

Updated Review

Cystic Fibrosis – a Born to Die disease: Current Status in Bangladesh

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What is CF?

Cystic fibrosis (CF) an autosomal recessive (genetic) disorder caused by mutations in both copies of gene encoding for CF-transmembrane conductance regulator (CFTR) protein. This life-limiting disease remain common among the Caucasian population living in America, Europe, Australia and Asia though found in non-Caucasian, ethnic minorities, too. The incidence of CF, a life limiting genetic disorder is 1 in 2500 children born in UK, but less common in African-Americans (1/15 000) and Asian-Americans (1:31 000). According to Indian experience, because of widespread belief that CF does not occur in Indo-Bangladesh subcontinent, the disease is rarely suspected, and, even if it does, the diagnosis is not always confirmed due to poorly available facilities for diagnosis like ours.

CF is an autosomal recessive disorder caused by mutations in the CFTR gene, fails to move chloride ions to the cell surface. Reduced chloride secretion coupled with increased sodium and water reabsorption, creates thick and dehydrated mucus that plugs airways and ducts. Viscous mucus in the lungs causes chronic bacterial infection, persistent inflammation, and progressive bronchiectasis. Obstruction of pancreatic ducts prevents enzymes from reaching the intestines, causing exocrine pancreatic insufficiency, fat malabsorption, and malnutrition. Inability to reabsorb chloride leads to high salt content in sweat (the basis for the sweat chloride test). The gold standard test is sweat chloride test for the diagnosis of CF.

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History of CF in Bangladesh

The first case of CF we suspected a case of CF in 1995 in the pediatric ward of Sylhet MAG Osmani Medical College where a female was admitted with recurrent pneumonia and the girl was referred to UK as they have relatives over there (Personal communication). The child was diagnosed as a case of CF and was given the treatment with antibiotics, chest physiotherapy, pancreatic enzyme replacement therapy and home schooling. Later, we first came across another case of CF in Bangladesh Shishu

Hospital and Institute (BSHI), the then Dhaka Shishu Hospital in the year 2000. The case was diagnosed in India. We could not diagnose the cases of CF because of non-availability of Gibson-Cooke's standard sweat test which require skilled manpower, special care and needs to be performed in accredited laboratories.

We started developing an indigenous method for collecting sweat. First, sweat chloride test was started in Combined Military Hospital (CMH), Dhaka by collecting sweat through an indigenous method of wrapping the child with an aluminum foil. Later, we started collecting sweat by wrapping using cheap and easily available polythene sheet and analyzing the sweat by an autoanalyzer at the Institute of Child and Mother Health (ICMH), Matuail. We continued collecting cases from ICMH, then at Sir Salimullah Medical College and Mitford Hospital, finally continued at the Addin Women's Medical College, Dhaka. Recently, we could have managed sweat testing by iontophoretic sweat conductivity test at different centers of Dhaka including BSHI and The Baraka General Hospital. We have started analyzing the CFTR mutations in a limited scale in Dhaka CMH on the 18 most common mutations out of about 2000 and also studying from India. The most common mutations we observed to be F508.

What we have learnt about CF in Bangladesh?

The CF disease is to be suspected when a child of might be born out of consanguineous parents presents with persistent cough, wet cough, muco-purulent sputum, malodor breath, wheezing, respiratory distress, chest indrawing, recurrent pneumonia, passing oily stool, malabsorption, growth failure, digital clubbing, and crackles. Mean-age of CF-cases at disease-onset was 17 months that significantly differed with age-at diagnosis of 90 months with a time lag of 73 months. However, this delay may be either the parental unwillingness to see a physician due to financial constraint or travel restraints; on the other hand, this might also happen that the physician/pediatrician himself might have missed the diagnosis because of lack of awareness of CF. A significant portion of children were given anti-tubercular therapy presuming to be suffering from PTB without having a strong evidence. Radio-imaging revealed hyperinflation, peribronchial thickening and bronchiectasis and pan-sinusitis.

Publications on CF

Several papers on CF have been published since the year 2004 focusing the existence of CF in Bangladesh, the collection of sweat by wrapping method, the diagnosis and management of 95 cases of CF over 17 years (2000-2017) by using indigenously wrapped technique, the existence of the disease in other Asian countries, and the deadly, dear and agonizing tale of the disease.

Latest development about CF in Bangladesh

Diagnostic facility in terms of facility for sweat conductivity test was started in BSHI in the year through purchasing a device in the year 2018 and later at the Barakah General Hospital, Rajarbagh, Dhaka in 2023 along with the indigenous method being continued in different centers.

From a global perspective, the epidemiological knowledge is limited mostly to high-income countries and is incomplete with respect to global genetic diversity, access to care, burden of disease, and life expectancy. The European Cystic Fibrosis Society (ECFS) has come forward to include CF patients from countries, in cooperation with the ECFS Patient Registry (ECFSR), is supporting Cystic Fibrosis (CF) patient registries for low- and middle-income countries (LMICs) outside of the WHO European Region. Analysis of a cohort at different center and country level gives the opportunity to see a broader picture regarding age distribution, age at diagnosis, disease progression, and the burden of therapy, and helps to identify opportunities for improvement in the structure and diagnostic/therapeutic strategy over time. Comparisons between centers in a country or between countries offer the possibility to discuss different diagnostic/therapeutic strategies, to learn from the best, and to improve care and outcomes over time.

We recently have been included in ECFPRS along with other 10 non-European countries to share our epidemiological data through a standard format. The ECFPRS have been kind enough to express interest to do the CFTR mutation test free for our patients. The total cost for each patient is around BDT 30,000/=. It will be of great help for our patients to know the genetics of our CF patients. This will lead us to future CFTR modulation therapy for the curative treatment of our CF children in the long run. We have almost completed the formalities to start to be trained by the ECFPRS authority about our CF cases data entry through ECFTracker. Moreover, the ECFPRS authority has offered to provide us with a sweat testing device shortly.

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