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One-Year Follow-Up of Cystic Fibrosis Patients Who Cannot Reach the Modulator Therapies Although Having Indications: What are Their Losses?

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Abstract

Objectives: It is shown that modulatory therapies(MT) in cystic fibrosis(CF) positively affect pulmonary function tests(PFT) parameters,patients' weight gain, decreasing lung infections and lung-related deaths and improving quality of life. Many CF patients cannot reach MT in our country. This study aims to evaluate the change of the clinical and laboratory parameters of CF patients who are indicated for MT but cannot receive it.

Methods: The retrospective cohort study compared the changes of clinical and laboratory parameters of 351 patients who had modulatory treatment indications in 2018 but could not reach the treatment still in 2019. Patient information was obtained from the CF Registry of Turkey.

Results: The mean of FEV1% was<50% in 35 patients,<30% in 6 patients in 2018;FEV1% was<50% in 9 new patients and<30% in 4 new patients in 2019,that indicates patients who need lung transplantation. The number of patients requiring oxygen and non-invasive mechanical ventilators(NIMV) had increased as 9 and 4 new patients in 2019 respectively. The mean weight and body mass index(BMI) of patients were significantly decreased during the follow-up($p<0.01$). Further analyses were made for patients who were≥18 years old; the average weight and BMI in 18 of them had decreased. The number of patients with BMI<18.5 kg/m² was 7 in 2018 and was 11 in 2019. Chronic bacterial colonization status increased by 1.7% in 2019 compared to 2018.

Conclusions: The study showed that the number of patients who need lung transplantation,oxygen,NIMV,ratio of chronic colonization is increased. BMIs of patients decreased. We want to emphasize using MT in patients with CF for our country.

Cystic fibrosis Treatments Quality of life

Footnotes

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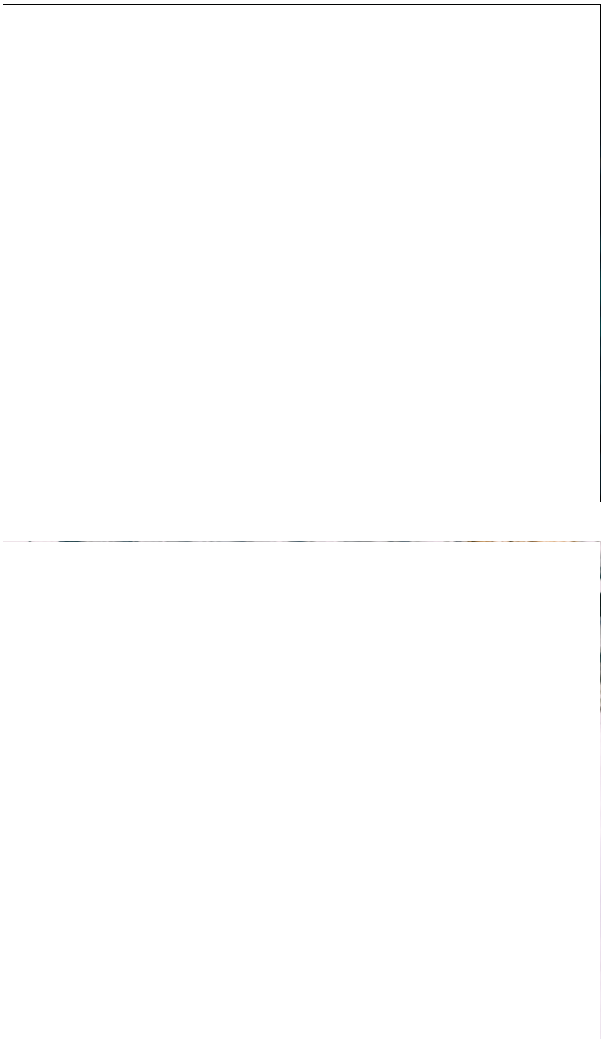

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