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Collecting and Interpreting Birth Defects Surveillance Data by Hispanic Ethnicity: A Comparative Study

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In the United States, many racial and ethnic minority populations bear a disproportionate burden of poor health outcomes (Krieger et al., '93; Hummer, '96). For example, vital statistics data for 1996 indicate that black infants are more than twice as likely as white infants to die before their first birthday and that Hispanic mothers are nearly 2.8 times as likely as non-Hispanic white mothers to receive late prenatal care (starting in the third trimester of pregnancy) (Ventura et al., '98; Peters et al., '98). Many of these minority populations will not meet Healthy People 2000 objectives set by the United States Public Health Service. These incongruities in perinatal health outcomes necessitate a refocusing of attention and resources to address and eliminate these disparities.

While health outcomes vary by race/ethnicity, many researchers have noted that lack of scientific knowledge about disparities in health outcomes by racial/ethnic categories are associated with poor conceptualization of variables measuring race and ethnicity, illogical or crude classifications, imprecise terminology, and other methodological weaknesses (Bennett and Bhopal, '98). Greater agreement on concepts and terminology used to define race/ethnicity in health research is essential for understanding and eliminating racial and ethnic variations in mortality, morbidity, and utilization of health services (Browne et al., '97).

Although these limitations to current health data on racial and ethnic subpopulations should raise caution, Hahn and Stroup ('94) note that the collection of racial and ethnic information is a critical component of any public health surveillance system used to provide information regarding the differences in health status among population subgroups. This is certainly true for birth defects, which are the leading cause of infant mortality in the United States and a major contributor to dis-

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ability; the rates of infant mortality associated with birth defects have been shown to vary by race and ethnicity (Petrini et al., '98). Statewide vital statistics and birth defects surveillance systems provide a unique opportunity to obtain critical information to address the discordance by race and ethnicity in these important perinatal indicators.

The Hispanic population is currently the fastest growing of any major population group in the United States (U.S. Bureau of the Census, '96). Although Hispanics are classified as a unique population, the major common elements for this population are the language and general focus on the family; "Hispanics" differ in country of origin, culture, and socio-economic status, and these differences may influence preconceptional, prenatal, and postnatal health (Tumiel et al., '98). Between 1989 and 1996, the proportion of U.S. live births to Hispanic women increased steadily from 14% to 18% (Mathews et al., '98; Ventura et al., '98). Overall, the infant mortality experience of the Hispanic population has been termed the "epidemiological paradox" because of generally good birth outcomes, despite a higher prevalence of socioeconomic and demographic risk factors (Pastore et al., '95). This "paradox" may reflect common cultural values related to reproduction among the diverse Hispanic populations. For example, in 1996, compared with non-Hispanic white mothers, Hispanic mothers were nearly 80% more likely to be teens (9.7% and 17.4%, respectively) and 44% less likely to have completed at least 12 years of school (87% and 48.6%, respectively) (Ventura et al., '98). In addition, although fewer Hispanic mothers than non-Hispanic white mothers received prenatal care during the first trimester (72.2% vs. 87.4%), infant mortality rates for Hispanic infants were lower than for non-Hispanic infants in 1996 (5.9 and 7.6 per 1,000, respectively) (Ventura et al., '98; Peters et al., '98).

Despite this "paradox," birth defects remain a persistent problem in the Hispanic population, as they do in all segments of the population. For some birth defects, rates are highest for Hispanic infants (Stierman, '94). Several previous studies have documented elevated birth rates of neural tube defects (NTDs) among Hispanic infants (Shaw et al., '94; Canfield et al., '96; Chavez et al., '88).

In this report, we first contrast the racial and Hispanic classifications used in each state's routine reports. We then present statistics data using comparable racial/ethnic categories among registries that submitted quantitative data for neural tube defects, oral clefts, and hypospadias. These conditions were selected to illustrate differences in the rates of specific types of birth defects by race and ethnicity between non-Hispanic white, non-Hispanic black, and Hispanic mothers.

METHODS

We used national summary data from the National Center for Health Statistics (NCHS) to identify all states with at least 10,000 resident Hispanic births per year (Ventura et al., '98). The state birth defects surveillance program directory published in 1997 was used to determine which of these states had functional birth defects surveillance programs with the potential to report data by race and Hispanic ethnicity for a recent three-year period (Edmonds, '97). Data were requested from the states of New Mexico, California, Texas, Arizona, Colorado, New York, New Jersey, and Illinois. The birth defects surveillance programs in each of these states were also asked to complete a questionnaire concerning race/ethnicity classifications used by the registry, and, if surveillance data are routinely linked to their vital statistics records, how race/ethnicity is reported on birth and death certificates.

We received data and questionnaires from all of the states except Illinois. However, only three states were able to provide data for the three-year period 1993-1995 (California, Colorado, and New York). Arizona provided for 1989-1991, while New Jersey, New Mexico, and Texas provided data for 1995. Except for Texas and California, which provided population-based regional data, data represent the statewide rates of the selected birth defects.

The seven states reporting data employ a variety of birth defects surveillance methodologies; brief descriptions of methods employed during the years when these data were collected can be found in Edmonds ('97). Generally, California, Texas, and Arizona use active case-finding methods, while New York and New Jersey use passive case-finding methods; New Mexico and Colorado use a combination of these methods for selected birth defects but primarily use passive methods. A more detailed discussion of these approaches can be found in Kirby ('99).

For comparative purposes, we calculated comparable rates for each state by grouping data into the following categories by the race/ethnicity of the mother: Hispanic, non-Hispanic white, and non-Hispanic black. In the statistical comparisons presented below, we calculated 95% confidence intervals using the method described by Fleiss ('81). For statistical comparisons of difference of proportion, we used the *G* statistic (maximum likelihood Chi-square) described by Sokol and Rohlf ('80). We did not include statistical data for New Mexico in the tables presented here because data were unavailable for several years and because only small numbers of cases reported.

RESULTS

Each of the seven states uses the standard NCHS race/ethnicity classifications for reporting the race of the mother: black, white, American Indian, Asian/Pacific Islander, and other; each state also includes a variable indicating whether the mother is of Hispanic ethnicity. Five of the states also use the standard NCHS classification of Hispanic categories (Mexican, Puerto Rican, Cuban, Central/South American, other); New Jersey and New York indicated that they do not. States were also asked how a child's Hispanic ethnicity was identified in relation to the race of the mother and whether race/ethnicity data from birth certificates were used instead of race/ethnicity data from birth defects case reports. Three states (Arizona, California, Colorado) routinely report Hispanic ethnicity as a separate, mutually exclusive category in their statistical reports. In these state, the category "white", for example, would exclude people of Hispanic ethnicity. Four other states (New Jersey, New Mexico, New York, Texas) report Hispanic ethnicity as an inclusive category (e.g., "white" includes people of Hispanic ethnicity). Six of the seven states link case reports to birth certificates; four report maternal race/ethnicity using information from the birth certificates only rather than information from birth defects case reports.

Live-birth rate of neural tube defects by race/Hispanic ethnicity is shown in Table 1. The rate of neural tube defects was higher among Hispanic mothers in all six states with comparable data; collectively the NTD rate of 6.1 per 10,000 live births among children of Hispanic mothers was significantly higher than the rate of 4.5/10,000 live births among children of non-Hispanic white mothers ($p<0.001$). Aggregate rates for non-Hispanic black infants did not differ from those for non-Hispanic white infants for all neural tube defects or for specific types of neural tube defects ($p>0.05$; for anencephalus, $p=0.06$). Infants born to Hispanic women were also more likely to have anencephalus (1.3/10,000 compared with 0.7/10,000, $p<0.001$) and spina bifida without anencephalus (4.2/10,000 compared with 3.0/10,000, $p<0.001$) than were infants born to non- Hispanic white mothers.

Table 1

Number and Rates of Neural Tube Defects by State and Hispanic Ethnicity, 1993-95

		Hispanic All			Non-Hispanic White			Non-Hispanic Black		
		Cases	Rate	95% C.I.	Cases	Rate	95% C.I.	Cases	Rate	95% C.I.
All Neural Tube Defects										
Arizona	**	66	11.4	(8.9, 14.6)	64	5.5	(4.3, 7.1)	3	4.0	(1.0, 12.8)
California		308	5.7	(5.1, 6.3)	76	3.5	(2.8, 4.4)	24	3.6	(2.4, 5.4)
Colorado		16	4.9	(2.9, 8.2)	46	4.0	(2.9, 5.3)	2	2.5	(0.4, 10.0)
New Jersey	*	15	8.1	(4.5, 13.3)	23	3.5	(2.3, 5.4)	10	5.2	(2.7, 10.0)
New York		84	5.3	(4.3, 6.6)	176	5.2	(4.5, 6.1)	67	4.6	(3.6, 5.9)
Texas	*	44	7.3	(5.3, 9.8)	14	4.1	(2.3, 7.1)	2	1.5	(0.3, 5.9)
Total		*533*	*6.1* #	*(5.6, 6.7)*	*399*	*4.5*	*(4.1, 5.0)*	*108*	*4.1*	*(3.4, 5.0)*
Anencephalus										
Arizona	**	14	2.4	(1.4, 4.2)	9	0.8	(0.4, 1.5)	0	0.0	(0.0, 6.4)
California		78	1.4	(1.1, 1.8)	12	0.6	(0.3, 1.0)	3	0.4	(0.1, 1.4)
Colorado		4	1.2	(0.4, 3.4)	7	0.6	(0.3, 1.3)	0	0.0	(0.0, 6.0)
New Jersey	*	0	0.0	(0.0, 2.6)	2	0.3	(0.1, 1.2)	0	0.0	(0.0, 2.5)
New York		7	0.4	(0.2, 1.0)	29	0.9	(0.6, 1.3)	7	0.5	(0.2, 1.0)
Texas	*	6	1.0	(0.4, 2.3)	3	0.9	(0.0, 3.5)	0	0.0	(0.0, 3.5)
Total		*109*	*1.3* #	*(1.0, 1.5)*	*62*	*0.7*	*(0.5, 0.9)*	*10*	*0.4*	*(0.2, 0.7)*
Spina Bifida without Anencephalus										
Arizona	**	43	7.4	(5.4, 10.1)	42	3.6	(2.6, 4.9)	2	2.7	(0.5, 10.8)
California		201	3.7	(3.2, 4.3)	45	2.1	(1.5, 2.8)	17	2.5	(1.5, 4.2)
Colorado		11	3.4	(1.8, 6.3)	31	2.7	(1.9, 3.9)	2	2.5	(0.4, 10.0)
New Jersey	*	9	4.9	(2.2, 9.2)	18	2.8	(1.7, 4.5)	6	3.1	(1.3, 7.2)
New York		69	4.4	(3.4, 5.6)	118	3.5	(2.9, 4.2)	42	2.9	(2.1, 3.9)
Texas	*	32	5.3	(3.7, 7.5)	11	3.2	(1.7, 6.0)	1	0.7	(0.0, 4.8)
Total		*365*	*4.2* #	*(3.8, 4.6)*	*265*	*3.0*	*(2.7, 3.4)*	*70*	*2.7*	*(2.1, 3.4)*
Encephalocele										
Arizona	**	9	1.6	(0.8, 3.1)	13	1.1	(0.6, 2.0)	1	1.3	(0.1, 8.7)
California		29	0.5	(0.4, 0.8)	19	0.9	(0.5, 1.4)	4	0.6	(0.2, 1.6)
Colorado		1	0.3	(0.0, 2.0)	8	0.7	(0.3, 1.4)	0	0.0	(0.0, 6.0)
New Jersey	*	6	3.2	(1.2, 7.1)	3	0.5	(0.1, 1.5)	4	2.1	(0.7, 5.8)
New York		8	0.5	(0.2, 1.0)	29	0.9	(0.6, 1.3)	17	1.2	(0.7, 1.9)
Texas	*	6	1.0	(0.4, 2.3)	0	0.0	(0.0, 1.4)	1	0.7	(0.0, 4.8)
Total		*59*	*0.7*	*(0.5, 0.9)*	*72*	*0.8*	*(0.6, 1.0)*	*27*	*1.0*	*(0.7, 1.5)*

*1995 data only
**1989-1991 data
Rates are per 10,000 live births
# $p < 0.001$ compared with non-Hispanic white.

The rate of encephalocele was similar across the three racial/ethnic groups.

The rate of oral clefts and hypospadias/epispadias for the three groups is compared in Table 2. The rate of cleft lip/cleft palate did not differ between infants born to Hispanic and those born to non-Hispanic white mothers. Non-Hispanic black infants were significantly less likely than non-Hispanic white infants to have cleft lip and/or cleft palate. The rate of hypospadias and epispadias was significantly higher among infants born to non-Hispanic white women than among those born to Hispanic or non-Hispanic black women. This statistical observation holds within state-level data as well for the comparison between infants born to Hispanic mothers and those born to non-Hispanic white mothers. Data concerning the rate of hypospadias were unavailable for the state of Texas.

Table 2
Number and Rates of Selected Birth Defects by State and Hispanic Ethnicity. 1993-95

		Hispanic All			**Non-Hispanic White**			**Non-Hispanic Black**		
		Cases	**Rate**	**95% C.I.**	**Cases**	**Rate**	**95% C.I.**	**Cases**	**Rate**	**95% C.I.**
Cleft Lip with and without Cleft Palate										
Arizona	**	78	13.5	(10.7, 16.9)	126	10.8	(9.1, 13.0)	7	9.4	(4.1, 20.3)
California		564	10.4	(9.5, 11.3)	217	10.0	(8.8, 11.5)	52	7.8	(5.9, 10.3)
Colorado		48	14.8	(11.0, 19.8)	136	11.7	(9.9, 13.9)	3	3.7	(1.0, 11.9)
New Jersey	*	8	4.3	(1.9, 8.5)	40	6.1	(4.4, 8.4)	7	3.7	(1.6, 7.9)
New York		91	5.8	(4.7, 7.1)	367	10.9	(9.9, 12.1)	63	4.3	(3.4, 5.6)
Texas	*	52	8.6	(6.5, 11.3)	26	7.6	(5.1, 11.4)	8	5.9	(2.7, 12.1)
Total		*841*	*9.7*	*(9.0, 10.3)*	*912*	*10.3*	*(9.7, 11.0)*	*140*	*5.4*	*(4.5, 6.4)*
Hypospadias and epispadias										
Arizona	**	105	18.1	(14.8, 22.0)	372	32.0	(28.9, 35.5)	16	21.5	(12.7, 35.7)
California		512	9.4	(8.6, 10.3)	394	18.2	(16.5, 20.1)	84	12.6	(10.1, 15.6)
Colorado		91	28.1	(22.7, 34.6)	652	56.3	(52.1, 60.8)	52	64.7	(48.9, 85.5)
New Jersey	*	44	23.7	(17.3, 31.9)	246	37.7	(33.2, 42.8)	52	27.2	(20.5, 36.0)
New York		353	22.4	20.1, 24.8)	1873	55.9	(53.4, 58.5)	442	30.4	(27.7, 33.4)
Total		*1,105*	*13.6* #	*(12.8, 14.5)*	*3537*	*41.7*	*(40.3, 43.1)*	*646*	*26.2*	*(24.2, 28.3)*

*1995 data only
**1989-1991 data
Rates are per 10,000 live births
# $p < 0.001$ compared with non-Hispanic white.

DISCUSSION

Although this study is not a representative sample of birth defects surveillance programs in the United States, the results suggest that disaggregating birth defects data by Hispanic ethnicity provides additional information with which to identify population subgroups at significantly higher risk for developing certain birth defects. These results build on those obtained by other studies, suggesting that Hispanic infants may be at a lower risk for hypospadias and epispadias and a higher risk for certain types of birth defects, including neural tube defects, Down syndrome, and hearing loss associated with external ear anomalies (Stierman, '94; Canfield et al., '96; Chavez et al., '88). The current study shows that rates of neural tube defects are significantly higher and rates of hypospadias are significantly lower among infants born to Hispanic mothers than among infants born to non-Hispanic white mothers. Further, this study suggests that rates for neural tube defects are similar across the states included, regardless of case-finding methodologies used or the number of years and volume of births supporting each rate and its corresponding confidence interval.

The variation in approaches to coding and analyzing birth defects data by race/ethnicity revealed in our study highlights the need for data-collection standards and procedures for surveillance programs. Where possible, birth defects registries should link to birth and fetal death certificates and use the race of the mother as listed in vital records documents. This does not eliminate the need to collect race/ethnicity data on surveillance records, as some records cannot be matched. Surveillance records for children older than one year of age may reflect race assignations different from those on the children's birth certificates; if birth defects data are linked to clinical genetics databases or databases on children with special health care needs, it may prove useful to collect race/ethnicity variables.

Researchers should conduct further studies of variations among Hispanic subgroups (e.g., Mexican, Cuban, Puerto Rican), as previous studies have suggested variations in pregnancy outcomes by these demographic groupings (Tumiel et al., '98). Birth outcomes have also been shown to vary by the nativity status of the mother. Infant mortality rates for offspring of U.S.-born mothers are consistently higher than corresponding rates for infants whose mothers were born outside of the United States (Kleinman et al., '91; Singh and Yu, '96). However, previously published data from the California Birth Defects Monitoring Program suggest that children of foreign-born mothers of all races have overall birth defects risks similar to those of their U.S.-born counterparts (Stierman et al., '94).

Birth defects contribute substantially to morbidity and mortality among all racial/ethnic groups, and selected conditions impact certain populations disproportionately. Therefore, national and state data systems need to reflect the diversity of their populations. We have much to learn about the prevalence and etiology of birth defects in all sectors of the population. It is vitally important for state and regional birth defects surveillance programs to adhere to national standard definitions set forth by the Centers for Disease Control and Prevention so that data from different areas are comparable. Adoption of birth defects surveillance reporting standards for race/ethnicity is an important step in understanding the impact of birth defects on Hispanics and the etiology of birth defects among all populations in the United States.

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