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The Department of Defense Birth Defects Registry: Overview of a New Surveillance System

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ABSTRACT

Background: The U.S. Department of Defense (DoD) is challenged with monitoring and protecting the health and wellbeing of its service members. The growing number of women on active duty and the diverse hazardous exposures associated with military service make reproductive health issues a special concern of DoD. To address this concern, the DoD Birth Defects Registry was established at the DoD Center for Deployment Health Research located at the Naval Health Research Center, San Diego, California.

Methods: The registry captures comprehensive data on healthcare utilization to calculate the prevalence of birth defects in the children of military beneficiaries. Population-based electronic surveillance is supplemented by active case validation efforts.

Results: Since its establishment in 1998, the registry has captured data on more than 90,000 births that occur in military families each year. Detailed analyses, to include linking registry data with military occupational exposure data (e.g., anthrax vaccination), are underway.

Conclusions: The DoD Birth Defects Registry provides important reproductive health information on the geographically dispersed military population. This program is expected to complement civilian public health programs and be especially valuable to military members and their families.

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BACKGROUND

Concern about the reproductive health of service members and their families is consistent with the U.S. military's concept of Force Health Protection (US DoD,'98). Although reproductive health issues affect both men and women, the growing proportion of women in the military (now greater than 14% of active duty forces), may have heightened concerns about potential hazards associated with military duty (ASD/FM, '99; Fox et al., '77).

Public health efforts to address reproductive issues in the Department of Defense (DoD) are similar to efforts in the civilian sector. The military may have some unique concerns, however, related to severe stressors (Hansen et al., '00) and the wartime deployment of its population. Concerns about possible teratogenic exposures were first considered among World War II veterans involved in the clean-up activities of Hiroshima and Nagasaki (IOM, '95). The Vietnam War experience prompted extensive retrospective research to evaluate associations between deployment and birth defects in the children of military members. Most of this work did not support findings of paternal reproductive risk (Aschengrau and Monson,'90; Donovan et al., '94; Erickson et al., '84; Wolfe et al., '95), but a recent evaluation of the relatively few women in Vietnam did reveal an association between maternal wartime service and delivering children with birth defects (Kang et al., '00).

The U.S. experience in the Persian Gulf War of 1991 underscored concerns about all health risks of deployment, and reproductive health risks in particular (Briggs, '95). Nearly 50,000 women were deployed to the Gulf War, and their health needs during and after deployment have not differed remarkably from those of men (Murphy et al., '97). Research exploring potential reproductive problems in Gulf War veterans has not revealed distinct risks associated with deployment (Araneta et al., '97; Araneta et al., '00; Cowen et al., '97). Because of concerns about the special threats of warfare exposures in the Gulf (Pour-Jafari, '94), studies of Gulf War veterans are expected to continue.

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DoD public health professionals have recognized the need to establish prospective studies and ongoing surveillance systems to better address the inevitable health concerns of future deployments (Goldberg, '92; Murphy et al., '97). Furthermore, the DoD's ability to provide reproductive health surveillance may be valuable to national public health efforts. Many states have established, or are in the process of establishing, registries to monitor birth defects prevalence (NBDPN, '00). Although these programs may collect comprehensive information about children with birth defects, state registries often cannot access data on military families. The development of a DoD birth defects registry that can link to valuable data on exposures of military concern is well justified.

Establishment of the DoD birth defects registry

The Assistant Secretary of Defense for Health Affairs directed the establishment of national surveillance for birth defects among DoD families on November 17, 1998 (ASD/HA, '98). The DoD Center for Deployment Health Research at the Naval Health Research Center (NHRC) in San Diego was given the responsibility of managing the DoD Birth Defects Registry, and providing systematic surveillance of DoD beneficiary births and calculations of birth defects prevalence.

Using guidance from the Centers for Disease Control and Prevention and the California Birth Defects Monitoring Program, professionals at NHRC conducted a successful feasibility study of the registry program (Bush et al., '98). They demonstrated that electronic data systems could be used to completely capture all inpatient and outpatient encounters of military beneficiaries and that new births and birth defects diagnoses were thoroughly represented in these systems. NHRC staff also established an active system to identify and validate birth defect cases at one of the DoD's largest medical treatment facilities, the Naval Medical Center in San Diego. The DoD Birth Defects Registry established the following surveillance parameters. The population denominator consists of all live-born infants financially sponsored by DoD, including infants born at all military and civilian medical facilities. Birth defects among these infants are identified by the International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) coding of records from all inpatient and outpatient encounters in the first year of life. ICD-9-CM codes included in surveillance range from 740.0 through 760.71 and, consistent with other surveillance programs (NBDPN, '00), the prevalence of all birth defects in 45 major malformation categories are calculated.

Population under surveillance

Preliminary data (Pershyn-Kisor et al., '00) reveal that 90,000 to 95,000 births in military families should be expected each year. To be DoD-sponsored, at least one parent must be a DoD healthcare beneficiary, such as an active duty military member, active reservist, military retiree, or other dependent. Approximately 39% of DoD births are sponsored by the Army; 25%, by the Air Force; 24%, by the Navy; 11%, by the Marine Corps; and 3%, by the Coast Guard or other service.

Although the percentage of women in the military is growing, for fewer than 19% of DoD-sponsored births is the mother identified as an active duty military member. In all other cases, the mother is the dependent of a military member or other beneficiary. Average maternal age is 26 years and ranges from 14 to 49 years. Among DoD-sponsored births, the race of the military parent is identified as Caucasian (70% of cases), African American (20%), Asian (3%) or other (7%).

DoD-sponsored infants are born in all 50 states and the District of Columbia (Table 1). California, Texas, and Virginia report the highest number of military births, with more than 7000 births expected in each of these states annually. Nearly 8% of military births take place outside of the United States. In 1999, DoD-

TABLE 1. Distribution of military births (n = 88,888) in the United States in 1999

State*	Number of military births	Percentage of military births
Alaska	1,343	1.5%
Alabama	1,097	1.2%
Arkansas	548	0.6%
Arizona	1,651	1.9%
California	10,020	11.3%
Colorado	2,137	2.4%
Connecticut	506	0.6%
Delaware	1,273	1.4%
Florida	4,849	5.5%
Georgia	3,922	4.4%
Hawaii	2,651	3.0%
Illinois	1,190	1.3%
Kansas	1,361	1.5%
Kentucky	2,531	2.8%
Louisiana	1,526	1.7%
Maryland	3,100	3.5%
Missouri	855	1.0%
Mississippi	1,099	1.2%
North Carolina	6,426	7.2%
North Dakota	505	0.6%
Nebraska	631	0.7%
New Jersey	639	0.7%
New Mexico	834	0.9%
Nevada	712	0.8%
New York	1,529	1.7%
Ohio	974	1.1%
Oklahoma	1,875	2.1%
Pennsylvania	633	0.7%
South Carolina	1,645	1.9%
Texas	8,267	9.3%
Utah	504	0.6%
Virginia	7,221	8.1%
Washington	3,643	4.1%
Outside of U.S.	6,891	7.8%

*Although DoD-sponsored births were reported in all states, fewer than 500 births were reported in each of the District of Columbia, Iowa, Idaho, Indiana, Massachusetts, Maine, Michigan, Minnesota, Montana, New Hampshire, Oregon, Rhode Island, South Dakota, Tennessee, Vermont, Wisconsin, West Virginia, and Wyoming.

sponsored infants were born in 34 foreign countries; 2434 babies were born in Germany, and 2086 babies were born in Japan.

Data sources

DoD Birth Defects Registry data analysts have established direct access to very large databases to thoroughly capture all births and birth defect cases in military families. Hospitalizations at military medical facilities are represented in the Standard Inpatient Data Records system, with up to eight ICD-9-cm coded discharge diagnoses. All outpatient encounters at DoD facilities are similarly represented in the Standard Ambulatory Data Records system, with up to three ICD-9-cm coded diagnoses. When any health care (inpatient or outpatient) is received at civilian facilities and financially supported by DoD, complete records with ICD-9-cm coded diagnoses are maintained by the DoD Tricare insurance system. Since 1998, approximately 60% of DoD-sponsored births have occurred at military facilities, and 40% of DoD births have been represented in Tricare data as occurring at civilian medical centers.

The DoD's ability to capture records of all health-care encounters, both inpatient and outpatient, at virtually any medical facility worldwide is analogous to a large civilian managed-care organization. The DoD also has access to complete demographic and service-related information about active duty members. Because all health-care data are coded with the military member's Social Security number, these data can be easily linked to Defense Enrollment Eligibility Reporting System and the Defense Manpower Data Center. Such data can provide important profiles of military parents, including deployment and occupational exposure histories that may be relevant to birth defects research.

Validation methods

Because complete inpatient and outpatient data are accessed, DoD Birth Defects Registry analysts have developed complex algorithms to identify multiple entries for the same diagnoses in the same infants. The resulting analytic database includes one entry for each child born to a military member in any given surveillance period and all ICD-9-CM coded birth defects identified within 1 year after birth.

To assess potential under-reporting, over-reporting, or miscoding in the electronic surveillance system, active case finding has been established at one of the largest DoD healthcare facilities, the Naval Medical Center in San Diego. DoD Birth Defects Registry staff review hospital and clinic logs, and contact clinicians and social workers, to identify newly diagnosed birth defects cases. Staff also review the full inpatient and outpatient records for suspected case-infants and their mothers. Medical center data are compared with electronic surveillance data to verify the presence of birth defects and the ICD-9-CM codes used, and to expand on diagnoses with the standardized coding used by other birth defects researchers (CDC, '00).

Because active case validation takes place at only one medical center, findings are used to comment on data obtained from the electronic surveillance system, rather than to directly modify the prevalence data reported. For example, among all abdominal wall defects recorded in the DoD Birth Defects Registry, the proportion suspected to be true gastroschisis cases can be estimated from the active surveillance findings in San Diego. The methodology of this surveillance system has been previously described (Bush et al., '99; Pershyn-Kisor et al., '00).

Strengths and limitations

The DoD Birth Defects Registry is a well resourced program that will provide timely, population-based surveillance on birth defects prevalence. The system is likely to compliment existing U.S. surveillance efforts. The DoD's ability to access large, complete databases on all health care provided to its beneficiaries is a strength found in few managed-care programs. The somewhat unique ability of the military to link to data on the occupational exposures of its members is potentially an even greater asset in the study of birth defects (Polednak and Janerich, '83; Selevan et al, '86).

As with most other birth defects registries (Holtzman and Khoury, '86; Kallen, '89), the DoD system cannot capture data on pregnancy terminations, miscarriages, or stillbirths. Other limitations associated with the DoD registry include its reliance on ICD-9-CM coding for diagnosing birth defects. The active case validation efforts in San Diego can only partially mitigate this challenge. Additional limitations may be related to the dynamics of the changing military population. Eligibility for DoD care at birth may not correspond to eligibility at the time of conception and pregnancy. Some children conceived before a parent's active duty service may be represented in the registry; some children conceived on active duty may be born outside of the DoD system if a member leaves the service or uses an alternative insurance system.

Other reproductive health research in DoD

Before establishment of the DoD Birth Defects Registry, researchers retrospectively addressed concerns that deployment to the Persian Gulf War was associated with subsequent birth defects in the children of service members. Leading studies used DoD hospitalization data (Cowen et al., '97; Araneta et al., '97) and data obtained from state birth defects registries (Araneta et al., '00). Although statistically significant associations between Gulf War deployment and birth defects were not established, this work underscored the need for a complete surveillance system, like the Birth Defects Registry, to be in place before major deployments occur.

The first study to directly use data from the DoD Birth Defects Registry recently was initiated at the DoD Center for Deployment Health Research in San

Diego. Researchers who have already reported on adverse events related to use of anthrax vaccine (Sato et al., '00b) will now explore possible long-term consequences of vaccination. An important part of this work will be linking military service records and vaccine records to birth defects data. The study will address the concerns of many service members who fear anthrax vaccination because of uncertainty about its potential as a reproductive health hazard.

Recognizing that birth defects may be only one manifestation of reproductive hazards, the DoD has sponsored other research on reproductive health issues in the military. The DoD Center for Deployment Health Research has surveyed Persian Gulf War-era veterans to address concerns that deployment may have been associated with miscarriage, stillbirth, ectopic pregnancy, and infertility (Sato et al., '00). In the future, DoD researchers will prospectively collect survey-based and objective evidence of all health and reproductive challenges among a large cohort of military members followed over more than 20 years (Gray et al., '00). Efforts like these, complemented by the DoD Birth Defects Registry, will better define the spectrum of reproductive health issues associated with military service.

CONCLUSION

Monitoring for birth defects is essential to and consistent with the military's mission to provide the best health care for its members and supplements national goals for increased birth defects surveillance. The establishment of the DoD Birth Defects Registry will provide important data to help protect the reproductive health of service members and their families. The DoD is uniquely positioned to collect comprehensive healthcare data and to assess occupational and environmental exposures in a geographically diverse population. DoD Birth Defects Registry information, along with data from other DoD research, will be vital for future public health studies, prevention efforts, and health policy decisions.

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