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Title: Cystic fibrosis registry: A preliminary report of CF patient from NRITLD

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Body: Introduction: Cystic fibrosis is an inherited chronic disease that affects the lungs and digestive system of about 70,000 children and adults in the worldwide.To Create more accurate picture of current state of Iranian CF patients, we started to collect and register the data of CF cases at pediatric Pulmonary ward of Masih Daneshvari Hospital. Material and Method: This cross-sectional study was performed on 66 CF patients aged 0-18 years (mean: 14.46 yrs) to describe the demographics, clinical features and outcome among patients hospitalized in Masih Daneshvari Hospital from (2000-2011). 56% of the patients, had Consanguinity marriage and 10.6% had family history of CF in one sibling .Regarding the age at the onset of symptoms, in 33.4% the symptoms was started at the newborn period but only in 9% diagnosis was made at this period. For all patients HRCT of the lung was performed and the dominant finding was Bronchiectasis in 92.70%. Bacteriological findings of cases detected P.A in 68.18% cases, Staph.a in 6.06% cases, AsP.F in 6.06% cases, Candida in 4.54% cases, B.Cepasia in 1.51%. According to the ABPA diagnostic criteria 4 patients diagnosed with ABPA. 17% of the patients are candidate for lung transplantation and 3 patients underwent lung transplantation. Out of 66 cases 19 cases expired due to respiratory failure. Considering the result of our study and high rate of morbidity and mortality in our cases, we propose that CF registry and evaluation of the disease progression by means of a routine monitoring will increase the survival and improve quality of life of the patients.