Pediatric autopsy registry studies infant mortality

Premature birth, low birth weight, and congenital anomalies are the number one cause of infant death in this country. According to the Centers for Disease Control and Prevention (CDC), sudden infant death syndrome (SIDS) is the second leading cause of infant mortality in the United States; homicide is the 15th. Stillbirth is common; generally, these fall into one of three categories: birth defects, problems with the placenta and umbilical cord, and maternal conditions. Each year approximately 25,000 babies (68 per day) are born still, about one in every 115 births.

One community’s resolve
In late 2003, Florida’s North Broward Hospital District (the District) and Broward County (the County), established a pediatric autopsy registry to study in detail the causes of local fetal and infant mortality. The idea for the registry came from civic groups and not-for-profit groups, as well as community leaders who wondered why babies in Broward County were dying, with black babies dying at nearly twice the rate of white babies.

The program is housed in the pathology department of the Broward General Medical Center in Fort Lauderdale, the flagship hospital of the District. Chosen by the District to head the project was Carmen K. Steigman, MD, MPH, a board-certified pediatric pathologist with hands-on public health experience from The Chris Evert Children’s Hospital at Broward General.

In addition to designing the details of the program and working with the various participants, Dr. Steigman was also responsible for educating local physicians about the program through individual face-to-face meetings, various written media, and short presentations at medical staff meetings at area hospitals. The only pediatric pathologist in Broward County, Dr. Steigman also serves as a consultant to local hospitals and the medical examiner’s office. Additional pediatric pathology consultations for unusually complex or difficult area cases are readily available from local medical schools.

Funding the program
The District and the County jointly fund the medical portion of the program, including the pediatric pathologist’s salary, direct and indirect expenses related to the autopsies, and any extra studies needed to establish a diagnosis. Because the District and the County underwrite the costs, autopsies are performed at no charge to Broward County residents who desire this service. The eligible patient population includes fetuses and infants who die from natural causes between 20 weeks’ gestation and the infant’s first birthday. The study includes both stillbirths and live births.

The Children’s Services Council of Broward County — a special taxing district that provides funding for community services that benefit children — contributes additional funds for expenses related to database administration. A local not-for-profit agency, Healthy Mothers Healthy Babies (HMHB), administers the database for the project, provides chart reviewers, and educates the local nursing community about the program. "I wish my doctor had explained my baby’s death to me better. I don’t understand what happened.” *

The prenatal and birth information in the autopsy database is the same as that used in the local Fetal and Infant Mortality Review (FIMR) registry. Separate data fields were developed to piggyback the placental and autopsy findings onto the existing FIMR data for a comprehensive perspective on infant death, encompassing the mother’s pre-pregnancy health, prenatal data, intrapartum data, and postmortem data. All autopsied cases are entered into the registry.

A multidisciplinary team, including experts representing public health, obstetrics, neonatology, pediatrics, pathology, and nursing, are in the process of evaluating preliminary data to look for emerging patterns and trends. Before statistically significant information can be obtained from the database, however, Dr. Steigman estimates that approximately 100 more cases will be needed. This should occur in the not-too-distant future because of the program’s recognition in the medical and lay communities and, sadly, the steady number of autopsy referrals.
Educating nursing support

HMHB plays several key roles in the autopsy registry. It established on-site educational seminars at the seven Broward County hospitals for the nursing staffs that provide obstetrical, neonatal, and pediatric services. The seminars instructed the nurses about the existence and purpose of the program as well as nuts-and-bolts issues, including necessary paperwork and transportation logistics. Based on these presentations, the hospitals’ nursing departments established easy-to-understand procedures to follow when a baby was to be referred for an autopsy. In general, these referrals have occurred with few or no problems related to paperwork. The nurses in the area hospitals proved to be a large source of motivated “missionaries” for the program, and they deserve much credit for the program’s success.

Providing essential services

Between 300 and 350 babies die each year in Broward County. Prior to the autopsy program, only 9% of these babies received autopsies, most of which were medical-examiner cases. By the end of the first year, the program had accomplished its goal of reaching an autopsy rate of 30%, which has remained constant throughout the life of the program. Currently, the registry contains over 180 cases. Local physicians have found the program highly effective for them and their patients.

Babies are transported from the referring hospital to Broward General Medical Center; nursing administration notifies the funeral home to pick up the baby when the autopsy is completed. The transport is arranged under a contract with a local body-removal service, the funding for which falls under the county’s medical examiner’s budget.

“I wish someone had told me about the autopsy project.”*

Medical examiners or coroners certify most infant deaths in most locals. At Broward General, Dr. Steigman performs approximately 75% of the autopsies; the remaining 25% falls under the medical examiner’s jurisdiction. The local medical examiner was a strong proponent of the project.

Although a handful of similar programs exists throughout the country, this appears to be the first “grass roots” program based in a community hospital, which utilizes local not-for-profit agencies. After 10 years of lobbying and discussion, this community’s vision had become a reality. □

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* Statement taken from Jan-June 2005 Semiannual Report, Broward County Fetal and Infant Mortality Report compiled by HMHB.