

Emotional Impact of COVID-19 Pandemic on Adults with Cystic Fibrosis

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Cystic Fibrosis (CF) is the most common lethal, genetic disease in the United States. While considered to be a rare disease, there are 70,000 people living with CF worldwide and 30,000 in the United States alone.¹ People with CF (PwCF) suffer from multiorgan dysfunction, and the most common cause of mortality is respiratory failure. CF has been associated with worsening respiratory function and death during prior respiratory virus pandemics.² While current observational data suggests that PwCF are not developing as severe COVID-19-related illness as originally expected, those with severely compromised lung function and those who have undergone lung transplantation have worse outcomes including hospitalization and death.³ Public health education to reduce the risk of transmission of Sars-CoV-2 align with long-standing infection control practices amongst PwCF, established by the Cystic Fibrosis Foundation (CFF) to reduce transmission of multidrug-resistant bacteria among PwCF.¹ As such, PwCF were already well versed in wearing masks, safe-distancing and avoiding group gatherings prior to the pandemic. We set out to capture this unique patient-centered perspective on the effects of the pandemic on psychosocial and physical aspects of daily life, as part of a larger study.

We hypothesized that PwCF would be significantly impacted by the COVID-19 pandemic and experience increased anxiety and stress due to perceived vulnerability but that there would be limited changes in behavior with respect to infection-control measures. We designed a telephone-based survey of PwCF at a single academic center (n = 62 adults) from May to July 2020 at Rhode Island Hospital/Hasbro Children's Hospital. The survey consisted of an assessment of social desirability bias, a validated scale for quality of life in individuals with Cystic Fibrosis (CFQR), and a voluntary open-ended question about how COVID-19 has affected them. A total of 16 individuals discussed the impact of COVID-19 on their lives (Table 1). Survey responses were modeled as binomial distributions and compared between the group of patients who mentioned COVID-19 concerns during the interview and those that did not, with p-values <0.05 reported as significant. Interestingly, there was an

Table 1. Patient Characteristics

	PwCF with COVID-19 response (n = 16)
Age (mean, range in years)	30.3 (18–49)
Sex, Female N (%)	13 (45)
BMI (mean)	22.9
FEV1 (% average, range)	63 (23–100)
Modulator therapy (% taking)	89.7%
Non-CF Lung Disease	4 (2 asthma, 1 MAC, 1 ABPA)
Pseudomonas aeruginosa sputum culture (%)	18 (62%)
Lung-transplant recipient (%)	2 (6.9%)
CF Exacerbation Prior Year (%)	5 outpatient (17%), 16 inpatient (55%)
Anxiety Diagnosis (%)	16 (55%)

increased agreement with the statement “you felt well” in the preceding 2 weeks amongst those who chose to discuss COVID-19 concerns compared to those who did not (mean response 2.29 vs 1.57 on 4-point scale, higher score indicates agreement, p-value 0.008), while there was no significant difference in response to the statement “you felt worried” (mean response 2.5 vs 1.93, p-value 0.121). Our survey did not capture the reasons for not discussing COVID-19 related issues.

Around the world, the COVID-19 pandemic has contributed to significant increases in anxiety, depression, and feelings of isolation. Of our total adult clinic population, 96% (n=60) patients were seen by a clinical social worker either in person or remotely with an average of 2.6 visits per year since November 2019 when Sars-CoV-2 emerged. Among patients seen in 2020, 87.7% were screened with the PHQ9 and GAD7 of which 10% presented with symptoms of depression and 33.3% presented with symptoms of anxiety compared with 8.9% and 25% respectively in 2019.

Our interviews demonstrated significant lifestyle changes and feelings of isolation amongst PwCF, but additionally highlighted the anxiety PwCF perceived their family members and housemates to have experienced. Fears of accidental transmission, and the concern about serious subsequent illness, significantly impacted the behaviors of PwCF and their loved ones (Table 2).

Table 2. Participants' Quotes Regarding Experience with Coronavirus-19

Topic	Illustrative Quotes
Concern for infection risk	<ul style="list-style-type: none"> • 24 yo M: "As a CF patient, it's difficult already, never mind a respiratory illness. COVID has made me take my daily routine more seriously and increase my precautions." • 37 yo M: "It is definitely a worry, for sure in terms of CF. Last week I had a tickle and it felt like a cold without cold symptoms - it has gotten better but I was taking my temperature like 10 times a day."
Lifestyle changes	<ul style="list-style-type: none"> • 49 yo M: "I am avoiding everyone until there is a vaccine or a treatment. I'm definitely a little worried." • 27 yo F: "Just trying to avoid the world pretty much. My anxiety pretty much stems from going back to work. I just don't want to be a part of the reopening." • 23 yo F: "It's hard to stay active because it's such a risk for us to go out and be around people."
Concerns of family	<ul style="list-style-type: none"> • 29 yo M: "It actually puts a lot of stress on my [partner]. Because I'm a new father and she worries about me getting it, because she says you know, I get it and I'm dead. She worries every time I step out of the house."
Concern for work	<ul style="list-style-type: none"> • 29 yo F: "It's keeping me out of work. I guess I'm a little more worried because I know it impacts people with lung problems." • 46 yo M: "Work is challenging in the sense that I work at [a university] and so I'm having to avoid places I usually oversee. I think it's only going to get more challenging." • 27 yo F: "Pretty much I decided once everyone was on board that this was an actual issue, I left work before it was mandated just to be safe...My anxiety pretty much stems from going back to work. I just don't want to be a part of the reopening."
Feelings of isolation	<ul style="list-style-type: none"> • 27 yo F: "I really haven't gone anywhere since like March. My parents are doing grocery shopping for me." [May 2020] • 24 yo F: "God forbid you are in the aisle and you cough, people walk away like you're diseased and it's like 'I mean, I am but I am not.' It has impacted me."
Hospital experience	<ul style="list-style-type: none"> • 37 yo F: "It was ... way more shortness of breath compared to what I'm used to. All my exacerbations in the past I've never had to be on oxygen. I was thinking to myself, this doesn't follow the typical course of my exacerbation." "I think the diarrhea was worse than the breathing – like the breathing and the chest pain was bad, but not being able to eat and being worried because I knew I had to keep the weight on, and constantly having to go to the bathroom and really be on top of my fluid intake, that was really difficult." • 27 yo M: "I think I was a little more apprehensive about coming into the hospital, and since I've been here, I've noticed all the extra precautions that are being taken."

In addition to the increased concern among PwCF and family members, many participants reported significant changes to their daily lives to minimize their exposure risk despite already practicing infection-control measures for their CF prior to the pandemic. Given the known psychosocial consequences of social isolation that the pandemic has forced on the general population, extreme quarantine for PwCF may have long-term impact on psychologic and emotional well-being.⁴ Early in the pandemic, study participants described staying home from work or leaving work

completely, a decision that can have lasting consequences for re-entry into the workforce. Many participants reported an increased sense of isolation compared to peers without CF and felt that their measures to avoid exposure were leading to further separation from loved ones.

Several participants were concerned about contracting SARS-CoV-2 infection in the hospital, and at least one reported delaying their presentation for concern about exposures during a hospital stay, a practice which can have grave ramifications. The Cystic Fibrosis Foundation reported 1,232 known COVID-19 infections of adults with CF and an additional 548 cases of children in the United States as of September 2021, with 14 deaths related to the infection.^{5,6}

Continued mental health screening and support remains a priority given the increased risk of depression and anxiety with lengthy periods of isolation and stress. Further rigorous qualitative study is warranted to better serve the CF community and other vulnerable populations during this time of transition and to clarify what the long-term psychological impact of the pandemic will be.

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