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Agreement Between Self-Report and Birth Certificate for Gestational Diabetes Mellitus: New York State PRAMS

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Abstract This study examined agreement (concordance or convergent validity) between self-report and birth certificate for gestational diabetes. Study population was 2,854 women who had live births 2–6 months earlier and responded to a questionnaire from the New York State Pregnancy Risk Assessment Monitoring System (PRAMS) survey, 2004–2006. Agreement between self-report and birth certificate was assessed for the study population overall, and for subgroups defined by race, age, education, marital status, number of previous live births, time of first prenatal care, and birth weight of the newborn. A total of 258 women self-reported gestational diabetes, while birth certificates indicated that 138 women had gestational diabetes. For the study population overall, percent agreement was 93.8% and Kappa was 0.53. Due to the moderate bias index (68.2% overall, ranged from 33.3 to 100% in subgroups) and the high skewed prevalence index (91.8% overall, ranged from 70.7 to 97.5% in subgroups), we determined Prevalence-Adjusted and Bias-Adjusted Kappa (PABAK) was a better measure of agreement. PABAK was 0.88 overall, indicating very good agreement. PABAK was uniformly high in all subgroups. The highest PABAK was found among women aged 25 years and younger (0.93), and the lowest PABAK was among Asian women (0.79). Although the absence of a gold standard for gestational diabetes hinders assessment of criterion validity, high PABAK measures suggest that self-reporting by PRAMS respondents is feasible for identifying cases of gestational diabetes for surveillance and population-based epidemiologic research.

Keywords Gestational diabetes · Self-report · Agreement · Birth certificates · PRAMS · Kappa · PABAK · New York State

Introduction

Self-report has been extensively used to identify medical conditions in surveillance and epidemiologic studies, because it is less expensive and simpler compared to physical examination or secondary data exploration. Self-report can be used for assessing gestational diabetes, but scant data are available to evaluate its validity. The purpose of this study is to assess agreement (i.e. concordance or convergent validity) between self-report and birth certificate for the reporting of gestational diabetes among a representative sample of women who recently gave birth to a live born infant.

Methods

Study population was derived from the respondents of the New York State Pregnancy Risk Assessment Monitoring System (PRAMS), 2004–2006. The PRAMS is an ongoing multi-state surveillance project to collect state-specific, population-based maternal health data before, during, and shortly after pregnancy [1]. The New York State PRAMS sample is drawn monthly from the state's birth certificate file (exclusive of New York City) and

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Table 1 Sample size, prevalence, and measures of concordance for birth certificate and self-reported gestational diabetes mellitus: New York State PRAMS data 2004–2006

	Total *N*	Birth certificate		Self-report (PRAMS)		Percent agreement	Kappa	PABAK	Bias index	Skewed prev. index
		GDM N	Prevalence (95% CI)	GDM N	Prevalence (95% CI)					
All cases	2,854	138	4.8 (4.1, 5.7)	258	9.0 (8.0, 10.2)	93.8	0.53	0.88	68.2	91.8
Maternal race										
White, Non-Hispanic	2,085	84	4.0 (3.2, 5.0)	170	8.2 (7.0, 9.4)	94.5	0.53	0.89	75.4	92.9
Black, Non-Hispanic	271	15	5.5 (3.1, 9.0)	25	9.2 (6.1, 13.3)	93.4	0.52	0.87	55.6	91.3
Hispanic	351	23	6.6 (4.2, 9.7)	33	9.4 (6.6, 13.0)	91.5	0.42	0.83	33.3	91.9
Asian	84	11	13.1 (6.7, 22.2)	20	23.8 (15.2, 34.3)	89.3	0.65	0.79	100.0	70.7
Other	63	5	7.9 (2.6, 17.6)	10	15.9 (7.9, 27.3)	92.1	0.63	0.84	100.0	82.8
Maternal age										
<25	677	13	1.9 (1.0, 3.3)	28	4.1 (2.8, 5.9)	96.3	0.37	0.93	60.0	97.5
25–34	1,534	74	4.8 (3.8, 6.0)	136	8.9 (7.5, 10.4)	94.1	0.54	0.88	68.9	91.7
≥35	643	51	7.9 (6.0, 10.3)	94	14.6 (12.0, 17.6)	90.5	0.53	0.81	70.5	85.6
Maternal education										
Less than high school	434	19	4.4 (2.7, 6.8)	31	7.1 (4.9, 10.0)	93.1	0.37	0.86	40.0	95.0
High school	638	29	4.5 (3.1, 6.5)	56	8.8 (6.7, 11.2)	92.3	0.39	0.85	55.1	93.9
Some college or more	1,782	90	5.1 (4.1, 6.2)	171	9.6 (8.3, 11.1)	94.6	0.60	0.89	83.5	90.3
Marital status										
Married	1926	104	5.4 (4.6, 6.5)	199	10.3 (9.0, 11.8)	93.4	0.55	0.87	74.8	90.2
Not married	928	34	3.7 (2.6, 5.1)	59	6.4 (4.9, 8.1)	94.7	0.45	0.89	51.0	95.0
Previous live births										
0	1257	61	4.9 (3.7, 6.2)	104	8.3 (6.8, 9.9)	94.7	0.57	0.89	64.2	91.8
1	869	47	5.4 (4.0, 7.1)	91	10.5 (8.5, 12.7)	92.9	0.52	0.86	71.0	90.6
≥2	728	30	4.1 (2.8, 5.8)	63	8.7 (6.7, 10.9)	93.5	0.46	0.87	70.2	93.2
First prenatal care										
1–3 months	2,201	108	4.9 (4.0, 5.9)	207	9.4 (8.2, 10.7)	93.9	0.54	0.88	73.3	91.3
4–6 months	298	14	4.7 (2.6, 7.8)	22	7.4 (4.7, 11.0)	93.3	0.41	0.87	40.0	94.2
7–9 months or none	355	16	4.5 (2.6, 7.2)	29	8.2 (5.5, 11.5)	94.1	0.50	0.88	61.9	92.8
Birth weight										
<1,500 g	233	13	5.6 (3.0, 9.4)	23	9.9 (6.4, 14.4)	91.4	0.40	0.83	50.0	92.5
1,500–2,499 g	1,003	58	5.8 (4.4, 7.4)	105	10.5 (8.6, 12.5)	92.3	0.49	0.85	61.0	90.7
2,500–3,999 g	1,433	57	4.0 (3.0, 5.1)	114	8.0 (6.6, 9.5)	95.0	0.56	0.90	80.3	92.7
≥4,000 g	185	10	5.4 (2.6, 9.7)	16	8.6 (5.0, 13.7)	95.7	0.67	0.91	75.0	89.8

consists of women who have had live births 2–6 months earlier. Sampled women receive a standardized confidential questionnaire in the mail. If there is no response to at least two additional mailings, women are contacted and interviewed by telephone. The average response rate for 2004–2006 was 72%.

Self-report of gestational diabetes was obtained by the respondent's selection of "high blood sugar (diabetes) that started *during* this pregnancy" in response to the question "Did you have any of these problems during your most recent pregnancy?" Self-report of pre-pregnancy diabetes was obtained by the selection of "high blood sugar (diabetes) that started *before* this pregnancy." Women who reported both gestational diabetes and pre-pregnancy diabetes were considered as having pre-pregnancy diabetes, and not counted as gestational diabetes in this study. Gestational diabetes information in the birth certificate was based on medical records, and it was submitted electronically to the New York State Department of Health by the health facility where the respondent gave birth. Birth certificates do not allow reporting pre-pregnancy diabetes and gestational diabetes in the same individuals. The birth certificate data and the PRAMS data were merged to form linkage at the individual level.

Agreement between self-report and birth certificate was assessed for the study population overall, and for

	Yes	No
Yes	a	b
No	c	d

Fig. 1 2 by 2 table for agreement

subgroups defined by race, age, education, marital status, number of previous live births, time of first prenatal care, and birth weight of the newborn. We assumed neither self-report nor birth certificate serve as a gold standard of gestational diabetes. We used three measures of concordance including percent agreement, Kappa (Cohen's Kappa), and Prevalence-Adjusted Bias-Adjusted Kappa (PABAK). In addition, prevalence of gestational diabetes and its 95% confidence interval, the bias index, and the skewed prevalence index were computed. The bias index was calculated as $|b-c|/(b+c)$, and the skewed prevalence index was calculated as $|a-d|/(a+d)$. (see Fig. 1 for a 2 by 2 table of agreement). The University at Albany Institutional Review Board approved the human subject protection protocol.

Results

Among a sample of 2,854 women who had live births in New York State, 258 self-reported gestational diabetes, with a prevalence of 9.0% (95% confidence interval: 4.1, 5.7%) (Table 1). Birth certificates indicated that 138 women had gestational diabetes, with a prevalence of 4.8%. (95% confidence interval: 8.0, 10.2%). The overall percent agreement was 93.8%. All subgroup categories had percent agreement higher than 89%. Kappa for the study population was 0.53, and ranged from 0.37 to 0.65 for subgroup categories. Kappa between 0.40 and 0.60 is considered "moderate agreement" [2]. The Kappa statistic, however, should be interpreted with caution, because it is influenced by bias between the ratings of categories and skewed prevalence [3]. Kappa value is greater for a lower bias [4]. Kappa value is greatest when prevalence equals 50% [4]. In our sample, the maximum attainable Kappa remained below 0.70, indicating that Kappa cannot reach the "very good agreement" range ($\geq$0.80) with the given bias and prevalence. We computed the bias index, which was 68.2% overall, and ranged from 33.3 to 100% in subgroup categories. We also computed the skewed prevalence index, which was 91.8% overall and ranged from 70.7 to 97.5% in subgroup categories. Because of these properties, we determined that PABAK was a better measure of agreement. PABAK for the overall population was 0.88, indicating very good agreement. The PABAK was uniformly high (0.79 and higher) in all sub groups. The highest PABAK was found among women aged 25 years and younger (0.93), and the lowest PABAK was among Asian women (0.79).

Conclusions

The high degree of agreement between self-report and birth certificate suggests that self-report by the PRAMS respondents is feasible for the identification of gestational diabetes. Studies assessing self-reported medical information have shown that patients can provide reasonably good reports of their morbidities [5, 6]. The finding of this study encourages the use of PRAMS data for surveillance and population-based epidemiologic study of gestational diabetes.

There are limitations in this study. The absence of a gold standard for gestational diabetes hinders assessment of criterion validity. Both birth certificates and PRAMS have intrinsic limitations in ascertaining gestational diabetes. Several studies have shown that birth certificates under-report gestational diabetes [7, 8]. Poor training of clerical staff, a lack of review by clinicians, and little incentive for quality improvement are suggested as causes of under-reporting [7, 9]. Studies suggest the use of birth certificates along with medical records to maximize the accuracy of reporting conditions occurring during pregnancy [7, 8, 10].

The quality of birth certificate reporting in the US, however, appears to vary among states. A medical chart review of a sample of New York State birth certificates showed that gestational diabetes had high validity measures, with sensitivity of 83% and specificity of 99% [11]. New York's sensitivity measure was the highest among the measures obtained from validity studies of birth certificates and hospital discharge data that included five other states [8]. New York State began separating pre-existing and gestational diabetes in birth certificates when it started electronic submission in 1993. The current improved format of birth certificates, which prohibits entering diabetes and gestational diabetes in the same individuals, was introduced in 2004. The adaptation of these measures is a likely contributor to the high validity of gestational diabetes reporting in New York State birth certificates.

The PRAMS collects information based on a self-administered survey, which is subject to recall bias, social desirability bias, and measurement bias resulting from wording and questionnaire design [12]. In this study, a large proportion of disagreement came from women who reported gestational diabetes in PRAMS only (148 of the 176 total disagreement cases). The use of "high blood sugar (diabetes)" in its wording might have caused over-reporting of gestational diabetes by women who had

elevated levels of blood sugar but not in the diabetic range. Previously published studies also report over-reporting of gestational diabetes by women. A study in Taiwan comparing self-report with medical records found over-reporting of gestational diabetes by the former: It was hypothesized that the women might have perceived presence of sugar in urine as gestational diabetes [13]. Yet in a study of pregnant Latina women in California, recall of gestational diabetes had the highest agreement with medical records compared to recalls of anemia, hypertension, tobacco, alcohol and vitamin use [14].

A close examination of the bias indexes by subgroup categories can provide a clue to the mechanism of disagreement. The bias index of 100% indicates that the disagreement came entirely from one cell—either yes/no (b) or no/yes (c). The bias index becomes 0% when (b) = (c). In our study, two sub groups, 'Asian' and 'Other' races (where subgroup 'Other' excludes non-Hispanic Whites, non-Hispanic Blacks and Hispanics), had the bias index of 100%, because all the disagreement cases came from women who reported gestational diabetes in PRAMS only. (i.e., all women in these subgroups, who were reported with gestational diabetes by birth certificate, also self-reported the condition in PRAMS). Women with some college education or more and women who delivered normal weight (2,500–3,999 g) babies also had a high ($\geq$80%) bias index, with the PRAMS-only category predominating. A lower (<55%) bias index was found among women with lower socio-economic status, including Hispanics, those who had less than high school education, had first prenatal care at 4–6 months of pregnancy, delivered very low birth weight (<1,500 g) babies, and unmarried women. For them, disagreements came from both PRAMS-only and birth certificate-only categories.

Finally, the significantly higher prevalence of gestational diabetes by PRAMS compared to birth certificate was reported in this study. The New York State PRAMS samples at-risk women for pregnancy-related adverse health outcomes at a higher rate. Post-stratification weights are used to correct the effects of over-sampling for statewide prevalence estimation. The present study used the unweighted PRAMS data. The prevalence of gestational diabetes presented in this study should not be interpreted as statewide estimates.

The true extent of gestational diabetes is very difficult to assess. Medical records are considered to be a gold standard for gestational diabetes reporting, but a review of medical records can be very expensive, and access to medical records is highly restricted. Birth certificate data are the most accessible, standardized, and frequently used source of statewide gestational diabetes information. Given the high level of agreement with birth certificate across diverse subgroups of women, it is feasible to conclude that self-report in the PRAMS provides sufficiently accurate identification of gestational diabetes.

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