

EVOLVING HEALTHCARE FOR CONGENITAL HEART DISEASE IN CHINA

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On June 30, 1998, Hillary Rodham Clinton officially opened the new Shanghai Children's Medical Center. This 410,000 square foot pediatric hospital with 250 beds is set in 13 landscaped acres of prime real estate in the boom area of Pudong. One of the core services of the hospital will be the cardiovascular service that will provide state-of-the-art care to patients of all ages with congenital heart disease.

CHALLENGES FOR CONGENITAL CARDIAC CARE IN CHINA

The People's Republic of China has faced particular challenges in the management of congenital heart disease. The most striking problem is the sheer magnitude of the problem. With a population nearly five times that of the United States, it is estimated that more than 125,000 children are born each year with congenital heart disease. During the critically formative years of cardiac surgery in the 60s and 70s, China was passing through the difficult years of the Cultural Revolution. In many centers, cardiac surgery was completely shut down for almost a decade. In Shanghai, for example, Dr. Ding Wen Xian, Chief of Cardiac Surgery at Shanghai Second Medical University's Xin Hua Hospital was sent to rural Anhui Province where he was unable to practice any surgery for many years. On his return to Shanghai, he was unable to obtain any medical journals describing the advances that were happening so rapidly in the field at that time. He had to build all his own equipment including cardiopulmonary bypass machines and oxygenators. The same story was repeated throughout China so that in the early 1980s, many centers had waiting lists of thousands of patients with unoperated congenital heart disease. Through the efforts of many outstanding Chinese groups, often working in joint ventures such as that supported by Project Hope of the United States with education efforts by physicians, nurses, and technicians from the USA and other countries, great strides forward have been made in the last 10 to 15 years. The new Shanghai Children's Medical Center symbolizes what can be achieved with vision, hard work, and philanthropy.

CHALLENGES AHEAD

Modern congenital cardiac care is truly a collaborative team effort. It requires sophisticated diagnostic and

monitoring equipment, highly trained nursing and technical support staff as well as skilled physicians and surgeons. It also requires a complex hospital infrastructure to support these capabilities. State-of-the art care involves accurate diagnosis in the neonatal period or at least in early infancy followed by early primary repair. This approach has been demonstrated without question to minimize the secondary deleterious effects of the cardiac problem. Although in the past, it has been possible to manage pediatric cardiac problems surgically in many small centers, often in conjunction with the management of acquired heart disease in adults, this approach is now clearly suboptimal. Several studies have demonstrated that present-day results of congenital cardiac surgery are closely tied to volume. Furthermore, there is a need for close-at-hand expertise in the management of neonatal and pediatric as well as obstetric problems. The obvious conclusion is that surgery for congenital heart disease should be centralized in a small number of major regional centers. In the United States, for example, this trend has resulted in the emergence of 5 or 6 major centers that are geographically appropriately located to share the management of a large percentage of the children requiring sophisticated care for congenital heart disease. Consolidation of congenital cardiac care into a few major regional centers allows the concentration of a critical volume of patients so that expertise can be developed in areas such as interventional catheter techniques that have become essential adjuncts to surgery. It allows, for example, the cost-effective development of an extracorporeal membrane oxygenation service which in many major centers in the USA has become an integral component of cardiopulmonary resuscitation. Most importantly, consolidation allows the training of a core of highly trained nursing staff who must play a critically important role in the operating room and in the intensive care unit. Probably, the most important difference that can be observed between more advanced and less advanced systems for delivery of congenital cardiac care lies in the status and independent capabilities of nursing staff. It is essential that nursing staff have a prominent role in administrative decisions as well as in direct patient care.

Apart from nursing staff, another group that must be empowered in order to elevate the care of patients with

congenital heart disease is the family. In the past, hospitals in China, and in so many other countries, have felt no need to include families in the hospitalization process. This is extremely traumatic to young families and even more traumatic to young patients. The design of new facilities must consider the importance of having at least one parent close to the child throughout the hospitalization including time in the intensive care unit. With modern ventilation systems and a better understanding of mechanisms of spread of infection, families will increasingly be involved in care in the future.

Although surgical care for congenital cardiac disease should be centralized in a few major regional centers, this does not hold for diagnostic cardiology support. Successful care requires early diagnosis followed by appropriate triage to the regional surgical center. Congenital anomalies requiring repair in early infancy should be referred immediately to the major regional center while in the case of simple septal defects, for example, where cardiology follow-up and judgment regarding the need for and timing of surgery is required, such children may be referred to a secondary level center. Thus, an extensive network of secondary level cardiology centers should be developed and a close working relationship should be maintained with the tertiary surgical center. In New England, for example, Children's Hospital, Boston, serves as the tertiary level care center for the smaller states of New Hampshire and Vermont, which although they have a combined population of more than 1.5 million, have no congenital cardiac surgical service. Both states however have comprehensive, statewide cardiology services.

In addition to a network of primary pediatricians, secondary level cardiology care and tertiary level cardiac surgical care, an important requirement for the development of sophisticated cardiac care is a neonatal and infant transport team system. With this capability, it is possible for sick neonates to bypass the secondary level care and to be started immediately on prostaglandin E₁ at the primary center even if there is just a suspicion of heart disease. The child is then transported to the tertiary center where both diagnosis and care can be given.

FINANCIAL ASPECTS OF CONGENITAL HEART DISEASE

The most serious challenge in the management of congenital heart disease is that it usually strikes young families at a stage in their lives when they are not well equipped financially to deal with the major expense of a cardiac surgical procedure. In Shanghai, the municipal government has had the foresight to recognize this problem and has developed a provincial insurance plan that guarantees coverage for any child under 14 years of age. However, government insurance is unlikely to be the whole answer. It will be important for China to develop systems of commercial insurance so that businesses can offer to their workers the assurance of excellent healthcare. In addition, hospitals will have to learn the art of cost shifting so that they can be in a position to offer care to all those in need, no matter what their capability to pay might be. As Mrs. Clinton put it so aptly in the closing of her book, "It Takes a Village," "Nothing is more important to our shared future than the well-being of children."