlled trial was undertaken. The primary aim of this multicenter randomized controlled trial was to determine if an oral health intervention (OHI) that included an advanced over-the-counter (OTC) oral home care regimen, oral hygiene instructions delivered by nurse-led staff, and supplemental educational video content improved gingival inflammation in pregnant women with moderate-to-severe gingivitis.

### METHODS

### Design

This was a multicenter randomized, controlled, singlemasked, 2-treatment, parallel group clinical trial to assess gingivitis and maternity outcomes in up to 750 participants assigned to 2 different daily oral hygiene routines. The perinatal outcomes are being summarized separately and are not included in this report. This study was approved by The University of Alabama at Birmingham (UAB) and the University of Pennsylvania (UPenn) Institutional Review Boards and was conducted in accordance with the Helsinki Declaration of 1975, as revised in 2013. The study was registered at Clinical-Trials.gov (NCT01549587).

### Setting and Sample

The research setting included 2 prenatal care clinic centers, one at the Center for Women's Reproductive Health at UAB in Birmingham, Alabama, and the other at Penn Ob/Gyn and Associates in affiliation with UPenn in Philadelphia, Pennsylvania.

Each center targeted women for participation who were between 8 and 24 weeks' gestation and were at least the age of legal consent, had at least 20 natural teeth, and had moderateto-severe gingivitis (at least 30 intraoral bleeding sites). Potential participants were excluded from the study if they had multifetal gestations, a history of HIV infection, AIDS, autoimmune diseases, or diabetes mellitus (other than gestational diabetes). Participants were also excluded if they had an indication for use of antibiotic premedication prior to dental procedures, systemic corticosteroid or immunosuppressive therapy within one month of baseline, a history of allergies or hypersensitivity to mouth rinse products containing CPC, severe periodontal disease or other conditions requiring urgent dental care needs, or other factors that in the opinion of the investigator could interfere with the safe completion of the study.

Prior to the study, sample size was estimated for perinatal (eg, gestational age) endpoints based on results from both

pilot studies involving an oral regimen treatment during pregnancy.<sup>18,34</sup> The initial sample size based on the power calculations was to enroll 750 in order to complete 600 evaluable participants. Three hundred participants per group were selected to ensure there were enough participants enrolled in the study and to increase power for subset analyses. This sample size was sufficient to yield at least 90% power to detect a 0.05 between-group difference in gingivitis with an estimated variability of 0.185 using 2-sided testing at an  $\alpha$ = 0.05 level. Per the study protocol, an interim analysis was planned using the first 184 participants. The final sample size was adjusted by enrolling up to 150 more participants to achieve a maximum total of 750 subjects overall to (1) replace nonevaluable subjects, (2) account for increased variability from the interim analyses versus the initial estimate of variability, and (3) increase power for certain subset analyses.

Enrollment began in April 2012, and the last dental visits were completed by April 2014. All participants underwent an informed consent process that was approved, along with the protocol, by the respective institutional review boards at UAB and UPenn. Eligible participants were randomly assigned to one of 2 oral hygiene regimens using a computer-generated program provided by the study sponsor that balanced for groups based on history of preterm birth, current smoking status, and number of gingival bleeding sites ( $<60, \ge 60$ ). Separate randomizations were generated for each study center. The baseline sample included 295 participants at UAB and 353 at UPenn.

### Procedures

The study consisted of 4 scheduled oral health visits: (1) baseline visit with oral hygiene treatment randomization, (2) 4-week (month 1) visit, (3) 8-week (month 2) visit, and (4) 12-week (month 3) visit. All visits were performed in conjunction with monthly perinatal care. Masked examiners who underwent a calibration exercise performed comprehensive oral examinations, including assessment of plaque deposits and clinical periodontal parameters. Pregnancy outcomes were assessed by a masked examiner.

At each study site, participants were randomized to either the OHI group or a standard control group. Participants in the OHI group received an oral hygiene kit that included a power toothbrush (Oral-B ProfessionalCare, Series 1000 with the Oral-B Precision Clean brush head), 0.454% stannous fluoride toothpaste (Crest Pro-Health), 0.07% alcohol-free CPC rinse (Crest Pro-Health Multi-Protection), and deep cleaning dental floss (Glide Pro-Health Deep Clean). In addition, OHI participants received a supplemental educational video on oral hygiene (as a DVD), approximately 4 minutes long, detailing 2-minute twice daily usage of the assigned brush and toothpaste and daily use of rinse and floss during pregnancy. The standard care control group kit contained a flat trim soft manual toothbrush (Oral-B Indicator regular), 0.243% sodium fluoride toothpaste (Crest Cavity Protection), and dental floss (Oral-B Essentials). Participants assigned to the control group also received oral and written instructions for brushing at least twice daily and daily flossing. Intervention and control group products (except for brushes) had new generic labels applied to disguise the product identity, and all products and instructions were dispensed in identical masked test kits. It was not possible to mask the identity of the test toothbrushes because one was electric and one was manual.

The nurse-led staff at each obstetric clinic were trained as dental health educators and delivered basic oral hygiene instructions to participants in both groups at each prenatal visit. They also supervised the initial use of the oral hygiene materials by participants. The participants in the OHI group also watched the educational video on oral hygiene at the study center at the baseline and month 3 visits, and the DVD was also available in their kit to view at home. All other use of study materials was at home and unsupervised. Oral hygiene kits for both OHI and control groups were resupplied monthly through month 3. The final monthly kit was sufficient to provide the participants oral hygiene supplies until they had given birth.

Clinical examinations at baseline and at months 1, 2, and 3 assessed, in order, oral safety, gingivitis and bleeding sites, and periodontal probing depth. The clinical safety examination consisted of a standard oral and perioral examination of soft and hard tissues. Adverse events, if any, were classified by site, severity, and causality. The level of gingival inflammation was measured per tooth, using the Löe and Silness Gingival Index (LSGI),<sup>6,36</sup> and number of bleeding sites was determined from individual tooth site scores (LSGI  $\geq$ 2). Full-mouth periodontal probing depth (PD), measured from the free gingival margin to the base of the periodontal pocket, was recorded to the nearest millimeter with a periodontal probe. Each measurement was assessed at 6 gingival areas per tooth (mesiobuccal, buccal, distobuccal, mesiolingual, lingual, and distolingual) and averaged to obtain a whole mouth average gingivitis score.

Dentists who were masked to treatment assignment and uninvolved with oral hygiene education or product use training carried out all oral health examinations and measurements. Oral health examinations were conducted in a dental unit located in the prenatal care clinics. Prior to study initiation, potential examiners received a single, common clinical training program and conducted a calibration exercise to ensure consistency in determining gingival inflammation, bleeding, and safety assessments. Data were monitored as collected to assess examiner qualification, and follow-on training was conducted to train new or replacement examiners. When logistically possible, examinations were conducted by the same examiner at each study site.

### Analysis

After study completion, the database was monitored prior to unmasking of treatments and statistical analyses. Relative to baseline, within-treatment differences in gingivitis (LSGI) scores were tested versus zero at each visit from an analysis of covariance (ANCOVA) model. Similar analyses were conducted for change from baseline for the total number of bleeding sites and probing depth (PD) at each visit. LSGI was considered the primary gingivitis endpoint. Between-group differences in LSGI, bleeding site, and PD change from baseline scores were tested using an ANCOVA with the analogous gingivitis baseline as the covariate and study center and gestational age at enrollment, along with all potential 2-way interactions as factors in the statistical model. Interactions were maintained in the model if significant at the 10% level. Because the month 3 scores were of primary importance, the month 3 model for each dental endpoint was used for the analogous month 1 and 2 analyses. One participant was identified as a statistical outlier at month 3 using Dixon's test,<sup>37</sup> and their LSGI data were not used in the analyses. Additionally, 95% CIs were generated on the treatment difference for the average change from baseline scores.

Demographic and baseline variables were summarized by treatment group, and adverse events reported during the study were documented, listed, and coded by treatment group. The categorical demographic variables were analyzed for treatment group differences using either Fisher's exact test or Cochran-Mantel-Haenszel test, and the continuous variables were analyzed using Wilcoxon rank sum test. All statistical tests were be carried out using SAS version 9 (SAS Institute Inc, Cary, NC).

### RESULTS

### **Study Participants**

Informed consent was obtained from 817 participants. Of these, 71 were ineligible, including 59 women who did not meet protocol criteria. A total of 746 participants met enrollment criteria and received baseline evaluations and treatment randomization (Figure 1). An additional 80 participants at one center (40 in the OHI group and 40 in the control group) were excluded from analyses due to a protocol deviation at the initial baseline assessment. This left a baseline sample of 648 participants eligible for inclusion in outcome analyses. Other factors affecting evaluability, such as missed visits or pregnancy loss or completion (dental examinations were limited to active pregnancies), resulted in loss of evaluable participants in the final analysis of dental outcomes. Although attendance differed slightly at the month 1 and 3 visits, most participants completed the dental examination at month 1 (548) and month 3 (532).

The baseline study participants sample exhibited considerable diversity. Mean (SD) age was 27.6 (5.92) years, ranging from 18 to 46 years; mean (SD) gestational age at enrollment was 17.0 (3.65) weeks, ranging from 8 to 24 weeks. Black women comprised approximately two-thirds of the study sample. Treatment groups were balanced ( $P \ge .12$ ) overall with respect to demographic, economic, and other pertinent factors at baseline (Table 1A).

### **Study Center Differences**

Study center differences were evident at baseline for several demographic parameters. The 2 study centers differed significantly (P < .001) with respect to age, ethnicity, dental insurance coverage, and tobacco use, but they did not differ for baseline obstetric or dental variables. Study centers did not differ statistically on gestational age at baseline enrollment (P = .22) or baseline number of bleeding sites (P = .37), with each averaging more than 50 bleeding sites (Table 1B).

All participants had gingivitis at baseline ( $\geq$  10% of tooth sites with gingival bleeding as defined by the 2017 World Workshop on the Classification of Periodontal and Periimpant diseases and Condiditions).<sup>38</sup> The overall whole mouth

### Table 1A.Demographic Characteristics Between Interventionand Control Groups (N = 648)

	Intervention	Control	
Characteristic	(n = 322)	(n = 326)	P Value
Maternal age, y			.452
Range	18-44	19-46	
Mean (SD)	27.4 (5.94)	27.8 (5.91)	
Ethnicity, n (%)			.477
American Indian	0 (0)	2 (0.6)	
East Asian	13 (4.0)	8 (2.5)	
Black	223 (69.3)	217 (66.6)	
White	70 (21.7)	73 (22.4)	
Hispanic	7 (2.2)	13 (4.0)	
South Asian	4 (1.2)	5 (1.5)	
Multiracial	5 (1.6)	8 (2.5)	
Insurance type, n (%)			.854
Private	149 (46.3)	159 (48.8)	
Medicaid	10 (3.1)	9 (2.8)	
None, self-pay	20 (6.2)	13 (4.0)	
None, unable to pay	134 (41.6)	138 (42.3)	
Military/VA	4 (1.2)	4 (1.2)	
Unknown/declined	4 (1.2)	5 (1.5)	
Tobacco use during			.329
pregnancy, n (%)			
Yes	22 (6.8)	29 (8.9)	
Gestational age, wk			.118
Range	8-24	8.3-24.1	
Mean (SD)	16.8 (3.78)	17.2 (3.50)	

Abbreviation: VA, Veterans Affairs.

<sup>a</sup> Categorical demographic variables were analyzed for treatment group differences using either Fisher's exact test or Cochran-Mantel-Haenszel test, and the continuous variables were analyzed using Wilcoxon rank sum test.

LSGI mean (SD) score was 1.3 (0.10), the mean (SD) number of bleeding sites was 51.1 (15.89), ranging from 30 to 144 sites, and whole mouth mean (SD) probing depth averaged 2.5 (0.32) mm. Treatment groups were well-balanced (P > .45) on periodontal clinical parameters at baseline (Table 2).

### **Gingivitis Assessment**

The number of bleeding sites was the variable used to categorize gingivitis severity at baseline to understand the relationship between gingivitis and other baseline status variables. Using regression analysis, both study center and maternal age at baseline were significantly (P < .02) related to the number of baseline bleeding sites. In contrast, gestational age at enrollment and ethnicity were not significantly (P >.32) related to baseline bleeding. Relative to baseline, both treatment groups exhibited significant (P < .001) reductions in gingivitis beginning at month 1. For number of bleeding sites, this represented a 35% to 39% improvement versus initial bleeding after one month of treatment use. Participants exhibited continued improvement in the number of bleeding





sites through month 3, reaching 43% to 47% improvement (Figure 2). Both groups exhibited significant (P < .03) whole mouth probing depth reductions beginning at month 1 and continuing through month 3.

Comparing treatments, the OHI group exhibited significantly higher (P < .05) reductions in gingivitis, as measured by whole mouth LSGI, beginning at month 1 and continuing through month 3 (Table 3). We observed similar outcomes for number of bleeding sites, with treatments differing significantly at months 1 and 3. Probing depth directionally favored the OHI group, but between-group differences were small (<0.03 mm) and not statistically significant (P > .18) at any postbaseline time point.

Adverse events reported or determined with oral examination were collected irrespective of causality at each dental visit. There were a total of 81 participants with 91 oral or perioral adverse events. Of these, there were 18 different adverse event types from multiple participants (Table 4). Oral mucosal exfoliation, tooth fracture, and tooth discoloration were the most common adverse events by type. Occurrence was more common in the OHI group (15% vs 10% of participants with at least one oral or perioral adverse event). Study groups differed significantly (P < .05) with regard to oral adverse event occurrence overall and oral mucosal exfoliation occurrence. Oral/perioral adverse events were generally mild in severity and were not factors in study dropout during the 3 months of routine dental monitoring and examination.

### DISCUSSION

Clinical examination of participants showed moderate-tosevere gingivitis to be common at baseline, with 96.6% of screened participants demonstrating at least 30 bleeding sites. Gestational age at baseline did not appear to be related to level of gingivitis as measured by the number of bleeding sites. Participants did not receive a clinical periodontal examination prior to pregnancy or after parturition. It is notable that at

Table IB.	Demographic Characteristics of Participants Between
<b>Study Sites</b>	(N = 648)

	UAB	UPenn	
Characteristic	(n = 295)	(n = 353)	P Value
Maternal age, y			<.001
Range	19-43	18-46	
Mean (SD)	24.0 (4.22)	30.7 (5.39)	
Ethnicity, n (%)			<.001
American Indian	0 (0)	2 (0.6)	
East Asian	0 (0.0)	21 (5.9)	
Black	271 (91.9)	169 (47.9)	
White	16 (5.4)	127 (36.0)	
Hispanic	8 (2.7)	12 (3.4)	
South Asian	0 (0)	9 (2.6)	
Multiracial	0 (0)	13 (3.7)	
Insurance type, n (%)			<.001
Private	12 (4.1)	295 (84.8)	
Not private/none	278 (95.9)	53 (15.2)	
Tobacco use during			<.001
pregnancy, n (%)			
Yes	47 (7.3)	4 (0.6)	
Gestational age, wk			.219
Range	8-24	8.3-24.1	
Mean (SD)	16.8 (3.77)	17.2 (3.54)	
Bleeding sites, n			.366
Range	30-144	30-129	
Mean (SD)	50.4 (14.12)	51.6 (17.23)	

Abbreviations: UAB, The University of Alabama at Birmingham; UPenn, University of Pennsylvania.

<sup>a</sup>Categorical demographic variables were analyzed for treatment group differences using either Fisher's exact test or Cochran-Mantel-Haenszel test, and the continuous variables were analyzed using Wilcoxon rank sum test.

Table 2. Baseline Gingivitis, Bleeding, and Probing Depth by Treatment Group (N = 648)							
	Overall	Intervention	Control	Group Differ	ences		
	(N = 648)	(n = 322)	(n = 326)				
Characteristic	Mean (SD)	Mean (SD)	Mean (SD)	95% CI	P Value <sup>a</sup>		
Gingivitis index, LSGI	1.32 (0.103)	1.32 (0.101)	1.31 (0.107)	(-0.011 to 0.021)	.536		
Bleeding sites, n	51.1 (15.89)	51.4 (15.41)	50.7 (16.36)	(-1.80 to 3.10)	.604		
Probing depth, mm	2.54 (0.323)	2.55 (0.334)	2.53 (0.312)	(-0.031 to 0.069)	.458		

Abbreviation: LSGI, Löe and Silness Gingival Index.

<sup>a</sup> Analyzed using a 2-sample *t* test.

<b>Table 3.</b> Efficacy Outcomes Change from Baseline Treatment Comparisons by Visit (N = 648)						
		Mean Treatment	Mean Treatment	Adjusted Mean		
		Reduction <sup>a</sup> (SE)	Reduction <sup>a</sup> (SE)	Treatment		
		Intervention	Control	Difference		
Outcome	Participants	(n = 266-273)	(n = 267-278)	(SE)	95% CI	P Value <sup>b</sup>
Gingivitis index, LSGI						
Month 1	548	0.125 (0.0045)	0.112 (0.0045)	0.013 (0.0064)	(0.0004 to 0.026)	.044
Month 2	548	0.137 (0.0045)	0.124 (0.0044)	0.014 (0.0063)	(0.001 to 0.026)	.031
Month 3	532	0.154 (0.0046)	0.141 (0.0046)	0.013 (0.0065)	(0.0005 to 0.026)	.042
Gingival bleeding sites, n	L					
Month 1	549	19.85 (0.712)	17.86 (0.709)	1.98 (1.005)	(0.011 to 3.958)	.049
Month 2	549	21.66 (0.712)	19.73 (0.701)	1.93 (0.998)	(-0.029 to 3.891)	.054
Month 3	533	24.02 (0.696)	22.04 (0.691)	1.98 (0.977)	(0.061 to 3.898)	.043
Probing depth, mm						
Month 1	549	0.056 (0.0139)	0.060 (0.0139)	-0.004 (0.0188)	(-0.041 to 0.033)	.836
Month 2	549	0.063 (0.0155)	0.035 (0.0155)	0.028 (0.0208)	(-0.013 to 0.069)	.186
Month 3	533	0.073 (0.0159)	0.059 (0.0158)	0.013 (0.0213)	(-0.029 to 0.055)	.538

Abbreviation: LSGI, Löe and Silness Gingival Index.

Reduction indicates improvement in the measure from baseline. Between-group differences were tested using an analysis of covariance model.

baseline examinations, participants universally demonstrated moderate-to-severe gingivitis regardless of gestational age. This observation is consistent with findings of increased gingivitis prevalence and severity in pregnancy.<sup>3-6</sup>

Participants at the 2 study centers in this investigation, one of the largest of its kind in recent years, differed appreciably with respect to age, ethnicity, and socioeconomic factors, including, specifically, insurance coverage. Despite the differences, participants at both centers demonstrated a ubiquitous presence of gingivitis at the baseline examination, with a mean of 50 bleeding sites. Socioeconomic factors are widely recognized to play a key role in access to care, including access to preventive dental care, and as such, underserved groups typically present with greater disease prevalence. Furthermore, it is notable that Alabama is one of 3 states that does not provide dental services to adults receiving Medicaid medical insurance. Individuals recruited at the UAB site over the age of 21 were unlikely to have access to comprehensive dental care if they had Medicaid insurance.<sup>39</sup>

Gingivitis is a reversible, site-specific inflammatory condition initiated by dental biofilm accumulation and characterized by gingival erythema, edema, and the absence of periodontal attachment loss.<sup>38</sup> Furthermore, pregnancy gingivitis is modified by the systemic inflammation. Thorough daily removal of dental plaque biofilm is critical in the treatment of pregnancy gingivitis. An initial pilot investigation was performed by our group to evaluate the benefit of nurse-directed education coupled with an intense oral hygiene therapy for pregnancy gingivitis. This intervention resulted in a statistically significant reduction in plaque and gingivitis<sup>18</sup> and a reduction in inflammatory mediators.<sup>19</sup> In the current study, both the OHI and control groups resulted in a marked improvement of oral health as evidenced by a significant reduction in bleeding sites and probing depths compared to baseline levels. The gingivitis reductions were statistically greater in the OHI group, although the intergroup differences may not have been clinically meaningful.

### Implications for Practice

Pregnancy presents a unique opportunity for behavior modification. Pregnant individuals are more likely to cease negative health behaviors and comply with advice from health care providers than their nonpregnant counterparts.<sup>40</sup> Furthermore, the adoption of positive health care behaviors following instruction by dental professionals has been reported.<sup>41</sup> Pregnancy is also a period when individuals require significantly more health care visits than at most other times.<sup>42</sup> This period

Treatment Group and Type $(N = 648)$				
	Intervention	Control		
Category/Occurrence	n (%)	n (%)	P Value <sup>a</sup>	
All participants	322 (100)	326 (100)		
Participants with	49 (15.2)	32 (9.8)	.04	
oral/perioral adverse				
events				
Oral adverse event type				
(2+ participants)				
Dental fistula	1 (0.3)	1 (0.3)	.99	
Device damage	0 (0.0)	2 (0.6)	.99	
Dysgeusia	2 (0.6)	0 (0.0)	.50	
Gingival abscess	1 (0.3)	2 (0.6)	.99	
Gingival hyperplasia	2 (0.6)	0 (0.0)	.25	
Gingival injury	1 (0.3)	1 (0.3)	.99	
Gingival pain	2 (0.6)	2 (0.6)	.99	
Lymphadenopathy	0 (0.0)	2 (0.6)	.50	
Mouth ulceration	1 (0.3)	1 (0.3)	.99	
Oral mucosal exfoliation	10 (3.1)	1 (0.3)	.006	
Sensitivity of teeth	4 (1.2)	1 (0.3)	.21	
Stomatitis	1 (0.3)	1 (0.3)	.50	
Tongue disorder	2 (0.6)	1 (0.3)	.62	
Tooth abscess	1 (0.3)	1 (0.3)	.99	
Tooth discoloration	6 (1.9)	2 (0.6)	.17	
Tooth fracture	5 (1.6)	6 (1.8)	.99	
Tooth impacted	1 (0.3)	1 (0.3)	.99	
Toothache	4 (1.2)	3 (0.9)	.72	

<sup>a</sup> Analyzed using Fisher's exact test.

offers an opportunity for multidisciplinary interactions to improve health care behaviors. In the current study, oral health care education, including oral home care instructions and dispensing of the oral hygiene kits, was performed by trained nurse-led staff at the same time as prenatal care visits.

Access to dental care is not universal. Factors that influence access to dental care include ethnicity, age, income level, education level, perceived need, insurance coverage, and sociodemographic differences.<sup>43–45</sup> Given that access to dental care for adult patients across the United States is variable, the importance of preventive care is elevated, particularly in groups with lower access to care. It is well established that oral health education is a powerful adjunctive, cost-effective tool to an oral hygiene regimen that can improve oral health.

Currently, oral health education is not included in global guidelines for prenatal care, resulting in significant disparities in maternal oral health experiences.<sup>46</sup> An impactful mechanism to facilitate improved oral and overall health may include delivery of oral health education as part of pregnancy counseling.<sup>47</sup> Obstetric nurses, midwives, and other perinatal care providers are well-positioned to incorporate oral health care education into perinatal care, particularly among underserved populations.<sup>23</sup> Having a positive effect on the

oral health of high-risk populations may result in overall improvement of maternal health and the oral health of subsequent offspring. Evidence exists that maternal periodontal disease and oral inflammation are associated with preterm birth and low birth weight in newborns.<sup>27,48-50</sup> Previous large-scale interventional trials for periodontal disease have been largely ineffective in reducing preterm birth rates.<sup>31,51</sup> This lack of effect may reflect a focus on timing and effectiveness of treatment delivery as well as limited focus on reducing gingival inflammation through patient-delivered home care. The residual inflammation reported after intervention for pregnancy gingivitis demonstrates that the treatment endpoints may not have been appropriate.<sup>51</sup> In previous pilot studies, gingival inflammation and other oral clinical indicators of periodontal disease were reduced by an intervention focused on oral health education, coupled with plaque control treatments.<sup>18,19,34</sup> These findings are supported by the results of this study, which demonstrated improvement in gingival health outcomes following oral health education and use of advanced oral hygiene home care products.

### Strengths and Limitations

Strengths of this research include the multicenter, randomized, controlled, parallel group study design and the inclusion of OTC oral hygiene products that are widely accessible to the population. Additionally, the coordination of oral hygiene counseling with obstetric visits and the delivery of oral health education by perinatal health care providers allowed circumvention of barriers to dental care that may exist for some pregnant women. The heterogeneity of the study population is another strength with important implications for generalizability of the findings. However, it is simultaneously a limitation, as it required larger sample sizes for subgroup comparisons and makes it difficult to ascertain contributing factors, unrelated to pregnancy, for the gingivitis prevalence across study sites. This unexpected finding could indicate a phenomenon of "severity without disparity," or it could be a function of selection bias or other unknown factors. Replication of the study with a standardized gestational age upon enrollment would further elucidate the role of oral health education and daily plaque control in prenatal care.

### CONCLUSION

In this study, we demonstrated near universal prevalence of gingivitis with significant severity among study participants relatively early in pregnancy. These gingivitis levels were evident across study sites and demographic and socioeconomic subgroups. Oral hygiene education delivered by nurse-led staff resulted in an improvement of gingival inflammation and bleeding during pregnancy. A modest but statistically significant additional improvement was noted when an intentional oral hygiene educational intervention, including an educational video, was combined with use of a powered toothbrush, 0.454% stannous fluoride toothpaste, dental floss, and 0.07% CPC mouth rinse compared with a control oral hygiene regimen and standard written instructions. Oral hygiene education delivered in conjunction with prenatal

pregnancy counseling may offer a novel approach for the improvement of maternal oral health.

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### **CONFLICT OF INTEREST**

Drs. Doyle and Grender are employed full-time by the Procter & Gamble Company. Dr. Gerlach is a former employee of the Procter & Gamble Company. They provided logistics and data analysis support for the study but did not participate in data collection. Dr. Geisinger has participated in the Procter & Gamble Speaker's Bureau.

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## Creating an Alianza: Group Perinatal Education for Newly Immigrated Latinx Pregnant People

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Pregnant people who are recent immigrants often face barriers navigating the health care system and establishing a support network to sustain them through pregnancy and new parenthood. The *Cultivando una Nueva Alianza* (CUNA) program from the Children's Home Society of New Jersey was created to address these obstacles. For over 20 years, CUNA has collaborated with local midwives to develop a program for newly immigrated, Spanish-speaking Latinx pregnant people. The curriculum, facilitated by trained members of the community, provides education around pregnancy, birth, and early parenting and connects participants with prenatal care and community resources while cultivating a social support network. The program's success is seen in improved clinical outcomes, ongoing involvement by graduates, and strong continued support from community stakeholders. The CUNA program has been replicated in nearby communities and offers a blueprint for a low-tech intervention to improve the health and wellness of this population.

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### INTRODUCTION

Newly immigrated, Spanish-speaking Latinx people who are pregnant are often isolated and lack knowledge to navigate the health care system or access social supports.<sup>1,2</sup> These barriers can negatively affect their pregnancy and birth outcomes.<sup>1,3</sup> Provision of culturally relevant and linguistically appropriate education, support, and resources can increase attendance at prenatal appointments, improve pregnancy and birth outcomes, increase breastfeeding initiation rates, and create community while reducing health disparities.<sup>4,5</sup>

Pregnant individuals who are immigrants often face obstacles such as language and cultural differences, low health literacy, and limited financial resources and transportation access, all of which impede overall access to care.<sup>1,6</sup> The adverse outcomes associated with these obstacles include increased incidence of hospital readmissions, cesarean birth, perinatal mood and anxiety disorders, and decreased patient satisfaction.<sup>1,7</sup> Fetal risks include preterm birth, birth defects, stillbirth, and admission to the neonatal intensive care unit.<sup>3</sup> Immigration and, in particular, documentation status are social determinants of health that also affect health and birth outcomes.<sup>8</sup> Lack of authorized immigration documentation, for example, has been associated with pregnancy complica-

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ORCID Julie Blumenfeld (D) https://orcid.org/0000-0003-2795-1941 tions, postpartum depression, and unplanned cesarean birth, all of which can be influenced by poor provider-patient communication, limited care during pregnancy, or insufficient patient participation in the clinical plan of care.<sup>8</sup>

Evidence supports the benefits of culturally and linguistically appropriate prenatal education and support and, in particular, the unique role of community-based prenatal support.<sup>4,9</sup> In the United States, about a third of birthing people engage in childbirth preparation, typically focused on labor and birth.<sup>10</sup> Reviews of efficacy of childbirth education are often inconclusive, but some literature supports positive impacts such as fewer interventions in labor, lower utilization of analgesics, lower cesarean birth rates, and higher breastfeeding rates.<sup>11–13</sup>

Studies of Spanish-speaking, newly immigrated individuals at hospital-based prenatal offices report that standard childbirth education classes may not meet the needs of this population.<sup>14</sup> Immigrant and low-income pregnant people are thus less likely to participate in prenatal childbirth education.<sup>11,12</sup> Several studies of outpatient programs have endeavored to enhance prenatal care and improve pregnancy outcomes by providing culturally congruent care for newly immigrated Latinx people with limited socioeconomic resources.<sup>4,9,15</sup> These programs provide a prenatal education curriculum, make referrals to community services and outreach, and strive to cultivate support systems. Outcomes across programs demonstrate increased utilization of health care, increased familiarity with community resources, and improved communication with hospital staff and health care providers.<sup>4,9,15</sup> Interventions that are culturally congruent facilitate relationships and emotional support. Other positive outcomes include improved access to interpretation services, improved breastfeeding exclusivity rates and duration, and increased resources for individuals with perinatal mood and anxiety disorders.4,8,9

# Quick Points

- Newly immigrated Latinx pregnant people frequently face barriers navigating the health care system and establishing a support network to assist them during pregnancy and early parenthood.
- Linguistically appropriate, culturally relevant group prenatal education can create community, improve pregnancy and birth outcomes, and reduce health disparities.
- Formed in 2001, *Cultivando una Nueva Alianza* (CUNA) provides education around pregnancy, birth, and early parenting and connects newly immigrated Latinx pregnant people with prenatal care and community resources while cultivating a social support system.

Although there are existing programs throughout the United States attempting to address the needs of this population, there is a paucity of research regarding the efficacy of programs addressing social needs of newly immigrated Latinx people in the perinatal population. To improve access to care, care delivery, and health outcomes, it is necessary to develop culturally congruent models in collaboration with target communities that have been historically marginalized. Care delivery must take into consideration the group's language, cultural beliefs, and practices that affect access to care.<sup>16</sup> *Cultivando una Nueva Alianza* (CUNA), Cultivating a New Alliance (English translation), is a program in central New Jersey that offers a blueprint for such an intervention.

Throughout the literature, *Latina, Hispanic*, and more recently *Latinx* are used synonymously. Here we refer to this group collectively as *Latinx*. There are diverse ethnic groups that speak Spanish, and these terms reference individuals of Puerto Rican, Cuban, Mexican, Spanish, Dominican, and Central or South American ancestry, irrespective of race.

### CULTIVANDO UNA NUEVA ALIANZA

For 2 decades, the Children's Home Society of New Jersey (CHSofNJ), a community-based organization in Trenton, New Jersey, has collaborated with local midwives to develop and implement a prenatal health education and support group program designed to assist Spanish-speaking Latinx people who are pregnant for the first time or for the first time in this country. In 2001, CUNA was created out of a collaboration between CHSofNJ, the Puerto Rican Community Day Care Center, and midwives at a local hospital. Building a community rooted in education and support and establishing a foundation of trust within the community were the intentional goals of the program.

CHSofNJ is located in Trenton, the capital of New Jersey, in Mercer County. The city sits in the center of the state and has a population of 90,871.<sup>17</sup> The city's residents identify as 37.2% Hispanic or Latino as compared with 18% nationally.<sup>17</sup> About 38% of Trenton residents speak a language other than English (as compared with 20% of US residents).<sup>17</sup> The median household income is \$37,000, and 27% of people in the city live in poverty.<sup>17</sup> Midwife-attended births for residents of this county surpass national averages. From 2016 to 2021, midwives attended 30.5% of the 20,282 births of Mercer County residents.<sup>18</sup> And notably, of the vaginal births funded by Medicaid in that period, 61.8% were attended by midwives.<sup>18</sup>

In the years leading up to CUNA's creation, Trenton experienced a rapid and dramatic shift in demographics with the arrival of immigrants from Central America. CUNA founders, working within the changing community, observed that pregnant residents faced specific challenges, including risk of isolation and depression, transportation obstacles, poor access to prenatal care, and lack of familiarity with preventive health care. To address these issues, these local community organizations and midwives collaborated to design a curriculum specifically curated for these newly immigrated Latinx pregnant people.

### **Program Objectives**

At its inception, CUNA had 2 explicit strategic goals: First, to improve pregnancy outcomes by providing health education and connection to early prenatal care and communitybased services for low-income, uninsured or underinsured, pregnant Latinx people. Second, to support mothers and their infants through pregnancy and into early childhood with parenting education and a seamless network of social, hospital, and community-based resources. These overarching goals led to specific program objectives: (1) begin primary prevention services in the earliest prenatal state; (2) provide health education, resources, and advocacy in a supportive and welcoming community-based environment that is linguistically and culturally sensitive; (3) integrate partners in prenatal education and health care; (4) facilitate social support networks among isolated Latinx people and their families by offering prenatal education services through a group session format; and (5) provide postnatal education support groups to promote parent-child bonding and early childhood development.

### **Program Enrollment**

CUNA participants reside in Trenton and the surrounding communities. Many are referred to CUNA through the local hospital system, which created a CUNA-patient liaison position at its prenatal clinic. The liaison serves as a link between the program and the hospital and provides many referrals to the program, although enrollment in prenatal care is not a requisite for registration. All participants are linked to health care providers and community services with the goal of preventing or reducing the number of newborns with low birth weights, premature births, and other outcomes associated with poor nutrition, substance use, depression, isolation, and lack of prenatal care. Additionally, local media coverage of the program has increased word-of-mouth referrals.

Tabl	le I.	Topics Covered in Cultivando una Nueva Alianza	
(CUNA) Prenatal Support and Education Groups			
-			

Topics

Cultural sensitivity Stages of pregnancy and the birth process Prenatal care, testing, and pregnancy complications Postpartum issues Breastfeeding Nutrition Provider-patient communication Substance use in pregnancy Managing stress Sudden infant death syndrome (SIDS) Safety issues with emphasis on prevention Stages of early childhood development: birth to 36 mo Childcare concerns and options Intimate partner violence information and available resources COVID-19 (as of 2020)

### **Participant Demographics**

Participants are from the Caribbean, Central America, and South America, but most are from Guatemala and do not have authorized immigration documentation. According to ongoing data collection over the past 20 years, approximately 20% of participants have been in the United States less than one year with most less than 5 years. Participants are mostly in their 20s, have a minimum of a high school education, and have limited English proficiency. More than 90% are not employed and have a household income less than \$25,000. Half of participants regularly have an identified health issue prior to becoming pregnant. About a third are pregnant for the first time, and the remainder are pregnant for the first time in the United States. Over two-thirds of participants rely on Charity Care assistance, in lieu of insurance, for access to health care, and most report no insurance at the time of program enrollment. Most participants eagerly welcome assistance in understanding and navigating the health care system here in the United States.19

### **Curriculum Development**

CUNA's 48-hour curriculum has been continuously evolving over its 20-year history. In its early stages, it was influenced by elements from the *Comenzando Bien* program from March of Dimes (M. Raimundi-Petroski, MPA, written communication, April 2022). Enhancements have been tailored to the individual and cultural needs of the participants. Overall, the content focuses on healthy pregnancy, mitigation of perinatal risks, and facilitating community support (Table 1).

The program consists of sessions that meet for 3 hours twice per week for a total of 6 to 8 weeks. Sessions are facilitated by bilingual certified community health workers who create an atmosphere that promotes interaction. Sessions include an education component, interactive activities (Table 2),

Table 2. Cultivando una Nueva Alianza (CUNA) Session           Activities
Session Activities
Journaling
Role-play
Interactive education games
Meal preparation demonstrations
Hospital orientation tour
Participant multimedia presentations: pregnancy journey
Exercise/yoga
Car seat installation and use
Belly painting
Cookbook with typical recipes
Baby shower

and a hot meal. Historically, participation has been facilitated by reimbursing participants for transportation and providing on-site childcare, although this funding is grant dependent and as such has varied over time. At the end of the curriculum there is a baby shower to celebrate participants' commitment to a healthy pregnancy. This family-centered event also ensures that participants have basic items such as a crib, stroller, and car seat.

The education is offered in a group setting over multiple weeks. Session activities include journaling about the pregnancy experience, role-playing, developing a birth plan, and meal preparation demonstrations. Experts in the community in critical areas are brought in for select sessions, such as a family planning counselor from a local health center, a nutritionist from the local university, a representative from the police department for a car seat safety demonstration, and a counselor from a local intimate partner violence agency to talk about safety. Childbirth and lactation education are part of the curriculum in addition to a tour of the local birthing hospital. Participants are encouraged to bring a support person to these activities.

### **EVOLUTION OF THE PROGRAM**

As the impact of the program was evaluated, ways to further enhance the curriculum were explored to address emerging needs among current group participants and graduates. This was accomplished with the assistance of additional funding from the New Jersey Department of Children and Families, the New Jersey Department of Health, the Mercer County Department of Human Services, and the philanthropic community who rallied around the goal of improving birth outcomes for immigrant Latinx people.

For the past 2 decades, the focus has been on developing a continuum of wraparound services (Table 3). This has included a peer-to-peer mentoring program for new mothers who are CUNA graduates, breastfeeding support groups, community peer lactation counselors, infant and early childhood development programming, and an annual Latino parenting conference coordinated by CUNA graduates. In 2019, the AMAR Community-Based Doula Program was launched

Table 3. Continuum of Maternal-Child Health Programming from the Children's Home Society of New Jersey				
Program	Meaning in Spanish	<b>Translation to English</b>	Program Description	
MAYA	Mujeres, amigas y apoyo	Women, friends, and support	Peer-to-peer mentoring program for new mothers who are	
			graduates of Cultivando una Nueva Alianza (CUNA)	
BURP	Bebes unidos resultados positivos	Babies united, positive results	Newborn and infant development programming (0-12 mo)	
MIO	Modelando interacciones con	Modeling interactions with	Early childhood development programming (13-36 mo)	
	orgullo	pride		
NENE	Nuestro enlace, nuestros exitos	Our bonds, our successes	Community newsletter	
AMAR	Apoyando madres, armando	Supporting mothers, creating	Community-based doula program	
	redes	networks		



Abbreviation: CUNA, Cultivando una Nueva Alianza.

in response to feedback from the community and midwives about people birthing alone with a language barrier and in need of social support. The midwives' role in the development of the doula program was a natural extension of their longstanding relationship with CUNA. Today, all the doulas employed by the agency participated in the CUNA program, and half were also part of the peer-to-peer mentoring program.

Approximately 1400 hundred Latinx pregnant people have participated in the CUNA program over the past 20 years (M. Raimundi-Petroski, MPA, written communication, April 2022). What started as a small program serving about 36 people in the first 2 years, with part-time staff and community volunteers, is now part of an agencywide division dedicated to maternal and child health services. Indeed, the sustainability of such a program is made possible by many factors (see Figure 1) with both financial and community-based support and continual reassessment. Ongoing solicitation of grants from funders has grown the operating budget from \$50,000 for CUNA in 2001 to over a million dollars for an expanded array of maternal-child health programming in 2021 (M. Raimundi-Petroski, MPA, written communication, April 2022).

### COMMUNITY IMPACT

CUNA continues to achieve its key objective of increasing access to prenatal care and rates of positive birth outcomes for Latinx birthing people and their infants. CUNA participants are observed to have higher attendance at prenatal visits, decreased rates of preterm labor and birth, and increased breastfeeding initiation rates. Hospital and neonatal intensive care unit stays are shorter for the CUNA participants than for their non-CUNA peers. CUNA also enhances social support for participants. In addition, the program's success has inspired increased programming for this community of patients, including mentoring, early infant development, breastfeeding support, and a community doula program. The consistency of findings over time should give confidence that the program is meeting its promise of improving birth outcomes for the community it serves. Most notably, this program has been sustained over 20 years and has grown markedly in scope and numbers.

Another result of the CUNA initiative has been the effect on its program facilitators. For these members of the community, the program serves as a workforce development opportunity. Although they start as facilitators, most eventually progress to program coordination, and ultimately some have become supervisors.

CUNA has been replicated in 2 other New Jersey counties. It has also inspired the creation of a sister program for Black pregnant people in Trenton. Despite these successes, like similar programming, CUNA's sustainability is dependent on a continual source of funding that can be varied and unpredictable. It is hoped that the success of CUNA encourages others to use this model as a blueprint to effect similar collaboration and outcomes in their communities.

### CONCLUSION

Perinatal care systems in the United States often invest in high-tech solutions, but simple innovative strategies can also produce improved outcomes.<sup>20</sup> CUNA is entering its third decade, and with financial support from the National Library of Medicine and clinical oversight of 2 midwives, a thorough review of the CUNA curriculum has been initiated. CUNA has expanded to other counties in the state and continues to be the only Spanish-speaking program exclusively serving this population in all 3 counties. The long-term impact of the program includes improved perinatal health outcomes and an increased social network system. CUNA graduates have benefited from workforce development opportunities, including employment within the agency as doulas, community health workers, advisory council members, and clerical support staff. Former participants are now maternal-child health advocates who promote prevention practices within their communities. CUNA continues to fulfil its goal of cultivating a new alliance; the success of this program makes it a model for community collaboration that can be replicated in other Latinx communities throughout the country.

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### CONFLICT OF INTEREST

The authors have no conflicts of interest to disclose.

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the Midwife

# **HPV** and Cervical Cancer



### What is Human Papillomavirus (HPV)?

Human papillomavirus (HPV) is a family of viruses. These viruses attack skin cells on the body. There are more than 200 different types of HPV. HPV can be spread through close contact such as during sexual activity. Some types of HPV cause warts on the genitals—the labia, vagina, cervix (opening to the uterus), the penis, scrotum, or rectum. While most types of HPV do not cause cancer, HPV can cause cancer of the vagina, vulva, mouth, throat, cervix, penis and anus.

### How does HPV cause cervical cancer?

HPV on the cervix injures the cells on the surface of the cervix. The immune system can often fight off HPV and heal the injured cells. If your immune system cannot fight off the HPV, more and more cells may be injured and can go through abnormal changes. Over a period of years, the injured cells of the cervix may become cancerous. Almost all cases of cervical cancer are caused by HPV (99%).

### How do you get HPV?

You get HPV by having close body contact with someone else who has HPV. HPV is very common. Anyone can become infected with HPV. Not everyone who has HPV knows that they do. Someone with HPV may not have visible warts or notice that they have warts. Warts on the cervix are not easy to see because of the location of the cervix. If you have sex with someone who has HPV on their genitals, you can get HPV on your genitals, mouth, throat, or on your cervix.

### How would I know if I have HPV on my cervix?

Someone with HPV on their cervix may be not have symptoms. Other people may experience vaginal bleeding or an abnormal vaginal discharge. Anyone with a cervix should have testing for cervical cancer and HPV screening. Pap testing guidelines for cervical cancer and HPV screening vary depending on age, timing of HPV vaccine, or if someone has medical condition that weakens their immune system. The Pap test is a test for changes in the cells of the cervix that can cause cancer. The Pap test can tell if you have HPV and the kind of HPV. Testing for HPV is not always done when you have a Pap test, so it is important to ask your health care provider if they are also testing for HPV.

### Can you get a shot to prevent cancer caused by HPV?

The HPV vaccine can keep you from getting 9 types of HPV. The vaccine is given in 2 doses (2 shots) if started before age 15. Or if started after age 15, 3 doses (3 shots) are given.

HPV Vaccine Schedule		
Age at first shot	Recommended doses	
9 to 14 years	Two-dose vaccine series:	
	1 <sup>st</sup> shot, 2 <sup>nd</sup> shot 6 to 12 months after 1 <sup>st</sup> shot	
	OR	
	Three-dose vaccine series:	
	$1^{st}$ shot, $2^{nd}$ shot – 2 months after $1^{st}$ shot, $3^{rd}$ shot – 6 months after $1^{st}$ shot	
15 to 45 years	Three dose vaccine series:	
	$1^{st}$ shot, $2^{nd}$ shot 2 months after $1^{st}$ shot, and $3^{rd}$ shot 6 months after $1^{st}$ shot	

### Should I get the HPV vaccine?

Here are some things to consider when deciding to get the HPV vaccine:

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### What the vaccine does

The vaccine that is available now protects against nine types of HPV. The vaccine protects against two of the HPV types that cause most cases of warts on the genitals. The vaccine also protects against two of the types of HPV that cause most cases of cervical cancer.

### What the vaccine does not do

The vaccine *does not give full protection from cancer caused by HPV*. There are more than 30 types of HPV that can cause cancer of the genitals, mouth, throat, and cervix, and the vaccine only protects against nine of these. The vaccine does not protect against most types of HPV. It is important to take steps to prevent exposure to sexually transmitted infections.

### Do I need a PAP test, after receiving the vaccine?

Even if you decide to get the vaccine, remember that you still need to get Pap tests. Because the vaccine only protects against 9 of the 30 types of HPV that can attack your genitals and cervix, you are still at risk for HPV and cancer of the cervix. By getting regular Pap testing and any recommended follow-up treatments, you can get almost 100% protection from cancer of the cervix. Early detection is important in preventing cervical cancer.

### How do you get rid of HPV?

The best way to get rid of HPV on any part of the body is for your immune system to fight it off. You can help your immune system do this by taking good care of yourself. Eat well. Get enough sleep. Exercise. And most importantly, stop smoking. Smoking is the number one risk factor for not being able to fight off HPV.

### If I have HPV on my cervix, do I have cancer?

Having HPV on your cervix does not mean you have cancer or that you will get cancer. There are more than 30 types of HPV that can attack the cells of the cervix. About half of these may lead to cancer, and they are called "high-risk" HPV types. "High-risk" HPV on the cervix takes many years to cause cancer. When caught early and treated, HPV changes on the cervix do not become cancer.

### If I have HPV on my cervix, what should be done?

If you do have a "high-risk" type of HPV on your cervix, your health care provider may examine your cervix with colposcopy. A colposcope is a microscope that makes the cells look very big so your provider can see which cells on your cervix have been injured by the virus. Your provider may follow-up with more frequent Pap tests, or may perform a biopsy (take a sample of the abnormal cells) to examine further. If the abnormal cells are worrisome, your health care provider may freeze (cryotherapy) or surgically removal (electrosurgery) or cut (LEEP) the injured cells off your cervix.

### For More Information

Ask the Midwife, Share with Women, **Genital Warts** https://onlinelibrary.wiley.com/doi/10.1111/jmwh.13348 National Cancer Institute www.cancer.gov/cancertopics/factsheet/Risk/HPV This Web site describes the HPV virus and reviews all the different types of abnormal cells that can be found on your cervix Centers for Disease Control and Prevention www.cdc.gov/STD/HPV/STDFact-HPV.htm This Web site has information about HPV and cervical cancer. The information is available in Spanish

### Flesch Kincaid Reading level 6.6

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