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Food insecurity and mental health during the COVID-19 pandemic in cystic fibrosis households

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Abstract

Background: The COVID-19 pandemic impacted many households due to shelter-in-place orders and economic hardship. People with cystic fibrosis (CF) experienced increased food insecurity compared to the general population before the pandemic, even though adequate food access is needed to maintain nutrition goals associated with improved health-related outcomes. Little is known about the impact the pandemic had on the food insecurity of people with CF and their families.

Objective: To investigate how the COVID-19 pandemic impacted food insecurity, mental health, and self-care in people with CF.

Methods: Adults with CF and parents/guardians of children with CF were recruited via social media to complete online questionnaires from May 2020 to February 2021. Questionnaires in English and Spanish included USDA 2-question food insecurity screening, Patient Health

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CONFLICT OF INTERESTS

The authors declare no conflict of interests.

SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

Questionnaire-4 for mental health screening, and directed questions on the impact of the pandemic.

Results: Of 372 respondents, 21.8% of the households experienced food insecurity during the pandemic compared to 18.8% prepandemic ($p < .001$). More food insecure patients with CF reported weight loss (32.1% vs. 13.1%, $p < .001$), worse airway clearance adherence (13.6% vs. 5.8%, $p < .01$), and worse medication adherence (12.4% vs. 1.7%, $p < .01$) compared to food secure patients. Food insecure subjects were more likely to have an abnormal mental health screen compared to food secure subjects (53.1% vs. 16.2%, $p < .001$).

Conclusion: Food insecurity increased in the CF population during the COVID-19 pandemic. Food insecure subjects reported worse mental health and self-care during the pandemic compared to food secure subjects.

Keywords

COVID-19; cystic fibrosis; food insecurity; health disparities; mental health

1 | INTRODUCTION

People with cystic fibrosis (CF) and their families face many challenges compared to the general population due to the time commitment and financial burden of managing the disease.^{1,2} Food insecurity, which is the limited or uncertain availability of nutritionally adequate and safe foods,³ is higher among families with CF than the general population. Previous studies have demonstrated that between 26% and 33% of families of children with CF report food insecurity, while over 40% of adults with CF have food insecurity.^{4,5} This is significantly higher than the general population: in the United States in 2019, 10.5% of households overall and 14.8% of households with children were food insecure.⁶ Access to plentiful, nutritious food is vital for people with CF to overcome malabsorption and maintain their ideal body weight, which is associated with higher pulmonary function.⁷ In addition, food insecurity increases the risk for depression and anxiety in the general population.⁸ The rates of depression and anxiety are already high among people with CF and their families,⁹ associated with decreased quality of life^{10,11} and increased risk of food insecurity.⁸

In 2020, as the novel coronavirus disease (COVID-19) spread worldwide, unprecedented measures, including shelter-in-place orders, business/school closures, and social distancing, were implemented across the United States. The pandemic led to significant financial and emotional hardships for millions of people, including reduction or loss of employment. The economic fallout included an increase in food insecurity across the country and inadequate resources at food banks.^{12,13} Many individuals under quarantine experienced increased anxiety, depression, posttraumatic stress disorder, and emotional exhaustion.¹⁴

With the pandemic having such a profound negative impact on the lives of the general population, we explored what the impact was on people with CF and their families. People with CF had a lower COVID-19 infection rate than the general population,¹⁵ likely due to the long-standing infection control guidelines implemented to prevent the spread of respiratory infections among people with CF.¹⁶ However, people with CF may be at

increased risk of the negative indirect consequences of the pandemic due to the financial and emotional burden of chronic disease and the immediate impact of poor nutritional status on their physical health. Because there is increased food insecurity, depression, and anxiety in people with CF, they are vulnerable to experiencing worsening food insecurity and mental health during the pandemic.^{5,9} The impact of the pandemic on food insecurity, mental health, and self-care in people with CF is not clear.

In this study, we investigated the impact the COVID-19 pandemic has had on people with CF and their families, with a specific focus on food insecurity, mental health, and self-care. We hypothesized that the prevalence of food insecurity and mental health issues increased during the COVID-19 pandemic and that this would be associated with decreased CF self-care.

2 | METHODS

2.1 | Study design

This was a cross-sectional, observational study on the impact of the COVID-19 pandemic on people with CF. Subjects were either an adult (age 18 years or older) diagnosed with CF or a primary caregiver of a child diagnosed with CF. All subjects resided in the United States. Subjects were recruited from May 2020 to February 2021 through Facebook advertisements and Twitter posts. Advertisements were available in English and Spanish. The questionnaires were conducted by web-based Redcap surveys available in English and Spanish (Supporting Information S1). Spanish translation was done by a certified translator. Flesch-Kincaid Grade Level of the survey was assessed and found to be a 5th grade level. We compared mental health, and COVID-19 experience variables between food insecure and food secure subjects. Written consents were obtained. The study was approved by the Institutional Review Board at the University of California San Francisco (IRB 20-31005).

2.2 | Measures

2.2.1 | Food insecurity—Food insecurity was assessed with the “Hunger Vital Sign,” a validated question screening tool based on the USDA Household Food Security Survey.¹⁷ Subjects were asked if the following two statements were often true, sometimes true, or never true in their household. The first statement was, “We worried whether our food would run out before we got money to buy more.” The second was, “The food we bought just didn’t last, and we didn’t have money to get more.” A response of “often true” or “sometimes true” to either statement indicates a positive screen for food insecurity. Subjects were asked about food insecurity before the COVID-19 pandemic and within the last 3 months during the pandemic.

2.2.2 | Mental health—Subjects’ mental health before the pandemic and in the last 3 months was assessed with the Patient Health Questionnaire-4, which consists of two anxiety questions and two depression questions. Scoring of symptoms was on a scale of 0 (*not at all*) to 3 (*nearly every day*). Scoring a total of ≥ 3 on either the anxiety or depression questions indicated positivity for either of those disorders and was considered to be an “abnormal mental health screen.”¹⁸

2.2.3 | COVID-19 experience—We inquired whether the person with CF had been diagnosed with COVID-19. We inquired whether the subject or their family was currently under shelter-in-place order, had any change in household income or employment during the pandemic, had difficulty obtaining food for the household, and if they had assistance acquiring food. We inquired whether the person with CF had obstacles obtaining CF-specific medications, had weight loss or gain, or had changes in how often they took their medications or did airway clearance adherence. We asked if the person with CF had a visit with their CF care team and if it was in-person or telehealth. Demographic information of the person with CF was collected, including age, sex, race, ethnicity, and insurance status.

2.3 | Statistical methods

Socioeconomic characteristics and demographics of the people with CF were compared overall and by age using Chi-squared tests for categorical variables. The proportion of subjects with food insecurity was compared pre-pandemic and during the pandemic overall and by subject type (adult with CF or primary caregiver of a child with CF) using Chi-squared test. Next, we compared variables between food insecure and food secure subjects using chi-squared tests of significant differences. A two-sided p value $<.05$ was considered statistically significant. All statistical analyses were conducted with STATA version 15.0 (StataCorp LP).

3 | RESULTS

Of 372 subjects, 247 were adults with CF and 125 were parents or guardians of a child with CF. The people with CF were predominantly female (245, 65.9%), non-Hispanic White (336, 90.3%), and had private insurance (236, 63.4%). There were no demographic differences between adults with CF or children with CF (Table 1).

Household food insecurity increased from 18.8% (70) before the pandemic to 21.8% (81) during the pandemic ($p < .001$, Table 2). Overall, 5.9% (22) subjects switched from food secure to insecure and 3.0% (11) of subjects switched from food insecure to secure during the pandemic. Food insecurity was more prevalent in children with CF compared to adults with CF, and children were more likely to change from food secure to food insecure (9, 7.2%) compared to adults with CF (13, 5.3%) during the pandemic. The prevalence of food insecurity in children with CF increased from 23.2% (29) prepandemic to 27.2% (34) during the pandemic, while in adults with CF, it increased from 16.6% (41) prepandemic to 19.0% (47) during the pandemic.

The COVID-19 pandemic had a significant impact on the lives of our subjects. Half of the subjects were under shelter-in-place orders at the time of the survey, and there was no difference by food security status (Table 3). Subjects who were food insecure during the pandemic were more likely to have decreased household income than food secure subjects (60.5% vs. 23.4%, $p < .001$). Food insecure subjects were more likely to experience unemployment during the pandemic than food secure subjects (45.7% vs. 16.2%, $p < .001$).

More food insecure subjects had difficulty in food procurement due to financial hardship or decreased food supplies in stores than food secure subjects (82.7% vs. 24.4%, $p < .001$)

during the pandemic. Among food insecure subjects, 45.7% received assistance with food compared to only 4.1% of food secure subjects ($p < .001$). Food insecure people with CF were more likely to have weight loss compared to food secure (32.1% vs. 13.1%, $p < .001$).

The COVID-19 pandemic also impacted how people with CF took care of their disease. Food insecure people with CF were more likely to have decreased medication adherence (12.4% vs. 1.7%, $p < .0001$) and decreased airway clearance adherence (13.6% vs. 5.8%, $p < .001$) during the pandemic compared to food secure people with CF. There was also more difficulty obtaining CF medications in food secure people with CF (17.3% vs. 5.5%, $p < .0001$). There were no differences in CF clinic attendance or COVID-19 diagnoses by food security status.

3.1 | Mental health

Mental health worsened during the pandemic for subjects with an increased proportion of depression (17.5% vs. 13.4%), anxiety (22.0% vs. 17.7%), and abnormal mental health screen (24.2% vs. 19.6%) compared to before the pandemic. Food insecure subjects were more likely to have depression (32.9% vs. 8.9%, $p < .001$) or anxiety (44.3% vs. 11.6%, $p < .001$) compared to food secure subjects before the pandemic (Table 4). During the pandemic, food insecure subjects were more likely to have depression (37.0% vs. 12.0%, $p < .001$) and anxiety (50.6% vs. 14.1%, $p < .001$) compared to those without food insecurity. Food insecure subjects were more likely to have a worsening of their mental health during the pandemic (53.1%) compared to before the pandemic (44.3%), while there was little change in food secure subjects during the pandemic (16.2%) compared to before the pandemic (13.9%).

4 | DISCUSSION

In this cross-sectional study of the impact of the COVID-19 pandemic on households with CF, we found that food insecurity increased during the pandemic. Although all people with CF faced significant challenges during the pandemic, those with food insecurity had worsening mental health, weight, treatment adherence, and financial security compared to those without food insecurity.

Food insecurity among households with CF increased from 18.8% to 21.8% during the pandemic in our study. Although this was a modest increase, 5.9% of subjects that were food secure before the pandemic became food insecure during the pandemic. We found that food insecurity was more prevalent in children with CF compared to adults with CF before the pandemic and that there was a larger increase in food insecurity in the pediatric population during the pandemic.

The worsening food insecurity of people with CF during the pandemic parallels that of worsening food insecurity in the United States. The estimates for food insecurity in the United States ranged from 23% to 39% during the pandemic in 2020,^{13,19,20} which is increased from 10.5% of US households before the pandemic in 2019.⁶ Two single-center studies found an increase in food insecurity in pediatric patients living in the United States during the pandemic, increased from 10% to 30% and from 11% to 31% respectively.^{21,22}

Increased food insecurity during the pandemic has also been reported in other chronic diseases.^{23,24}

The etiologies for increased food security were multifactorial but seemed to be primarily financial. More food insecure subjects reported loss of employment, decreased household income, or difficulty obtaining food due to finances compared to food secure subjects. Unfortunately, this is a new group of CF patients and families experiencing financial hardships and potentially poverty. Financial assistance during the pandemic has been shown to decrease food insecurity.²⁵ We did find that 3% of our subjects switched from food insecure to secure during the pandemic, which may be due to increased government financial assistance during the pandemic, but the reason for the change in status was not specifically determined. We also found that food insecure subjects were also more likely to have difficulty obtaining food due to limited food supply in stores.

Of the households that experienced food insecurity, only 45.7% of those households had food assistance during the pandemic. Thus, over 50% of families who were food insecure did not receive any aid. This was higher than we expected given the resources available to people with CF and their families, including nutritionists and social workers who are integral members of the CF care team. These findings highlight the need for universal screening for food insecurity in CF clinics, and for providing resources regarding food banks or food assistance programs at every CF visit. Alarming, we found that almost a third of food insecure people with CF had weight loss during the pandemic. This is worrisome as weight and nutritional status are closely associated with pulmonary function.²⁶

In our study, people with CF had more difficulty taking care of themselves during the pandemic if they were food insecure. Food insecure people with CF were more likely to have worse medication adherence, worse airway clearance adherence, and difficulty obtaining their CF medications. We did not find any differences in CF clinic attendance by food security status, but given the worse treatment adherence, food insecure patients may benefit from closer follow-up with their CF care team. In contrast to our findings, a study of people with CF in Belgium found improved mucus clearance, increased medication adherence, and better quality treatments during the pandemic.²⁷ The difference in outcomes may be due to the timing of the studies: the Belgium study was conducted at the beginning of lockdown, while our study was conducted further into the pandemic when food insecurity was more prevalent. Given these disparate findings, it remains inconclusive if the pandemic worsened the association of decreased adherence and food insecurity in the CF population. However, our findings are consistent with studies in other diseases that show that food insecurity is associated with poor adherence^{28,29} and that this association was worse during the pandemic.^{24,30} The decreased treatment and medication adherence are concerning as adherence is an important prognostic indicator for likelihood of having a CF-related hospitalization or ED visit.³¹

Mental health worsened in people with CF and their families during the pandemic. Depression, anxiety, and abnormal mental health screens all increased during the pandemic in our study. Prior studies of mental health changes during the pandemic in the CF population have mixed findings. A study of people with CF in Belgium found that people

with CF and parents of children with CF had increased stress and depressive symptoms.²⁷ In a matched study of children in the United Kingdom, there was decreased anxiety in children with CF compared to healthy children during the pandemic, however, mothers of children with CF had increased anxiety compared to mothers of healthy children.³² A study of adults with CF in the United Kingdom found increased anxiety but no change in depression.³³ A study of adults with CF in Italy matched to the general population found lower levels of psychological distress, lower levels of anxiety, and no difference in depression in adults with CF.³⁴ These studies were all conducted in other countries with different socioeconomic and cultural safety nets than the United States and were conducted very early in the pandemic, while our study was conducted further into the pandemic, which might explain the discordant results.

In our study population, there was a much larger increase in depression, anxiety, and abnormal mental health screens among food insecure subjects compared to food secure subjects, with over 50% of food insecure households reporting mental health challenges. Although food insecurity is associated with poor mental health in the general population, to our knowledge, this is the first study to evaluate the association of food insecurity with mental health problems among people with CF.^{35,36} Further studies in the CF population are needed after the pandemic to understand if the association of poor mental health and food insecurity continue to be negatively impacted by the pandemic. There are likely other social determinants of health, such as poverty, that contribute to both poor mental health and food insecurity. Because there is a cyclical reinforcing relationship between poor mental health and food insecurity,⁸ it is important to evaluate for both poor mental health and food insecurity in CF clinic visits to break this cycle.

This study adds to the available data informing healthcare providers of the prevalence of food insecurity and psychosocial challenges among households with an individual with chronic diseases, especially during periods of crisis that may be missed if not appropriately screened for during clinical visits. Time needs to be allotted during visits for universal screening for food insecurity in conjunction with mental health screening so that appropriate resources can be provided to families.

5 | LIMITATIONS

One limitation of our study is recall bias for prepandemic food insecurity and mental health as it may fluctuate over time. With recall bias, there is the potential to answer questions about before the pandemic more positively. Another limitation was that this was a one-time questionnaire that was administered over 10 months. During this time, the pandemic impact was changing and local guidelines varied across the United States, which altered the experiences our subjects faced and altered the responses of our subjects. There could be self-reporting biases as these questionnaires were completed anonymously, and the accuracy of individual responses cannot be verified. We also only asked if weight changed (increased/decreased) during the pandemic but did not ask for specific weight data before and during the pandemic so responses cannot be verified. Households with food insecurity or poor mental health may have a more negative view of their health overall and may over-report weight loss. Medication and airway adherence were assessed with a categorical variable and

not a validated instrument, which limits the reliability of the results. Another limitation is that we did not have a control group from the general population for comparison in our study.

Unfortunately we had a low response rate from racial and ethnic minority patients, despite efforts to target a diverse population, including Spanish translation. Therefore, our findings are not generalizable to all patients with CF. Additionally, our use of social media recruitment may have led to selection bias as a majority of our subjects had a college degree or higher. This is particularly unfortunate as the pandemic had a more negative impact in racial or ethnic minorities compared to the general population.^{37,38} Despite these limitations, our study identified areas that need to be addressed by CF care teams, including food insecurity screening and support, mental health screening and support, and ongoing education on CF self-care to improve health outcomes for people living with CF.

6 | CONCLUSION

The COVID-19 pandemic has disproportionately impacted people with CF and their families with food insecurity compared to those who were food secure. The long-term effects of the COVID-19 pandemic in the CF community continue to be unknown, but the findings of significantly increased financial and mental health burdens on patients with CF who have food insecurity are concerning and deserve close follow-up. Ongoing studies are needed to evaluate the long-term effects of food insecurity on mental health and clinical outcomes postpandemic.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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TABLE 1

Subject characteristics by during pandemic food security

	All subjects	Food insecure	Food secure
Number (%)	372	81 (21.8%)	291 (78.2%)
Subject type			
Adult with CF	247 (66.4%)	47 (19.0%)	200 (81.0%)
Child with CF	125 (33.6%)	34 (27.2%)	91 (72.8%)
Sex			
Male	124 (33.3%)	23 (28.4%)	101 (34.7%)
Female	245 (65.9%)	57 (70.4%)	188 (64.6%)
Declined	3 (0.8%)	1 (1.2%)	2 (0.7%)
Race and ethnicity			
Non-Hispanic White	336 (90.3%)	75 (92.5%)	261 (89.7%)
Hispanic	26 (7.0%)	3 (3.7%)	23 (7.9%)
Other race, multiracial	10 (2.7%)	3 (3.7%)	7 (2.4%)
Insurance			
Private	236 (63.4%)	33 (40.7%)	203 (69.7%)
Medicaid medicare	95 (25.5%)	37 (45.6%)	58 (19.9%)
Other	41 (11.0%)	11 (13.6%)	30 (10.3%)
Household education			
High School	43 (11.6%)	13 (16.1%)	30 (10.3%)
Some College	73 (19.6%)	27 (33.3%)	46 (15.8%)
College Degree	157 (42.2%)	32 (39.5%)	125 (43.0%)
Advanced Degree	99 (26.6%)	9 (11.1%)	90 (30.9%)

Abbreviation: CF, cystic fibrosis.

TABLE 2

Food insecurity before pandemic and during pandemic

	<u>During pandemic</u>		Total
	Food secure	Food insecure	
Before pandemic			
Food secure	280 (75.3%)	22 (5.9%)	302 (81.2%)
Food insecure	11 (3.0%)	59 (15.9%)	70 (18.8%)
Total	291 (78.2%)	81 (21.8%)	372 (100%)

Note: p < .001.

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TABLE 3

COVID-19 pandemic experience by food insecurity

	Food insecure	Food secure	<i>p</i> value
Number	81	291	
Subject type			.07
Adult with CF	47 (58.0%)	200 (68.7%)	
Parent/guardian of child with CF	34 (42.0%)	91 (31.3%)	
COVID-19 pandemic factors			
Patient diagnosed with COVID-19	3 (3.7%)	12 (4.1%)	.9
Under shelter -in-place	37 (45.7%)	146 (50.2%)	.5
Decreased household income	49 (60.5%)	68 (23.4%)	<.001
Became unemployed	37 (45.7%)	47 (16.2%)	<.001
Nutrition			
Difficulty obtaining food	67 (82.7%)	71 (24.4%)	<.001
Required food assistance	37 (45.7%)	12 (4.1%)	<.001
Reported weight loss	26 (32.1%)	38 (13.1%)	<.001
CF care and treatment			
Difficulty obtaining medications	14 (17.3%)	16 (5.5%)	<.001
Decreased medication adherence	10 (12.4%)	5 (1.7%)	<.001
Decreased airway clearance	11 (13.6%)	17 (5.8%)	<.001
Did not have CF appointment	10 (12.4%)	51 (17.5%)	.3

TABLE 4**Mental health prepandemic and during pandemic**

	Food insecure prepandemic	Food secure prepandemic	p value
Number (%)	70 (18.8%)	302 (81.2%)	<.001
Mental health prepandemic			
Anxiety	31 (44.3%)	35 (11.6%)	<.001
Depression	23 (32.9%)	27 (8.9%)	<.001
Positive mental health screen	31 (44.3%)	42 (13.9%)	<.001
	Food insecure during pandemic	Food secure during pandemic	
Number (%)	81 (21.8%)	291 (78.2%)	
Mental health during pandemic			
Anxiety	41 (50.6%)	41 (14.1%)	<.001
Depression	30 (37.0%)	35 (12.0%)	<.001
Positive mental health screen	43 (53.1%)	47 (16.2%)	<.001