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Maternal characteristics, pregnancy complications and adverse birth outcomes among women with disabilities

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Abstract

Objectives—The objective of this study is to describe the maternal characteristics, pregnancy complications, and birth outcomes among a representative sample of Rhode Island women with disabilities who recently gave birth.

Methods—Data from the 2002–2011 Rhode Island Pregnancy Risk Assessment Monitoring System (PRAMS) survey were analyzed.

Results—Approximately 7% of women in Rhode Island reported a disability. Women with disabilities reported significant disparities in their health care utilization, health behaviors and health status before and during pregnancy and during the postpartum period. Compared to nondisabled women, they were significantly more likely to report stressful life events and medical complications during their most recent pregnancy, were less likely to receive prenatal care in the

first trimester, and more likely to have preterm births (13.4%; 95% CI, 11.6–15.6 compared to 8.9%; 95% CI, 8.5–9.3 for women without disabilities) and low birth weight babies (10.3%; 95% CI, 9.4–11.2 compared to 6.8%; 95% CI, 6.8–6.9). There was no difference in the rates of cesarean section between women with and without disabilities.

Conclusion—These findings support the need for clinicians providing care to pregnant women with disabilities to be aware of the increased risk for medical problems during pregnancy and factors that increase the risk for poor infant outcomes.

Keywords

prenatal care; pregnancy complications; women with disabilities; birth outcomes; disability

INTRODUCTION

Emerging literature suggests that women with disabilities who become pregnant are at elevated risk for poor health, pregnancy complications and adverse birth outcomes.¹ Women with chronic physical disabilities are as equally likely as their nondisabled peers to be currently pregnant but are at greater risk for having multiple chronic conditions and are more likely to report fair to poor health than other women.^{2, 3} Mitra et al. documented the increased risk of postpartum depression,⁴ physical abuse during pregnancy,⁵ and smoking before, during and after pregnancy among women with heterogeneous disabilities compared to other women.⁶ Others have also documented the increased risk of adverse maternal outcomes in women with specific disabilities.^{7–10}

To the best of our knowledge, however, there are no population-based studies that examine the maternal characteristics, pregnancy complications and birth outcomes among women with a spectrum of disabilities.¹ To fill this gap, we used Pregnancy Risk Assessment and Monitoring System (PRAMS) data¹¹ to present the descriptive epidemiology of pregnancy among women with disabilities; to examine maternal characteristics; pregnancy complications; health care utilization before, during, and after pregnancy; and birth outcomes of a representative sample of women with disabilities. Based on previous findings on the association between pregnancy complications and birth outcomes and disability status,^{2–10} we hypothesized that women with disabilities will have worse prenatal and postpartum health care experiences as evidenced by less access to care, greater numbers of pregnancy complications, and poorer birth outcomes than other women.

METHODS

Study Participants

Study data came from the 2002–2011 Rhode Island (RI) PRAMS, a population-based surveillance system that collects state-specific, cross-sectional data on maternal attitudes and experiences before, during, and shortly after pregnancy. RI is one of only two states to include disability status items in the PRAMS and the only state to have accrued ten years of data on disability status; the study sample was thus limited to RI. During 2002–2011 9,324 RI women were sampled and the weighted response rate ranged from 69.2% to 71.7%.

Details about the purpose, sampling methods, and data collection of the PRAMS are available elsewhere.^{11, 12}

Measures

Disability status in the RI PRAMS survey was ascertained by responses to the following question: “Are you limited in any way in any activities because of physical, mental, or emotional problems?” We obtained maternal demographic characteristics, pre-pregnancy health status, health behaviors, health care utilization, pregnancy experiences and complications, birth outcomes, and postpartum health care utilization from birth certificate data or PRAMS survey items.

PRAMS items related to pre-pregnancy and pre-delivery health behaviors, health status, and health care utilization included pregnancy intention, height and weight, exercise, vitamin use, diagnosis of asthma or diabetes, screening and treatment for high blood pressure and diabetes, and dental care.

Pregnancy-related health behaviors and complications were obtained from PRAMS items related to maternal smoking or drinking, pregnancy complications, stressful life events, physical abuse and perception of safety in respondents’ neighborhoods, prenatal care as measured by the Adequacy of Prenatal Care Utilization Index (APNCU),¹³ derived from information on the birth certificate, categorized based on initiation of care during first trimester and total number of visits. Additional pregnancy-related health care utilization items from PRAMS related to HIV testing, influenza vaccination, and dental care.

Preterm birth, (< 37 weeks), low birth weight (< 2500 grams), infant transfer to ICU and length of hospital stay, method of delivery, and infant mortality were derived from birth certificates.

Survey items elicited information on postnatal experiences and health care utilization, including maternal postpartum support, postpartum check-up, infant health care visits, health care worker availability, postnatal tests for hearing loss and genetic conditions, and breastfeeding.

Analytic Methods

Overall trends and differential trends over time did not differ by disability status. Data from all years were therefore combined for analysis. We present point estimates and 95% confidence intervals of all indicators by disability status. Bivariate analyses compared between-group differences in these characteristics. SAS Software, Version 9.1, copyright, SAS Institute Inc., Cary, NC, and SUDAAN Version 10, RTI International, Research Triangle Park, NC, were used to account for the complex PRAMS survey design. The University of Massachusetts Medical School Institutional Review Board approved the use of the RI PRAMS data in this study.

RESULTS

Overall 6.7% (95% CI, 6.2–7.2) of RI women who recently gave birth reported having a disability. Women with disabilities were younger, less educated, more likely to be unmarried, receive public insurance, and have a household poverty status equal to or less than 100% of Federal Poverty Level compared to women without disabilities. (Table 1)

Approximately 85% of women with a disability intended to become pregnant compared with nearly 92% of those with no disabilities (Table 2). Prior to pregnancy, women with disabilities were less likely to be a healthy weight, take a prenatal vitamin every day, have a pre-pregnancy teeth cleaning, were more likely to have ever been diagnosed with diabetes or asthma, and currently have asthma than their nondisabled peers.

With respect to pregnancy characteristics and experiences, women with disabilities were over twice as likely to smoke and more likely to report a medical complication during pregnancy compared women without disabilities (Table 3). Specific medical problems more common among women with disabilities included vaginal bleeding, kidney/bladder infections, nausea, injury due to a car crash, preterm labor, and premature rupture of membranes. Compared with other women, women with disabilities were more likely to report experiencing stressful life events and physical abuse during pregnancy, and over twice as likely to report feeling unsafe in their neighborhood than women without disabilities.

Nearly 84% of nondisabled women received prenatal care in their first trimester, compared with approximately 78% of women with disabilities. Women with disabilities were nearly twice as likely to begin prenatal care after their first trimester, and more likely to report inadequate prenatal care based on the APNCU than their nondisabled counterparts. Significant differences in the receipt of oral health care were also noted. Women with disabilities were more likely to receive an HIV test during pregnancy than women with no disabilities, but no more likely to be offered or administered a flu vaccine.

Over 10% of women with disabilities had a low birth weight infant and over 13% preterm birth, compared with 7% and 9%, respectively, among women without disabilities. (Table 4) Women with disabilities were more likely to have a long hospital stay, an infant in NICU, and to have had an infant who died than their nondisabled peers.

Postpartum, approximately 70% of women with disabilities reported ever breastfeeding or pumping and 45% reported currently breastfeeding, compared with 75% and 53%, respectively, of women without disabilities. (Table 5) Women with disabilities were less likely to report postpartum social support, and were less likely to visit the doctor for a postpartum check-up.

DISCUSSION

This study is the first population-based examination of maternal characteristics, health behaviors, and health care utilization among women with disabilities who have given birth to a live infant. Findings from this study suggest that recent mothers with disabilities have

lower levels of education, are less likely to be married, and more likely to be receiving public insurance and have lower household income. This study also highlights significant disparities in their pre-pregnancy, pregnancy-related and postpartum health status, health behaviors, health care utilization, and in adverse birth outcomes between women with and without disabilities.

Similar to earlier studies on the health of pregnant women with disabilities,^{2, 5, 6, 14–16} this study emphasizes the disability-related disparities in pregnancy-related risk factors associated with adverse birth outcomes. Women with disabilities compared to their nondisabled peers are more likely to report medical complications and stressful life events during pregnancy. Our findings are similar to earlier studies examining risk factors associated with adverse maternal and infant outcomes among women with disabilities.^{2, 14, 15}

In addition women with disabilities in our study were at greater risk of stressful life events during their pregnancy. They also reported higher rates of physical abuse from a current or former partner during their pregnancy and reported receiving less social support following delivery. Research on the association of maternal stress and birth outcomes suggest that maternal stress is an important risk factor for adverse birth outcomes.^{17–21} These adverse birth outcomes observed in the general population could potentially have greater impact for pregnant women with disabilities. The additional medical complications of pregnancy among women with disabilities compounded by the high levels of financial, partner-related, traumatic, and emotional stress and the lack of perceived social support could potentially further compromise their health and the health of their infants.

In addition, women with disabilities were more likely to delay prenatal care until after the first trimester, report inadequate prenatal care, and were less likely to report having a postpartum check-up within six weeks of birth. The delay in accessing health care could in part be attributed to the negative experiences of women with disabilities with their health care providers. Women with disabilities often report that their health care providers are not able to manage their pregnancies effectively, possess negative stereotypes about their sexuality, disapprove of their pregnancy, and question their ability to parent.^{23–38} These negative and humiliating experiences with health care providers could potentially prevent women with disabilities from seeking timely prenatal and postpartum care.

Pre-pregnancy differences in the health of women with disabilities in this study, including a significantly increased prevalence of asthma and an increased likelihood of unplanned pregnancy, have implications for clinicians caring for women with disabilities during their childbearing years. Delayed prenatal care increases the likelihood that these health problems may result in poor maternal and infant outcomes, including delayed recovery of women with disabilities during the postpartum period. The increased likelihood of poor infant outcomes (i.e., low birth weight baby, preterm birth, long hospital stay, infant in NICU, and infant mortality) in women with disabilities necessitates greater attention of clinicians to the health of women with disabilities before and during pregnancy.

The purposes of the PRAMS surveys are to identify groups of women and infants at high risk for health problems, and to measure progress towards goals in improving the health of mothers and infants.¹¹ Nevertheless, only two states (Rhode Island and Massachusetts) include questions that identify disability status in their surveys. Given the disparities in health and health care utilization of mothers with disabilities as well as adverse pregnancy outcomes, it is vital that the PRAMS survey going forward includes the full set of disability questions to systematically identify and monitor the health of US mothers with disabilities.

Limitations

There are several limitations to this study. The RI PRAMS is subject to self-report bias. The number of women reporting a disability is relatively small, which affects the precision and the generalizability of our findings. Women who responded to the disability screening question are likely heterogeneous with mental, physical, cognitive, or sensory disabilities, which may be associated with different risks and needs. Future research is needed to examine the pregnancy complications and outcomes among mothers with specific types of disabilities. Given the cross-sectional nature of this study, we cannot ascertain whether pregnancy preceded disability. Future studies using a more comprehensive set of disability screeners are vital to understanding the health needs of pregnant women with disabilities. Finally the PRAMS survey does not include pregnancies that result in stillbirths or in live births of multiples of four or more.

Conclusion

This study advances earlier studies by documenting disparities in prenatal and postnatal health care utilization and pregnancy-related complications and outcomes experienced by women with disabilities. The findings point to a need for a systematic effort to investigate pregnancy risks, complications, and outcomes of women with disabilities and highlight the need for clinicians who provide care to pregnant women with disabilities to be aware of their increased risk for poor maternal and infant outcomes. The delayed utilization of prenatal care by women with disabilities, likely due in part to social factors, necessitates a society-wide approach to ensure that women with disabilities are provided with resources to access reproductive health care and timely prenatal and postpartum care, and the support they need for successful childbearing experiences.

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Table 1

Demographic Characteristics of Women with Live Births, by Disability Status, Rhode Island (2002–2011)

	Women with disability (n=1,015)	Women without disability (n=12,346)
	% (95% CI)	% (95% CI)
Age ***		
Age <20	14.2 (11.7–17.2)	8.7 (8.1–9.3)
20 age 29	48.5 (44.7–52.4)	46.6 (45.5–47.6)
30 age 39	33.7 (30.2–37.4)	41.5 (40.5–42.5)
Age 40	3.6 (2.5–5.2)	3.3 (3.0–3.7)
Race/ethnicity ***		
White, non-Hispanic	59.5 (55.7–63.2)	66.8 (65.9–67.6)
Black, non-Hispanic	10.6 (8.5–13.2)	7.3 (6.8–7.8)
Hispanic	21.1 (18.1–24.3)	20.2 (19.4–20.9)
Asian, non-Hispanic	4.4 (3.0–6.3)	3.6 (3.3–4.0)
Other, non-Hispanic	4.5 (3.1–6.3)	2.2 (1.9–2.5)
Marital status ***		
Married	41.8 (38.1–45.6)	61.5 (60.5–62.5)
Other	58.2 (54.4–61.9)	38.5 (37.6–39.5)
Education ***		
Less than high school	21.6 (18.5–25.1)	14.9 (14.2–15.6)
High school	37.5 (33.7–41.5)	28.3 (27.4–29.3)
More than high school	40.9 (37.1–44.8)	56.8 (55.8–57.8)
Federal Poverty Level (FPL) ***		
Above 100% FPL	60.0 (56.2–63.7)	77.6 (76.7–78.4)
Below 100% FPL	40.0 (36.3–43.8)	22.4 (21.6–23.3)
Insurance status ***		
Public	60.5 (56.7–64.2)	40.1 (39.1–41.0)
Private/Other	39.5 (35.8–43.3)	59.9 (59.0–60.9)
Previous live birth $\neq$	59.0 (55.1–62.7)	55.2 (54.1–56.2)

 $\neq$ p<0.1;

* p<0.05;

** p<0.01;

*** p<0.001

Table 2

Before Pregnancy Characteristics and Experiences of Women with Live Births, by Disability Status, Rhode Island (2002–2011)

	Women with disability (n=1,015)	Women without disability (n=12,346)
	% (95% CI)	% (95% CI)
Pregnancy intention ***	85.1 (82.1–87.7)	91.8 (91.2–92.3)
BMI before pregnancy *		
<19.8	12.5 (10.1–15.3)	11.4 (10.7–12.1)
19.8–26.0	48.5 (44.6–52.5)	54.2 (53.1–55.2)
26–29	14.5 (11.9–17.7)	13.9 (13.2–14.7)
>29	24.5 (21.3–28.0)	20.6 (19.7–21.5)
Multivitamin or prenatal vitamin use **		
Every day of the week	28.8 (25.5–32.5)	35.2 (34.3–36.2)
1–6 times a week	15.6 (13.0–18.7)	13.6 (12.9–14.4)
Did not take vitamins	55.5 (51.7–59.3)	51.2 (50.1–52.2)
^a Exercise 3 or more days/week 12 months before pregnancy	44.1 (37.1–51.5)	45.5 (43.5–47.4)
Talked to health care worker about family medical history	37.1 (30.4–44.3)	32.1 (30.3–33.9)
^a Pre-pregnancy teeth cleaning **	53.1 (45.8–60.3)	63.4 (61.5–65.2)
Chronic health conditions		
^a Checked or treated for diabetes, pre-pregnancy	10.7 (7.0–15.9)	8.4 (7.4–9.6)
^a Checked or treated for high blood pressure, pre-pregnancy ≠	14.3 (9.9–20.0)	9.5 (8.4–10.7)
^a Diabetes before pregnancy *	6.4 (3.5–11.4)	1.9 (1.4–2.5)
^a Ever had asthma ***	32.8 (26.2–40.0)	16.2 (14.8–17.7)
^a Current asthma status **	76.7 (63.7–86.0)	57.2 (52.3–62.0)
^aFelt unsafe before pregnancy ***		
Always	1.3 (0.5–3.6)	1.3 (0.9–1.8)
Often/almost always	3.9 (1.9–7.5)	1.1 (0.7–1.6)
Sometimes	13.6 (9.3–19.5)	5.1 (4.3–6.1)
Rarely	19.5 (14.3–26.0)	14.2 (12.9–15.6)
Never	61.8 (54.5–68.5)	78.4 (76.7–79.9)

≠ p<0.1;

* p<0.05;

** p<0.01;

*** p<0.001

^aPhase 6 only

Table 3

Characteristics and Experiences of Women with Live Births During Pregnancy, by Disability Status, Rhode Island (2002–2011)

	Women with disability (n=1,015)	Women without disability (n=12,346)
	% (95% CI)	% (95% CI)
<i>Risk behaviors</i>		
Smoking during last 3 months of pregnancy**	21.7 (18.7–25.0)	10.5 (9.8–11.2)
Alcohol use during last 3 months of pregnancy [≠]	7.2 (5.4–9.5)	9.1 (8.6–9.7)
<i>Pregnancy complications</i>		
Medical problems during pregnancy (any)***	78.1 (74.7–81.1)	61.8 (60.8–62.8)
Blood transfusion	1.3 (0.8–2.4)	1.2 (1.0–1.5)
High blood pressure	14.6 (12.2–17.4)	13.1 (12.5–13.8)
Vaginal bleeding***	23.0 (19.9–26.4)	15.8 (15.1–16.6)
Placenta	6.6 (5.1–8.5)	5.4 (4.9–5.8)
Kidney/bladder infection***	21.0 (18.0–24.4)	12.8 (12.2–13.6)
Nausea***	41.7 (37.9–45.6)	26.9 (26.0–27.8)
Cervix closed	2.2 (1.3–3.6)	1.7 (1.5–2.0)
Car crash injury*	4.9 (3.5–6.8)	2.7 (2.4–3.1)
Preterm labor***	32.5 (29.1–36.2)	19.0 (18.2–19.8)
Premature rupture of membranes (PROM)*	7.0 (5.6–8.7)	5.1 (4.8–5.5)
^a Gestational diabetes, this pregnancy [≠]	17.1 (12.3–23.2)	12.3 (11.1–13.6)
<i>Stressors and stressful life events during pregnancy</i>		
Emotional stress***	42.8 (39.0–46.6)	30.7 (29.7–31.6)
Partner-related stress***	51.7 (47.9–55.6)	29.0 (28.1–30.0)
Financial stress***	67.4 (63.6–70.9)	49.4 (48.4–50.4)
Traumatic stress***	33.8 (30.3–37.6)	16.2 (15.4–17.0)
3 or more stressful life events***	51.1 (47.2–54.9)	26.3 (25.4–27.3)
Physical abuse during pregnancy***	7.2 (5.4–9.4)	2.3 (2.0–2.6)
^a Felt unsafe before pregnancy***		
Always	1.3 (0.5–3.6)	1.3 (0.9–1.8)
Often/almost always	3.9 (1.9–7.5)	1.1 (0.7–1.6)
Sometimes	13.6 (9.3–19.5)	5.1 (4.3–6.1)
Rarely	19.5 (14.3–26.0)	14.2 (12.9–15.6)
Never	61.8 (54.5–68.5)	78.4 (76.7–79.9)
<i>Health care utilization during pregnancy</i>		
Prenatal Care, 1 st trimester***	77.5 (74.1–80.6)	83.6 (82.8–84.4)
Prenatal Care, after 1st trimester***	11.0 (8.8–13.7)	6.7 (6.2–7.3)

	Women with disability (n=1,015)	Women without disability (n=12,346)
	% (95% CI)	% (95% CI)
<i>The Kotelchuck Index (Adequacy of Prenatal Care Utilization (APNCU))*</i>		
Inadequate	8.8 (6.8–11.4)	5.5 (5.0–6.0)
Intermediate	12.0 (9.6–14.9)	12.2 (11.5–12.9)
Adequate	36.2 (32.4–40.2)	41.0 (40.0–42.1)
Adequate plus	43.0 (39.1–47.0)	41.2 (40.2–42.3)
^a HIV test during pregnancy*	86.3 (80.4–90.6)	80.2 (78.5–81.8)
Flu vaccine administered during pregnancy	37.1 (33.4–41.0)	37.0 (36.0–37.9)
^a Dental visit during pregnancy**	42.1 (35.1–49.6)	53.3 (51.3–55.2)

[†]p<0.1;

* p<0.05;

** p<0.01;

*** p<0.001

^aPhase 6 only

Table 4

Birth Outcomes of Women with Live Births, by Disability Status, Rhode Island (2002–2011)

	Women with disability (n=1,015)	Women without disability (n=12,346)
	% (95% CI)	% (95% CI)
Low birth weight ***	10.3 (9.4–11.2)	6.8 (6.8–6.9)
Preterm birth ***	13.4 (11.6–15.6)	8.9 (8.5–9.3)
Caesarian section	29.3 (26.0–32.8)	32.2 (31.6–33.2)
14 or more days in the hospital *	8.7 (6.8–11.1)	6.3 (5.8–6.8)
Infant in ICU at birth ***	13.8 (11.7–16.2)	9.6 (9.1–10.1)
Infant currently living ***	98.8 (98.3–99.1)	99.6 (99.5–99.7)

≠
p<0.1;

*
p<0.05;

**
p<0.01;

p<0.001

Table 5

Maternal Characteristics and Experiences during Postpartum, by Disability Status, Rhode Island (2002–2011)

	Women with disability (n=1,015)	Women without disability (n=12,346)
	% (95% CI)	% (95% CI)
Breastfeeding		
Ever breastfed or pumped**	70.1 (66.3–73.6)	75.1 (74.2–76.0)
Currently breastfeeding**	45.1 (40.4–49.8)	52.9 (51.7–54.1)
Adequacy of postpartum social support		
Have someone to loan \$50***	72.4 (68.7–75.9)	84.4 (83.7–85.1)
Have someone to help if sick in bed***	84.8 (81.7–87.4)	90.0 (89.4–90.6)
Have someone to talk to about problems***	81.3 (78.1–84.2)	88.2 (87.5–88.8)
Have someone to help if feeling tired/frustrated with new baby***	83.9 (80.8–86.6)	90.3 (89.7–90.9)
Have someone to drive to the doctor***	87.0 (84.0–89.5)	92.8 (92.3–93.4)
Postpartum care		
Postpartum checkup for mother***	87.1 (84.3–89.4)	93.5 (92.9–93.9)
Baby visit 1 st week	94.4 (92.3–95.9)	93.5 (93.0–94.1)
^a Have health care worker to contact 24/7	90.7 (85.0–94.5)	90.7 (89.5–91.9)
Baby tested for hearing loss	88.5 (85.8–90.7)	89.6 (88.9–90.2)
Baby tested for genetic conditions	72.9 (69.3–76.2)	73.5 (72.6–74.5)

≠
p<0.1;

*
p<0.05;

**
p<0.01;

p<0.001

^aPhase 6 only