COMPARATIVE STUDY OF CEREBRAL PALSY INFORMATION REGISTRY SYSTEMS IN AMERICA, ENGLAND, AUSTRALIA, AND IRAN

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ABSTRACT

Introduction: The aim of this study was to investigate and compare cerebral palsy information registry systems in America, England, Australia, and Iran.

Methods: This descriptive-comparative study was done in 2014. Data were collected through observation, study, and face to face or telephone interviews. Data sources included articles, books, journals, databases, related websites, and also experts from different countries. Forms reliability was approved by experts in health information management, neurologists, and pediatric specialists across the country. The analysis was descriptive-theoretical.

Results: In each state and area, data is collected and managed by different centers and eventually all databases send their reports in the form of electronic and minimum data sets to Australian Cerebral Palsy Registry. In England, the Ministry of Health is responsible for data collection. In Iran, there is no national cerebral registry system; therefore, some suggestions were provided in 7 different bases.

Conclusion: registry systems can help to collect and analyze data related to all patients who have a specific disease. When this registry is established nationally, it is a valuable clinical tool for improvement of care quality and it can be considered an important step toward improvement and care of CP patients in rehabilitation centers as well as healthcare centers. This system can also prevent incidence of CP, and increase patients' quality of life.

KEYWORDS: Cerebral Palsy, Cerebral Palsy Registry, Minimum Data Set