ABSTRACT

Medical data registries serve an important role in the support, investigation and application of emerging treatments and technologies in health care, and in the study of rare or unusual diseases or treatments. By consolidating information of interest into databases designed to support a specialized role, they seek to improve the delivery of health care to specialized groups. By enabling exchange of information, and interrogation of large databases, health care workers can probe for knowledge not available in traditional medical record systems. The Extracorporeal Life Support Organization maintains a registry of patients treated with an extraordinary therapy for life-threatening cardiopulmonary failure, known as extracorporeal life support (ECLS). The registry is a database on patients from 120 domestic and international centers. Its initial implementation as a localized relational database imposed significant limits on dissemination of information for benchmarking, and for ad hoc queries to support on-going patient care. This paper reviews the legacy implementation of the database, and the development and transformation of the database from a limited localized database into a global information management and decision support tool to assist domestic U.S. and international centers in their application of this dynamic technology.

Keywords: decision support, extracorporeal life support, extracorporeal membrane oxygenation, information management, large databases, medical data registry, online information system

INTRODUCTION

Health care is a rapidly advancing field with considerable inherent uncertainty. New medical treatments are constantly being developed. Some of these, especially the development of new drugs, undergo rigid controlled clinical trials under protocols approved through regulatory agencies such as the U.S. Food and Drug Administration. Other advances, such as chemotherapy treatment combinations, new uses for drugs already approved for use, and novel applications of existing devices are often conducted less formally. Medical data registries provide a mechanism for accumulation of data that can allow the sharing of data and experiences, and coordinate
these advances among investigators at remote locations.

Medical data registries are used throughout the various disciplines of health care. Tumor registries, such as the one implemented at the State University of New York Health Science Center (SUNY, 2001), provide information for education, lifetime patient follow-up, and research. Another application of medical registries is to collect and accumulate data on rare diseases, or on diseases in which epidemiological studies may be desirable. The study of pediatric trauma is assisted with the use of a registry maintained in Boston, MA (National Pediatric Trauma Registry, 2001). Answers to questions such as the relative contributions of the environment versus genetics to human development and behavior may be provided through the study of twins with a registry hosted at the Karolinska Institute in Stockholm, Sweden (Karolinska Institute, 2001). Another registry example is the National Exposure Registry, a collection of data on environmental exposures to toxic substances maintained by the U.S. Public Health Service (Agency for Toxic Substances and Disease Registry, 2001).

A medical data registry is a database and associated data management procedures developed in support of the study of a rare or unusual disease or treatment, or one in which the examination of aggregate data might provide elucidation of information not available in individual medical records or case reports. A registry exists apart from a medical record, and contains information specific to the disease and/or treatment of interest. Registry data collection forms may also contain data collected specifically for the registry and not available in the medical record.

The Extracorporeal Life Support Organization (ELSO) is a voluntary organization composed of medical centers that provide a treatment known as extracorporeal life support (ECLS) or extracorporeal membrane oxygenation (ECMO). ECLS provides support of heart and/or lung function in patients with severe cardiopulmonary failure, in whom cardiac or pulmonary function cannot be supported with traditional treatment methods such as mechanical ventilation (Zwischenberger, Steinhorn, & Bartlett, 2000). ECLS procedures involve the application of technologies developed for short-term cardiopulmonary bypass used in cardiac surgery (for up to six hours duration) to patients for long-term support in the intensive care unit (for durations of up to 30 days or more). The diffusion of this technology requires dissemination of experiences and other information from individual centers.

The organization, headquartered in Ann Arbor, MI, consists of approximately 120 participating centers providing ECLS. The majority of these centers are based in the U.S., but in recent years, international centers in the United Kingdom, Europe, South America, Australia, and Asia have been added. The international centers pose challenges with respect to data collection and reporting because of the geographic distances involved.

Part of the mission and charter of ELSO is to maintain a registry of patients who have been treated with ECLS. This registry contains basic demographic data, disease information for which the treatment is sought, details about the technologies used in the treatment, complications of the treatment, and outcome data (Conrad & Rycus, 2000). The registry was developed for respiratory failure in neonates (infants up to 30 days of age) in the late 1970s and initially implemented as a dBase database with a flat file format. Additional databases were subsequently created for pediatric patients, adult patients, and cardiac support patients,
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