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## Community and Federal Collaboration to Assess Pregnancy Outcomes in Alaska Native Women, 1997–2005

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### Abstract

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The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

The objectives are to report the estimated prevalence of pregnancy complications and adverse pregnancy outcomes in a defined population of Alaska Native women and also examine factors contributing to an intensive and successful collaboration between a tribal health center and the Centers for Disease Control and Prevention. Investigators abstracted medical record data from a random sample of singleton deliveries to residents of the study region occurring between 1997 and 2005. We used descriptive statistics to estimate the prevalence and 95 % confidence intervals of selected pregnancy complications and adverse pregnancy outcomes. Records were examined for 505 pregnancies ending in a singleton delivery to 469 women. Pregnancy complication rates were 5.9 % (95 % CI 4.0, 8.4) for gestational diabetes mellitus, 6.1 % (95 % CI 4.2, 8.6 %) for maternal chronic hypertension and 11.5 % (95 % CI 8.8, 14.6) for pregnancy associated hypertension, and 22.9 % (95 % CI 19.2–26.5 %) for anemia. The cesarean section rate was 5.5 % (95 % CI 3.5, 7.5) and 3.8 % (95 % CI 2.3, 5.8) of newborns weighed >4,500 g. Few previous studies reported pregnancy outcomes among Alaska Native women in a specific geographic region of Alaska and regarding the health needs in this population. We highlight components of our collaboration that contributed to the success of the study. Studies focusing on special populations such as Alaska Native women are feasible and can provide important information on health indicators at the local level.

### Keywords

Alaska Native; Pregnancy; Collaboration

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### Background

Although women of childbearing age and infants comprise approximately 46 % of Alaska's native population [1], few population-based studies of the health status of Alaska Native women and infants have been conducted [2]. Furthermore, most existing studies combine all American Indian and Alaska Native women into one group, despite the fact that more than 500 American Indian and Alaska Native tribes exist in the US, each with its own unique culture and traditions [3]. Tribal communities and health care providers, as well as local, state, and federal agencies often wish to obtain health information from a specific population for health planning purposes. Conducting health studies in remote areas can be challenging for a number of reasons, including time constraints imposed by grant requirements, expense associated with long-distance travel, and logistical difficulties associated with compiling population-based data for a particular ethnic group.

This secondary analysis used data from a random sample of pregnancies that served as a control group in an earlier case–control study of tobacco use and adverse pregnancy outcomes [4]. We report the estimated prevalence of pregnancy complications and adverse pregnancy outcomes in a defined population of Alaska Native women. We also examined factors contributing to an intensive and successful collaboration between a tribal health center and the Centers for Disease Control and Prevention (CDC). Our findings and recommendations can be used by community providers to inform clinical and public health programs for Alaska Native pregnant women and their offspring, as well as for women of reproductive age needing preconception care.

## Initial Community Generated Research Question

This study was initiated when local medical providers expressed concerns about potential adverse health effects of maternal smokeless tobacco use during pregnancy. In particular, some providers worried that use of smokeless tobacco might result in an increased risk of preeclampsia and/or placental abruption. CDC investigators met with local providers and tribal health center board members to discuss these concerns. Based on the high prevalence of tobacco use, availability of exposure data in the medical record, and severity of the outcomes of concern, both organizations agreed to jointly conduct a study of pregnancy outcomes in smokeless tobacco users. In addition, local medical center staff expressed an interest in the prevalence of these and other adverse outcomes in their community. The current analysis focuses on the latter topic. The collaborative research team included local, state, and CDC professionals.

## Methodology Employed in Original Study

### Study Region

The study region is in a remote area of western Alaska with a large indigenous population that is relatively homogenous with respect to socioeconomic status and culture. This region has its own health care system consisting of a single main outpatient and hospital facility and individual village clinics. The village clinics are staffed by lay health care workers who treat minor and some major illnesses based on clinical guidelines. Nearly all pregnant Alaska Native women in the study region (96 %) receive their health care through this system. Women from the study region who are experiencing pregnancy complications or who otherwise have high risk pregnancies are referred to the Alaska Native Medical Center in Anchorage (ANMC) or to Providence Alaska Medical Center in Anchorage (PAMC) for specialty care during pregnancy and/or for delivery. Of approximately 500 deliveries a year, <15 per year occur at home or in villages.

### Study Population

Singleton deliveries were identified using discharge codes recorded in the regional hospital/medical center's and the Alaska Native Medical Center's electronic Resource and Patient Management System (RPMS). The research team searched for hospitalizations of Alaska Native women residing in the study region with the International Classification of Diseases, 9th Revision (ICD9-CM) discharge codes indicating delivery of an infant (liveborn or stillborn): any V27.0 or V27.1 or any 656.4 (intrauterine death after 22 weeks gestation). Because ICD9-CM code lists for hospitalizations are sometimes truncated, the following procedure codes were also used: 73.5, 74.0–74.2, 74.4, 74.99 (manually assisted delivery or cesarean section). Deliveries were excluded if the ICD9-CM codes indicated a multifetal gestation, including 651 (multiple gestation delivery, regardless of the 4th or 5th digit extension) or 652.61 (multiple gestation delivery with malpresentation of 1 or more fetus). Deliveries at PAMC to women residing in the study region were identified from hospital transfer records, as this hospital does not utilize the RPMS system.

## Process for Medical Record Abstractions and Data Entry

As previously described [4], the research team developed a study protocol, and created and piloted abstraction forms based on standard clinical and hospital forms used by the medical facilities. CDC staff held intensive training sessions with two chart abstractors (a nurse practitioner and a hospital data manager) at the beginning of the study and reviewed their completed abstraction forms several times throughout the study period to ensure that abstractors understood and adhered to abstraction procedures and that data were being abstracted from medical record sources in a consistent manner. CDC staff developed a data entry system using Epi Info and ensured that each data entry screen closely resembled the corresponding abstraction form page. Abstractors first examined medical records for all potential study deliveries to verify that they met inclusion criteria; deliveries were excluded if the mother was not a resident of the study region during the pregnancy of interest or was not Alaska Native, the pregnancy had more than one fetus, the delivery occurred before 22 weeks' gestation. In addition, we excluded any pregnancies indicating that the mother used alcohol in late pregnancy or used cocaine, amphetamines, or opioids at any time during pregnancy, or if the infant was born with a major congenital anomaly. Exact numbers of women excluded for prenatal drug exposure or congenital anomalies are not reported in order to protect the privacy of the study population and the community.

Once inclusion status was confirmed, additional data were abstracted from medical records, including: maternal demographic factors (age at delivery, marital status, highest level of education); gravidity; parity; trimester of prenatal care initiation; maternal height, prepregnancy weight, medical conditions (including type 1 or type 2 diabetes mellitus and chronic hypertension); tobacco exposure; birth weight; pregnancy complications [including gestational diabetes mellitus (GDM) and pregnancy associated hypertension (PAH)]; mode of delivery; and selected birth outcomes.

As part of routine data management procedures and to identify additional training needs to ensure data quality and accuracy, CDC investigators reviewed for accuracy abstracted data for 23 selected variables in approximately 10 % of the study deliveries. Each original response recorded on the abstraction form was reviewed to confirm that it could be verified in the medical record. Errors in abstractions were noted and then reviewed with the abstractors and, when necessary, retraining was provided. Frequent study meetings were held by phone to address questions about the abstraction process. The percentage of variables selected for review in which abstracted information could be verified ranged from 88 to 100 %.

## Dissemination of Findings

Once primary data were analyzed, the results and the study's implications were presented to local providers and the hospital executive board and to perinatologists in Anchorage. During these presentations, local providers and board members gave input as to the implications of the findings. During the drafting of the manuscript, Alaska collaborators provided input as to the cultural appropriateness of the text. In addition, they provided feedback on the processes at the hospital and in the community. Based on the findings, local providers are now able to more accurately counsel patients about health risks, based on data from their own

community. Importantly, the study was able to provide data to providers to address their specific concerns and provides baseline data that can be used for many purposes, including resource planning and grant applications. The original case-control study has been published in a peer-reviewed journal [4].

## Methodology for Current Secondary Analysis

### Study Population

Our study population consisted of a population-based random sample of approximately 10 % of all singleton deliveries to Alaska Native women who resided in the study region during pregnancy, used health care services at the regional hospital/medical center, and who delivered their infants at the regional hospital or referral hospital (ANMC or PAMC) between January 1, 1997 and December 31, 2005. As previously stated, data for this prevalence study came from a control population from a larger case-control study of pregnancy outcomes in smokeless tobacco users, previously described elsewhere [4].

### Variables Included in Analysis

The research team classified maternal prepregnancy BMI using categories of the National Heart, Lung, and Blood Institute: <25 kg/m<sup>2</sup> (underweight and normal), 25–29.9 (overweight), 30–34.9 (class I obesity), 35–39.9 (class II obesity), and 40+ (class III obesity). High parity was defined as one or more previous births for adolescents (<18 years), 3 or more previous births for 18–21 years, 4 or more previous births for 22–24 years, or 5 or more previous births for 25 and older [5]. Tobacco users were categorized into four mutually exclusive categories: tobacco non-users, cigarette smokers only, smokeless tobacco users only (iq'mik or commercial chew), or users of both cigarettes and smokeless tobacco. Iq'mik is a handmade mixture that includes leaf tobacco and ash from burned punk fungus, willow bush, or driftwood [6]. Pregnancies in which women quit using tobacco during pregnancy were categorized according to the type of tobacco used before cessation.

Maternal prenatal conditions included chronic diabetes, GDM, PAH, anemia, urinary tract infection (UTI), and pyelonephritis. Diabetes case definitions were as follows: GDM cases were identified using laboratory data and Carpenter-Coustan criteria [7]. We used physician or provider diagnosis of preexisting diabetes to identify chronic diabetes. Five mutually exclusive diabetes categories were developed: GDM, possible GDM (1-h screen was >140 and an incomplete 3 h glucose tolerance test), chronic diabetes, no diabetes, and unknown. PAH was defined as clinician-diagnosed pregnancy induced hypertension, gestational hypertension, PAH, preeclampsia, eclampsia, or HELLP syndrome. Chronic hypertension was defined as clinician-diagnosed chronic hypertension, pregnancy induced hypertension superimposed on chronic hypertension, or preeclampsia superimposed on chronic hypertension. Anemia was defined as hemoglobin <10 g/dL during pregnancy.

Labor and delivery outcomes included cesarean delivery, polyhydramnios, oligohydramnios, fetal distress, and abruption; all were based on clinician diagnoses as recorded in the medical record. Adverse birth outcomes included shoulder dystocia, preterm delivery, admission into the neonatal intensive care unit, low birth weight, and macrosomia. We defined preterm delivery as delivery at <37 completed weeks gestation based on the provider's estimated

date of confinement. Low birth weight was defined as birth weight <2,500 g. Macrosomia was defined both as birth weight >4,000 g and as birth weight >4,500 g.

### Statistical Analysis

After limiting our study sample to the randomly-selected control group, we calculated the proportion of pregnancies with selected maternal characteristics, maternal medical conditions, and adverse birth outcomes with corresponding 95 % confidence intervals. We excluded pregnancies ending in a stillbirth or fetal death when calculating the percentage of pregnancies with adverse birth outcomes. Statistical analyses were performed using SAS software V.9 (SAS Institute Inc., Cary, NC) for Windows. The study proposal and data collection tools were reviewed and approved by the institutional review boards (IRBs) of the CDC and the Mayo Clinic, and by the Alaska Area IRB.

### Results of Current Secondary Analysis

Our study sample included 505 pregnancies that ended in a singleton delivery to 469 women. Less than 10 % of singleton pregnancies had substance abuse or congenital anomalies concerns and were excluded ( $n = 52$ ). Of the 505 pregnancies, 61.4 % were to women between the ages of 20–29 years, 55.9 % were to women with a BMI  $\geq 25$  kg/m<sup>2</sup>, 15.1 % were to women with a high parity-forage, 52.7 % were to women that were single, divorced, or widowed, 27.4 % were to women with less than a high school education, and 75.5 % were to women who used some form of tobacco during pregnancy (mainly smokeless products) (Table 1) [4]. Notably, none of the pregnancies were complicated by preexisting diabetes, however 5.9 % (95 % CI 4.0, 8.4) of pregnancies were complicated by GDM based on the Carpenter and Coustan criteria (Table 2). Six percent (95 % CI 4.2, 8.6 %) of pregnancies were complicated by maternal chronic hypertension and 11.5 % (95 % CI 8.8, 14.6) by PAH. 23 % (95 % CI 19.2–26.5 %) of pregnancies were complicated by anemia, 5 % (95 % CI 3.5, 7.5) were delivered by cesarean and 3.6 % (95 % CI 2.2, 5.7) resulted in deliveries of newborns weighing >4,500 g.

### Discussion

We describe the prevalence of pregnancy complications and adverse birth outcomes in a random sample of deliveries to Alaska Native women. Mothers in the study population were generally younger, multiparous, and less educated; had a higher BMI; and had higher use of tobacco than the general US and Alaska Native population [5, 8]. For example, we found that maternal overweight and obesity was present in approximately 56 % of pregnancies, compared to approximately 42 % reported in Alaska among Alaska Natives from the Pregnancy Risk Monitoring System in 2000 to 2003 [8]. Furthermore, in more than 70 % of pregnancies in the current study, women reported using some form of tobacco. These rates are much higher than published prenatal smoking prevalence estimates of 21.0 % for American Indian, 4.4 % for Hispanic, and 16.4 % for non-Hispanic white women from 1995 to 2001 [5].

We found that while the prevalence estimates of some pregnancy complications and adverse birth outcomes were higher than the general population, others were not. GDM prevalence

was consistent with the range reported in multi-state analyses of women with a recent live birth [9]. The prevalence of cesarean deliveries in the study population was low compared to estimates reported in the literature on American Indians and Alaska Natives. This may reflect the fact that cesareans are not routinely performed in the local hospital.

In contrast, the estimates of the prevalence of hypertensive disorders were high in this population; 6.1 % had chronic hypertension and 11.5 % had PAH without underlying chronic hypertension. In a 1995–2001 US study comparing American Indians (including Aleuts and Eskimos) to Hispanics and non-Hispanic whites using live birth infant and death cohort files from 1995 to 2001, Alexander and colleagues found that the prevalence of all hypertensive disorders combined was 5.5 % for American Indians, 3.0 % for Hispanics, and 4.5 % for non-Hispanic whites [5]. This discrepancy could reflect true difference in prevalence or that medical record reviews have higher sensitivity for ascertainment of pregnancy complications [10]. Public health interventions to address maternal tobacco use, obesity, and hypertension in this population, should be of high priority.

### Key Factors Contributing to Study Success

A major strength of the current analysis is that the investigators were able to examine characteristics among Alaska Native women living in a defined region in western Alaska; unlike previous studies, this study did not combine Native populations. A number of factors were critical to the successful completion of this study. First, the investigators had access to a population-based, searchable hospital discharge data system (RPMS). This allowed for identification of nearly all deliveries among Alaska Native women living in this region during the study period. In addition, all deliveries except home births occurred in three main hospitals, making a complete population-based study design feasible. Because the study had strong local institutional support, the investigators had access to important resources, such as local medical record staff, facilities for reviewing records and convening meetings, and access to hospital staff for consultation and other types of support. The hospital/medical center was able to identify and hire local staff willing to be trained and to conduct medical record abstractions, and these employees stayed for the duration of the project. Computer and statistical programmers employed at local hospitals were available to provide assistance on site. The investigators also had access to a funding mechanism that provided sufficient flexibility to accommodate an extended timeframe. This was particularly important as this project required multiple institutional study protocol reviews, long-distance travel for development of study tools and abstractor training, and delays associated with staff absences due to seasonal activities such as fishing and hunting.

In this study, privacy concerns were especially important. In order to avoid inadvertently sharing sensitive information not directly related to the study topic, deliveries involving maternal alcohol or illicit substance use and deliveries of infants with congenital anomalies were excluded from data collection at the onset of the study. Strengths of the research staff that likely contributed to the study's success included personal commitment, flexibility, and both organizations remaining open minded about the research process. CDC staff made on average 2–3 site visits a year and spent on average 2–3 h per week by phone providing technical and operational assistance. In addition, both organizations were willing to accept

multiple study modifications and to tolerate delays. Clear and consistent communication between staff in Alaska and CDC in Atlanta was important since continuous, on-site supervision of the chart abstraction process was not feasible. For example, the chart abstractors were very diligent in taking detailed notes regarding questions that come up during chart abstractions, so that CDC staff could help clarify these questions during regular conference calls. Finally, a major factor in the project's success was the team's commitment to giving careful consideration to varying points of view and to resolving conflicts in a mutually respectful manner.

### Limitations

Our analysis has several limitations. As previously stated, this study only includes singleton deliveries among women who did not use alcohol in late pregnancy or illicit drugs at any time during pregnancy and who did not give birth to an infant with a major congenital anomaly. Thus our results cannot be generalized to all Alaska Native women in the study region. Our exclusions likely resulted in an underestimation of some adverse health outcomes, such as pre-term delivery and low birth weight. In addition, the size of our random sample was based on requirements for the main case control analysis and it was too small to generate stable estimates for rare outcomes such as meconium aspiration, placenta previa, sepsis, and very low birth weight. Therefore, these outcomes were not included in our analysis.

### Conclusions

This descriptive analysis of maternal characteristics and pregnancy outcomes of Alaska Native women in a specific geographic region of Alaska provides unique information regarding health needs in this population. Common health problems in pregnant women in this community include a very high prevalence of smokeless tobacco use, chronic hypertension and obesity. Critical to the completion of this study were collaborative relationships between the government and local health care providers and the tribal health corporation. Local health center staff provided maximum input on study priorities, protocol development, and dissemination of findings. Future studies in remote areas focusing on unique populations such as Alaska Native women are feasible and can provide previously unavailable information on health indicators at the community level.

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**Table 1**

Maternal and prenatal care utilization characteristics of Alaska Native women in western Alaska, 1997–2005

| Characteristic                            | n   | %    | 95 % CI    |
|---|-----|------|------------|
| Overall N                                 | 505 | 100  |            |
| Maternal age (years)                      |     |      |            |
| <20                                       | 65  | 12.9 | 10.1, 16.1 |
| 20–29                                     | 310 | 61.4 | 57.0, 65.7 |
| 30–39                                     | 117 | 23.2 | 19.6, 27.1 |
| 40+                                       | 13  | 2.6  | 1.4, 4.4   |
| Maternal BMI (kg/m <sup>2</sup> )         |     |      |            |
| Lean/normal (<25)                         | 187 | 44.1 | 39.3, 49.0 |
| Overweight (25–29.9)                      | 127 | 30.0 | 25.6, 34.6 |
| Obese                                     |     |      |            |
| Class I (30–34.9)                         | 61  | 14.4 | 11.2, 18.1 |
| Class II (35–39.9)                        | 34  | 8.0  | 5.6, 11.0  |
| Class III (40+)                           | 15  | 3.5  | 2.0, 5.8   |
| Previous births                           |     |      |            |
| 0   | 115 | 22.9 | 19.3, 26.8 |
| 1   | 118 | 23.5 | 19.8, 27.4 |
| 2+  | 270 | 53.7 | 49.2, 58.1 |
| High parity <sup>a</sup>                  | 76  | 15.1 | 12.1, 18.5 |
| Marital status                            |     |      |            |
| Married                                   | 226 | 47.3 | 42.7, 51.9 |
| Single/divorced/widow                     | 252 | 52.7 | 48.1, 57.3 |
| Education                                 |     |      |            |
| Less than high school                     | 111 | 27.4 | 23.1, 32.0 |
| High school/general education development | 245 | 60.5 | 55.5, 65.3 |
| Greater than high school                  | 49  | 12.1 | 9.1, 15.7  |
| Tobacco use during pregnancy              |     |      |            |
| Smoke only                                | 87  | 17.3 | 14.1, 20.9 |
| Smokeless only                            | 249 | 49.6 | 45.1, 54.1 |
| Both                                      | 43  | 8.6  | 6.3, 11.4  |
| None                                      | 123 | 24.5 | 6.3, 11.4  |
| Trimester prenatal care initiation        |     |      |            |
| First                                     | 279 | 55.9 | 51.4, 60.3 |
| Second/third                              | 220 | 44.1 | 39.7, 48.6 |

<sup>a</sup>One or more previous births for adolescents (<18), 3 or more previous births for 18–21 years; 4 or more previous births for 22–24 years; 5 or more previous births for 25 and older

**Table 2**

Maternal medical conditions and birth outcomes of Alaska Native women in western Alaska, 1997–2005

| Characteristic                         | n   | %    | 95 % CI    |
|--|-----|------|------------|
| Maternal prenatal conditions           |     |      |            |
| Preexisting diabetes mellitus          | 0   | 0    |            |
| Gestational diabetes mellitus (GDM)    |     |      |            |
| No GDM                                 | 417 | 82.6 | 79.0, 85.8 |
| Possible GDM                           | 28  | 5.5  | 3.7, 7.9   |
| GDM                                    | 30  | 5.9  | 4.0, 8.4   |
| Unknown                                | 30  | 5.9  | 4.0, 8.4   |
| Hypertension                           |     |      |            |
| No Hypertension                        | 416 | 82.4 | 78.8, 85.6 |
| Chronic Hypertension                   | 31  | 6.1  | 4.2, 8.6   |
| Pregnancy associated hypertension      | 58  | 11.5 | 8.8, 14.6  |
| Anemia                                 | 115 | 22.9 | 19.2–26.5  |
| Urinary tract infection (UTI)          | 126 | 25.0 | 21.2, 29.0 |
| Pyelonephritis                         | 7   | 1.4  | 0.6, 2.8   |
| Labor and delivery                     |     |      |            |
| Cesarean section                       | 28  | 5.5  | 3.5–7.5    |
| Polyhydramnios                         | 9   | 1.8  | 0.6–2.9    |
| Oligohydramnios                        | 11  | 2.2  | 0.9–3.5    |
| Fetal distress                         | 20  | 4.0  | 2.3, 5.7   |
| Abruption                              | 8   | 1.6  | 0.5–2.7    |
| Birth Outcomes <sup>a</sup>            |     |      |            |
| Shoulder dystocia                      | 18  | 3.6  | 2.2–5.7    |
| Preterm delivery                       | 39  | 7.9  | 5.7–10.6   |
| Neonatal intensive care unit admission | 23  | 4.6  | 2.9–6.8    |
| Low birth weight (<2,500 g)            | 13  | 2.6  | 1.4–4.4    |
| Macrosomia (>4,500 g)                  | 18  | 3.6  | 2.2–5.7    |
| Macrosomia (>4,000 g)                  | 117 | 23.6 | 20.0–27.6  |

<sup>a</sup>Excludes pregnancies that ended in a stillbirth or fetal death