In an ongoing effort to reduce mortality, the New England Regional Infant Cardiac Program (NERICP) was initiated in 1969. This program is a voluntary association of all hospitals in the New England states that offer definitive care for infants with heart disease. The purpose of improving infant cardiac care, the program began in 1968 and continues to the present. Specific activities include professional education to improve case finding and earlier referral; identification and subsidy of appropriate transportation facilities; improved communication with participating hospitals; subsidy of follow-up where needed; provision for room and board for indigent parents when their baby has been moved some distance from home; and continuing nursery nurse education in the recognition of infants with heart disease. All participating hospitals agree to tabulation of their entire experience with infants with heart disease (3626 infants in 9 years). Case histories of surviving infants have been updated systematically.

The period of July 1968 to June 1974 was selected for this detailed analysis because data from this period form the basis of an ongoing long-term follow-up study and have been verified several times. This analysis is continued to the first year of life. More recent data, July 1974 to June 1977, are discussed separately and italicized numerically from 1974 to 1977 have been added to tables where the results may be of interest.

In the early years, case finding rose by 20% and has continued to increase gradually. By 1976, there were 2.4 NERICP infants per 1000 live births identifiable in the New England states. Surveys of state vital statistics showed a 50% decrease in infants who died with heart disease who did not reach a participating hospital. Neonates are admitted to participating hospitals earlier; admissions of infants less than 2 days old increased from 20% to 34% in 1977. Of infants admitted in 1977, more than 50% were in the first week of life.

During the period of study from 1969 to 1974, there was a consolidation of hospital services for infants with heart disease. Of the initial 11 participating hospitals in 1969, by 1974, there were 5 hospitals offering a full range of cardiac services, 3 hospitals offering limited surgical services, 2 hospitals no longer performing cardiac catheterizations or cardiac surgery in infants, and 1 hospital that had discontinued all pediatric cardiology.

Despite expected differences in case findings, the patient material and management of patients among the various hospitals were surprisingly comparable. There was little variation in the kinds of heart disease encountered over the years, among the states, and among the hospitals. There was a significantly higher mortality among infants whose birth weight was less than 2.0 kg and among infants who had additional, severe noncardiac anomalies. Mortality was significantly higher for infants admitted in the first days or weeks of life and cardiac surgery resulted in higher mortalities in this age group.

Among the many specific anatomic diagnostic categories, there was little change in outcome during the years 1969 to 1974. Subsequently, immediate and 30-day survival from surgical procedures showed improvement whether viewed by age at surgery, diagnosis, operative procedure, or years.

The introduction of early reparative surgery, as opposed to early palliative surgery followed by late repair, occurred in 1973. Subsequent data showed an increasing number of “open heart” procedures in infants with steadily improving 30-day mortality. A similar fall in mortality for closed heart procedures was documented. Results of palliation versus repair for ventricular septal defects, transposition of the great arteries, and tetralogy of Fallot were investigated.

The average number of days of hospitalization, the number of cardiac catheterizations, and the numbers of cardiac operations were evaluated. By using hospital charges for 1975, the estimated cost for care of an average cardiac infant for the first year of life ranged from $3800 to $7200 (average $6699). Among the hospitals, the payments by state agencies for hospital costs in the first year of life were estimated to range from $4300 to $8000 per patient for the same year.

Because NERICP can provide detailed data on a consecutive series of infants from a finite geographic area, epide-
miologic information can be gleaned (Am J Epidemiol 1976; 104:527, Am J Epidemiol 1979; 109:433). Similarly, detailed experience with the various anatomic cardiac lesions was extracted and presented as a guideline for expected average experience for regions outside of New England.

COMMENTARY

The report of the New England Regional Infant Cardiac Program (NERICP) was a landmark publication when it appeared as a lengthy supplement to Pediatrics in 1980. For the first time, a region had cooperatively and critically analyzed the care it was delivering to seriously ill infants with heart disease. As such it became a model for subsequent attempts to assess all aspects of care delivery, not only for those with heart disease but for other diseases as well. This is particularly important at present, given the concerns that have been raised about outcome data, costs, access, and long-term results.

When one reviews this supplement in 1998, the breadth of the study still appears most impressive. There was attention focused on such items as case finding, transportation to a cardiovascular center, communications between community physicians and the centers, cost of diagnostic and surgical procedures, education of parents, psychosocial elements, and outcome. All these items that were addressed in the 1970s assume even more importance as we approach the 21st century.

The NERICP also served as the model from which other regional programs that focused on infants with cardiac disease could be studied and led to the Baltimore-Washington and the Midwestern pediatric cardiac programs.

The report provided a wealth of epidemiologic data that have been extremely useful when current programs are analyzed. Mortality rates declined with fewer infants dying before being evaluated at a regional center. An increased awareness on the part of community physicians of the possibility of the existence of a cardiac problem was notable as evidenced by more sick newborn infants being admitted to regional centers for diagnostic evaluation and management.

The report covers a period of time when interventional procedures and early surgical repair of certain lesions were just beginning to be undertaken. For example, this was before arterial switch operations for transposition of the great arteries, balloon valvuloplasty for critical pulmonary valve stenosis, and the Norwood procedure for the hypoplastic left heart syndrome. Nevertheless, each center was able to review its results and compare them with other centers in the region. This interchange led overall to improved survival statistics and, in some instances, discontinuing surgical management at some of the centers.

Today, and for the future, each regional cardiovascular center must closely evaluate its total operation in terms of patient volume, short-term and long-term outcome data, costs and case findings, communication, and parent patient education as was done in the NERICP. Although access to a center should be facilitated, the number of regional centers per population base has to be critically assessed by impartial consultants. This approach is a necessity given the current emphasis on access to specialized care, cost containment, and results. Although extremely important, currently there is a strong likelihood that this will assume even more importance in the future as well. Thus, this initial report of the NERICP has served admirably as the template for what now must take place in all regions of the country. It was ahead of its time but fortunately has stood the test of time and, therefore, is deemed a worthy contribution to the exciting history of pediatric cardiovascular disease in the United States.

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