Cystic Fibrosis and Autism Spectrum Disorder: Unique challenges of this dual diagnosis

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Abstract

Background Cystic Fibrosis (CF) and autism spectrum disorder (ASD) are life-long conditions with intense treatment burdens for patients and families. Patients with a concurrent diagnosis (CF-ASD) experience unique challenges to CF care. This study describes the experiences of our multidisciplinary CF team in caring for patients with CF-ASD and provides insight into provider and parental perspectives on clinical management. **Methods** This is a three-part IRB-approved study involving 1) retrospective chart review of patients with CF-ASD, 2) qualitative interviews with multi-disciplinary care teams, and 3) qualitative interviews with caregivers of patients with CF-ASD. Challenges in clinical management of this specific cohort were compiled using data from chart review and care team interviews. Strategies to address these challenges were identified and rated by individual families based on relevance and practicality. **Results** Within our CF center, 12 patients have an official diagnosis of ASD. Median age of patients with CF-ASD was 8.5 years (range 3-20 years), 75% were male, and 83% were on highly effective modulator therapy. Clinical challenges included sensory processing issues, environmental overstimulation, intolerance to procedures and disrupted routines. Potentially impactful strategies include patient-specific coping plans, guided behavioral interventions, parental advocacy, and improved communication between the family and multidisciplinary team. **Conclusions** Children with CF-ASD face extraordinary challenges beyond the experience of neurotypical children with CF. Increased awareness of this complex dual diagnosis will help providers be sensitive to the unique needs of these patients, to help build consistent and trustworthy relationships with families, and to provide effective clinical care despite limitations.

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