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CYSTIC FIBROSIS PATIENT REGISTRY TO ASSESS OUTCOMES AND IMPROVE CYSTIC FIBROSIS CARE IN IRAN

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ABSTRACT

Introduction: Cystic fibrosis (CF) patient registries have become an important epidemiological tool for demography, networking, and quality management. This review describes recent developments in patient registries, outcome research, and pilot projects in quality improvement.

Methods: At Tabriz University of Medical Sciences in northwest Iran, CF registry efforts have been producing consolidated data. Classical outcome indicators describing nutritional status and lung function are now being used in a more precise way, based on body mass index percentiles and longitudinal data. Electronic documentation of each patient's visits was based entirely on the CFQA software system. participants were required to complete the data before the evaluation was carried out. The project collected variables included age, sex, respiratory function, weight, height, presence/absence of Pseudomonas aeruginosa and Burkholderia cepacia and history of medical complications. For the purpose of the evaluation, written informed consent was obtained from the parents and/or patients. The project used the following indicators of quality: the presence of Pseudomonas aeruginosa, weight for height (WH), BMI, FEV1, maximal expiratory forced flow 25% (MEF25) and the presence of massive complications (pneumothorax, severe hemoptysis, global pulmonary insufficiency, distal intestinal obstruction syndrome). Genetic analysis was done for each patient.

Results: There were 85 (25.7%) deceased patients and 246 (74.3%) living patients at the time of the study. Of the 246 living CF patients, 202 (82.2%) were less than nine years of age, and 77 (90.6%) out of the 85 deceased CF patients had died younger than four years of age. There was a significant difference between outcome and location of residence. The risk of mortality was 50% less in urban patients than in rural patients ($P = 0.03$). The risk of mortality was approximately two times higher in patients with a positive family history than in those with a negative family history ($P = 0.02$). The proportion of mortality was approximately two times, or 94%, higher for those in a consanguineous marriage than for those in a non-consanguineous marriage ($P = 0.01$).

Conclusion: Cystic fibrosis (CF) patient registries have become an important epidemiological tool for demography, networking, and quality management. This review describes recent developments in patient registries, outcome research, and pilot projects in quality improvement. CF provides a model of the link between healthcare delivery and outcomes in patients. CF registry data can be used to improve quality in CF healthcare. Quality improvement is a continuous endeavor involving the reinforcement of standards and programs as well as individual attitudes and soft skills. One particularly powerful technique is benchmarking, that is, learning from the best.

KEYWORDS: Electronic documentation, Cystic fibrosis, Child, Genetic.