

# Rounding out the pediatric CF care team: Including the profession of occupational therapy

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## Abstract

The literature has identified continued needs for children with cystic fibrosis. The profession of occupational therapy is uniquely equipped and trained to address a variety of needs that children with cystic fibrosis experience during daily life engagement, potentially filling this gap in services. Despite this, occupational therapists are rarely consulted or included in patient care plans. It is the goal of this letter that professionals working in the field of cystic fibrosis will gain an understanding and appreciation for the profession of occupational therapy when considering care plans for their patients.

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## Summary

The literature has identified continued needs for children with cystic fibrosis. The profession of occupational therapy is uniquely equipped and trained to address a variety of needs that children with cystic fibrosis experience during daily life engagement, potentially filling this gap in services. Despite this, occupational therapists are rarely consulted or included in patient care plans. It is the goal of this letter that professionals working in the field of cystic fibrosis will gain an understanding and appreciation for the profession of occupational therapy when considering care plans for their patients.

To the Editor,

The care team surrounding children and adults with cystic fibrosis is historically interdisciplinary in nature. However, the profession of occupational therapy is seldom utilized during outpatient or inpatient based services. Therefore, there are opportunities for occupational therapists to provide a unique, holistic, and client-centered service to address the negative impacts on quality of life and independence in everyday occupations.

Occupations, or individualized everyday activities that an individual engages in to occupy their time while seeking meaning and purpose in one's life <sup>1</sup>, is an area of skill and expertise for occupational therapy professionals. Occupational therapists provide services for the purpose of habilitation, rehabilitation, and promotion of health and overall wellbeing for individuals across the lifespan to promote function and participation in everyday occupations. Being that occupational therapists are knowledgeable and skilled in providing therapy services in a variety of areas (i.e., cognition, gross/fine motor, emotional regulation, etc.), the profession is a crucial addition to the interprofessional team for patients with cystic fibrosis to address the presently unmet needs in the population.

Individuals with cystic fibrosis may experience a decline in functional skills required for everyday engagement, specific to motor performance. Motor performance is essential for everyday life activities like functional mobility and provides a sense of independence for individuals across the lifespan. Gruber and colleagues identified a significant difference in children, ages six to 17, in health related and motor performance related fitness ( $p < 0.05$ )<sup>2</sup>. Findings also displayed a linear progression in motor performance aligning with peers, until the age of 14 where children with cystic fibrosis were noted to experience a plateau or decline in motor performance <sup>2</sup>. Findings support the need for additional support in motor development for children, an area supported in the scope of occupational therapy.

Health management, an area of occupation outlined by the practice framework of the profession, includes activities specific to enhancing, maintaining, and developing routines to support health and wellness<sup>1</sup>. Individuals experience increased needs in health management during the transition period from adolescents into adulthood where an increase in treatment burden occurs. The transition is linked to the expectations that young adults will gain independence in managing their chronic illness. Christian and D'Auria evaluated the effectiveness of a life skills program focuses on assisting children with cystic fibrosis in balancing the functional demands of their chronic illness while supporting psychosocial and developmental deficits<sup>3</sup>. Children in the intervention demonstrated significant decline in perceived impact of illness ( $p < .0001$ ) and significant decline in feelings of isolation ( $p < .0001$ ). Findings after the nine month follow up displayed children in the intervention group were able to retain the skills learned with significant difference from base line in the areas of impact of illness and loneliness ( $p < .01$ ;  $p < .01$ , respectively) <sup>3</sup>. Findings support the need for interventions focused on cognitive skill development, (e.g., problem solving), social skill development, (e.g., social acceptance), and health related functional skill development (e.g., adherence to treatments). Occupational therapists are uniquely equipped to address these needs through a health promotional approach to support children while transitioning into adulthood.

Knudsen and colleagues sought to understand the association between medication adherence and depression symptoms with health-related quality of life in young adults with cystic fibrosis <sup>4</sup>. Findings showed that 74%

of participants reported low adherence to medications with an additional 18.2% reporting medium adherence. Researchers also identified that 32.8% of participants reported symptoms of depression which was associated with low scores in health-related quality of life. Negative impacts on health-related quality of life associations include treatment burden and vitality<sup>4</sup>. Associations between low medication adherence and depressive symptoms were identified. With social work already being a recognized member of the interprofessional team, an additional provider to support mental health concerns through client-centered interventions is crucial. The complex needs in the scope of mental health warrant the additional support, specific to adherence to medications and health related quality of life in children and young adults. As displayed by Knudsen and colleagues, the association between mental health concerns and medication adherence is apparent; therefore, a professional trained to support individuals from both aspects is warranted<sup>4</sup>.

The apparent needs of the population through the outpatient lens are striking, however the impact while in the hospital is equally as important in managing the care of children with cystic fibrosis. Hegarty and colleagues sought to evaluate the quality of life of children during inpatient hospital stays. Children ranged in age from six to 18 and as hypothesized, reported lower levels of quality of life in areas of emotional state, body image, and treatment burden/respiratory symptoms<sup>5</sup>. Researchers did not find significance in a reduction of lung function; however, children while admitted to the hospital experienced large declines in quality of life<sup>5</sup>. With the potential for deconditioning, excess fatigue, and looming weakness during inpatient stays, children with cystic fibrosis would be best supported by occupational therapy practitioners to ensure their unmet needs are being met; with the training and knowledge of an occupational therapist, children would be supported in a variety of areas of need, making the costs of the billable service not only warranted, but necessary in the child's care plan.

As depicted through an overview of literature, the profession of occupational therapy is prepared to address the areas through skilled, billable services; yet these professionals are rarely consulted or referred to on the team. Lorenzo and Metz (2013) surveyed occupational therapy practitioners in their knowledge as well as perception of the role when working with children with chronic respiratory diseases, including asthma and cystic fibrosis<sup>6</sup>. Researchers reported that 91% of respondents endorsed a least one role of the profession with this population<sup>6</sup>. These roles included: developing efficient ways to complete everyday occupations (85%), patient education (84%), energy conservation (81%), and engagement in physical activity (78%)<sup>6</sup>. Findings supported the addition of an occupational therapists feel prepared to address the needs of this population, yet little advancements in bringing occupational therapists onto the team have occurred. Similar findings were noted through collecting needs assessment information from professionals in the area during an occupational therapy student project. A unanimous agreement from occupational therapists and pediatric physicians was reached that a child with cystic fibrosis would benefit from outpatient services. Similarly, 75% endorsing the need for occupational therapy during inpatient/acute services due to pulmonary exacerbation. However, providers reported rarely utilizing the profession thus far.

Upon inquiring with patients and families at a local cystic fibrosis care center, apparent needs the profession can address were identified, including life skills (i.e., attention and stress management), mental health (i.e., coping skills and emotional regulation), medication management (i.e., identifying/communicating symptoms and managing medications), and daily needs (i.e., routines and feeding). Being that the needs of the population span into a variety of areas of occupation, an occupational therapist would strengthen the interdisciplinary team. An occupational therapist could be added to the staff in the care center, supported through a position in an outpatient clinic, and/or developing supports for inpatient/acute therapy services. In the care center, grant funding would be secured, similar to funding for other providers such as social work. In the outpatient and inpatient/acute therapy setting, services would be billable through CPT codes making financial restrictions less burdensome.

Therefore, it is apparent that children with cystic experience an impact on their quality of life, daily routine, and mental health remain. Although the literature depicts a clear area of need in the patient population, the profession of occupational therapy is rarely included. In order to address the gap in education, one purpose of this manuscript is to bring awareness to the needs as well as contribute education to the provider network.

With education, providers will be equipped to identify the unmet needs of the population and include the profession of occupational therapy in order to ensure the needs are met. During upcoming rounds, sick visits, or regular scheduled check-ups, consider if the patient, or family, is expressing concerns that an occupational therapist can address. A referral to occupational therapy and/or development of a position, may address these needs and best serve this population as they progress into adulthood and beyond.

Words: 1350 /1500

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