

Airway Clearance after Highly Effective CFTR Modulators: Normalizing Life and Reducing Treatment Burden

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Abstract

Objectives: Airway clearance therapy (ACT) is an important component of therapy for cystic fibrosis (CF) but is associated with significant treatment burden. Highly effective CFTR modulator therapy (HEMT) has improved pulmonary function for many people with CF(pwCF). We sought to understand changes in attitudes and practices about ACT in the post-HEMT era. **Study design:** Surveys of CF community members and CF care team members **Methodology:** Separate surveys were created for the CF community and CF care providers to evaluate attitudes towards ACT and exercise in the post-HEMT era. We solicited answers from pwCF via the CF Foundation's Community Voice and from CF care providers via CF Foundation listservs. Surveys were available between July 20 and August 3, 2021. **Results:** Surveys were completed by 153 community members (parents of children and pwCF) and 192 CF care providers. Belief that exercise can substitute partially for ACT was endorsed similarly by community members (59%) and providers (68%) . After starting HEMT, 36% of parents of children and 51% of adults did fewer ACT treatments including 13% who stopped ACT. Adults reported altering their ACT regimen more than parents of children. Half of providers had changed their ACT recommendations for those on HEMT. Fifty-three percent of respondents had discussed changing ACT with their care team (36% of parents, 58% of pwCF). **Conclusions:** Providers should be aware that ACT management changes may have been undertaken by pwCF who have pulmonary benefits of HEMT. Treatment burden should be considered in co-management decisions regarding ACT and exercise.

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Table 1 - ACT after HEMT.docx available at <https://authorea.com/users/562675/articles/610040-airway-clearance-after-highly-effective-cftr-modulators-normalizing-life-and-reducing-treatment-burden>

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treatment-burden