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Impact of the COVID-19 pandemic: How our response is shaping the future of cystic fibrosis care

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ABSTRACT

The findings of this body of work are presented in the eight articles included in this supplement. The impact and perspectives of adult and pediatric care teams and patient/families are covered with special attention to mental health care, the financial and personnel impacts within care programs, the experiences of vulnerable and underrepresented patient populations, and implementation of remoting monitoring. Commentaries from colleagues provide a broader perspective, offering reflections on the findings and their implications regarding the future CF care model.

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The onset of the SARS-CoV-2 (COVID-19) pandemic globally disrupted health care delivery. Health professionals were called upon to provide urgent care for individuals infected by this novel virus. At the same time, in response to a lockdown to prevent spread of the virus, they were also pushed to use telehealth for their ambulatory care practice despite little or no experience. The healthcare system was also challenged financially because of reduced revenue stemming from factors such as cancellation of clinics, elective surgeries, and other medical procedures. These revenue losses were coupled with the high medical costs of providing care for COVID-19 patients. This led to redeployments, furloughs, pay cuts and other measures.

Cystic fibrosis (CF) care in the U.S. is delivered by interdisciplin ary teams of health professionals based in hospitals and organized as pediatric and adult care programs. CF Centers are held to a high standard of care, accredited by the CF Foundation through a peer review system and expected to actively participate in quality improvement initiatives. Teams see patients/families in-person at regular intervals (e.g. quarterly) to assess signs and symptoms, to monitor pulmonary and nutritional status, to collect lab and throat/sputum cultures, and to screen for anxiety and depression and other social determinants of health such as food security. In addition to seeing a physician and nurse, patients/families also meet individually with a dietitian, social worker, and respiratory therapist during clinic appointments. Many patients/families will also meet with a pharmacist, mental health coordinator, physical therapist and other health care professionals as needed.

This model of care requires careful planning to ensure each team member is available to meet with the patient/family and that the patient/family commit their time to travel and engage in lengthy appointments. When the pandemic struck the U.S. in March 2020, teams and patients/families were also forced to adopt telehealth to ensure continuity of care. However, the rapid pivot to telehealth and the urgent re-deployment of medical professionals to care for COVID-19 patients raised concerns at the CF Foundation about access, equity, and the quality of CF care. Prior to the pandemic, the U.S. CF community had limited experience delivering care using telehealth. Strategically, however, the CF Foundation was looking ahead at how it might be used to meet the care needs of a growing adult patient population, alleviating cost and time burdens, and in the context of many patients experiencing better health after initiation of CFTR modulator therapy.

To assess the impact of the pandemic on the state of care across the network of programs and to learn more about the facilitators, barriers, and perceptions of telehealth among care teams and patients/families, the CF Foundation assembled an organization-wide team. This team in partnership with care team members, patients/families, and researchers from The Dartmouth Institute for Health Policy and Clinical Practice, developed and fielded three national surveys and conducted interviews and focus groups between July 2020 and May 2021. Also, during this time, national survey data pertaining specifically to mental health screening and care
were collected and analyzed by the CF Foundation mental health advisory committee.

The findings of this work are presented in the eight articles included in this supplement. The impact and perspectives of adult and pediatric care teams and patient/families are covered with special attention to mental health care, the financial and personnel impacts within care programs, the experiences of vulnerable and under-represented patient populations, and implementation of remoting monitoring. Commentaries from colleagues provide a broader perspective, offering reflections on the findings and their implications regarding the future CF care model.

We are encouraged that many care teams and patients/families were able to deliver and receive high quality, interdisciplinary care throughout the pandemic. It is a testament to the genuine passion and commitment of the CF community to provide the best possible care to all individuals with CF. We are also encouraged that these findings indicate that there may be a vital role for telehealth going forward and that there is interest in conducting research to address key questions that these analyses surfaced.

Declaration of Competing Interest

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