Impact of COVID-19 on social determinants of health for adults with cystic fibrosis

Dana Albon, Heather Bruschwein^D, Morgan Soper, Rhonda List, Deirdre Jennings, Lucy Gettle, Martina Compton, Molly Bailey, Elissa Starheim, Rachel Murray, John Kalmanek and Lindsay Somerville

Abstract

Introduction: Outcomes in cystic fibrosis are influenced by multiple factors, including social determinants of health. Low socioeconomic status has been shown to be associated with lung function decline, increased exacerbation rates, increased health care utilization, and decreased survival in cystic fibrosis. The COVID-19 pandemic disrupted the US economy, placing people with cystic fibrosis at risk for negative impacts due to changes in social determinants of health.

Methods: To characterize the impact of COVID-19-related changes in social determinants of health in the adult cystic fibrosis population, a social determinants of health questionnaire was designed and distributed to patients as part of a quality improvement project.

Results: Of 132 patients contacted, 76 (57.6%) responses were received. Of these responses, 22 (28.9%) answered yes to at least one question that indicated an undesired change in social determinants of health. Patients with stable employment prior to COVID-19 were more likely to endorse undesired change in all domains of the questionnaire, and the undesired changes were most likely to be related to employment, insurance security, and access to medications. Patients receiving disability were more likely to report hardship related to utilities and food security compared with patients previously employed or unemployed. Of patients endorsing risk of socioeconomic hardship, 21 (95.5%) were contacted by a social worker and provided resources.

Conclusion: Utilizing a social determinants of health questionnaire to screen for social instability in the context of COVID-19 is feasible and beneficial for patients with cystic fibrosis. Identifying social issues early during the pandemic and implementing processes to provide resources may help patients with cystic fibrosis mitigate social hardship and maintain access to health care and medications.

Keywords: COVID-19, cystic fibrosis, social determinants of health, social issues, socioeconomic status

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Introduction

Cystic fibrosis (CF) is an autosomal recessive systemic disorder primarily characterized by respiratory disease. Mortality and morbidity in CF are influenced by multiple genetic and nongenetic factors. Over the past 10 years, CF survival has increased; however, among patients with similar genotypes, outcomes can differ greatly due to socioeconomic factors.^{1,2} Social determinants of health (SDH) are 'conditions in the places where people live, learn, work, and play that affect a wide range of health risks and outcomes'.³ The Centers for Disease Control and Prevention (CDC) further delineates SDH into five key areas: health care access and quality, economic stability, education access and quality, social and community context, and neighborhood/environment.³ Ther Adv Respir Dis

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SDH have been found to impact the outcomes of patients with CF, even from a young age. Differences in weight, lung function, and survival have been noticed in children with CF from different socioeconomic backgrounds despite similar prescriptions of CF medications. Lower socioeconomic status (SES) has been associated with increased pulmonary exacerbations, disease severity, increased antibiotic requirements, greater health care utilization, and decreased quality of life and survival in CF.1,2,4-9 Disparities in access to health care based on access to insurance have been attributed to differences in CF outcomes between the United States and Canada. A 41% lower risk of death in Canada compared with the United States has been shown, but when adjusted for private insurance, there was no difference in CF survival.¹⁰ The gap in survival widened to 44% when compared with Medicaid/ Medicare insurance and to 77% when compared with no insurance or unknown insurance status in the CF population in the United States.¹⁰

During the COVID-19 pandemic, large disruptions in the economy and changes in SES occurred that could negatively impact health outcomes of people with CF. Between March and April of 2020, the time during which this project occurred, 22 million people applied for unemployment in United States, independent of education and median household income.¹¹ As a result, we are facing socioeconomic hardship even in patients with high-level education and previously robust SES; this may lead to self-care disruptions, chronic disease instability, and increased health care utilization and hospitalizations in a health care system already weakened by the pandemic. Patients with known socioeconomic hardship, low income, and housing and food instability are even more vulnerable to economic turmoil. Consideration of SDH during COVID-19 cannot be overlooked, and there is a growing call for prioritization of policies, public initiatives, and research related to this area.^{12,13}

Aim

This project sought to investigate and describe the impact of the COVID-19 pandemic on SDH in our adult CF patient population. We sought to understand the new social environment and facilitate access to assistance resources to minimize disruptions in health insurance, health care and access to medications, and other domains.

Methods

Intervention

A COVID-19-specific SDH questionnaire was designed and distributed by an adult CF multidisciplinary team at an academic health center in the Southeastern United States as part of a quality improvement project. The questionnaire was distributed to adults with CF who had been seen in the CF clinic in 2019 and 2020 (Figure 1). The questionnaire administration and follow-up occurred between March and April, 2020. Most

Table 1	Ι.	Social	determinants	of	health	questionnaire.
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Domains	Questionnaire item	Response ^a
Housing	 Has your housing situation changed due to COVID-19? (for example, you cannot afford rent/mortgage or you are facing eviction/foreclosure) 	Yes or No
Employment security	2a. Have you lost your job due to COVID-19?	Yes or No
	2b. Are you concerned about losing your job due to COVID-19?	Yes or No
Health insurance	3a. Have you lost your insurance as a result of COVID-19?	Yes or No
	3b. Are you concerned about losing your insurance due to COVID-19 job loss or other financial reasons?	Yes or No
Transportation	 Has your transportation been affected due to COVID-19? (for example, you no longer have access to a car or driver) 	Yes or No
Utilities	5. Are you concerned that your utilities (gas, water, electricity) will be shut off in the next few weeks?	Yes or No
Food security	6a. Are you able to afford enough food to feed yourself and your family?	Yes or No
	6b. Are you concerned that in the next few weeks you will no longer be able to afford food?	Yes or No
Access to CF medication	7. Are you concerned that you will not be able to afford or access your CF medications (i.e. Pulmozyme, ivacaftor/tezacaftor, ivacaftor/tezacaftor/elexacaftor, etc.) in time for your next refill?	Yes or No
CF, cystic fibrosis; SDH, so	ocial determinants of health.	

^aResponses in bold italic indicate an undesired change in SDH.

patients received the questionnaire through the electronic medical record (EMR) patient portal known as MyChart. Patients not enrolled in MyChart were contacted by phone or secure email. The QI methodology of plan-do-study-act (PDSA) cycles was utilized. Data were collected by the CF multidisciplinary team and stored on a Health Insurance Portability and Accountability Act (HIPAA)-compliant, organization-maintained health system server. Institutional review board (IRB) approval was waived per the institution's policies.

The SDH questionnaire (Table 1) included seven domains: housing, employment, health insurance, transportation, utilities, food security, and access to CF-specific medications. It was designed as an easy-to-answer yes or no questionnaire; 'Yes' answers were considered affirmative for questions 1, 2a, 2b, 3a, 3b, 4, 5, 6b, and 7 and 'No' considered affirmative for question 6a. An affirmative answer indicated an undesired change in SDH or risk of socioeconomic hardship and prompted a contact from the CF team social worker. The social worker contacted patients by phone, MyChart, secure email, or in person during clinic appointments and provided resources related to the patient's particular concerns.

Participants

Patients who had attended CF clinic appointments in 2019 and 2020 were sent the questionnaire between March and April 2020. All participants were at least 18 years old.

Results

Demographics

The CF multidisciplinary team contacted 132 (94.3%) of 140 patients who had attended appointments in the adult CF clinic in 2019 and 2020 and received responses from 76 (57.6%) patients; eight patients could not be reached because they did not have an active MyChart or had a nonfunctional phone number in their EMR (Figure 1). The demographic distribution of patients who answered the questionnaire was similar to that of the entire adult CF clinic

Table 2. Patient of	demographics.
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	All clinic patients (<i>N</i> = 132) <i>n</i> (%)	Patients who answered questionnaire ($N = 76$) n (%)
Sex		
Women	69 (52.3)	44 (57.9)
Lung disease severity ^a		
Normal (FEV1 \ge 90%)	31 (23.7)	20 (26.7)
Mild (FEV1 \ge 70% < 90%)	45 (34.4)	28 (37.3)
Moderate (FEV1 \geq 40% <70%)	41 (31.3)	20 (26.7)
Severe (FEV1 $<$ 40%)	14 (10.7)	7 (9.3)
Employment status		
Unemployed	13 (9.8)	9 (11.8)
Employed	66 (50.0)	40 (52.6)
Disability	42 (31.8)	22 (28.9)
Retired	4 (3.0)	3 (3.9)
Student	7 (5.3)	2 (2.6)
Age (mean \pm SD)	34.9 ± 11.9	36.4 ± 12.4
Health insurance status		
Uninsured	4 (3.0)	3 (3.9)
Medicaid/Medicare	50 (37.9)	27 (35.5)
Private	78 (59.1)	46 (60.5)
Education level		
High school or less	67 (50.8)	35 (46.1)
College or higher	65 (49.2)	41 (53.9)

FEV1, forced expiratory volume in 1 s.

^aOne patient unable to perform pulmonary function tests (PFTs) due to cognitive impairment; *N* equals 131 and 75, respectively.

population, and the sample group of respondents was considered representative of the target population, adults with CF seen in this CF clinic (Table 2).

SDH questionnaire results

Out of 132 patients contacted by the team, 76 (57.6%) responses were received (Table 3). The majority of responses (93.4%) were received via

phone, email, or MyChart, and five patients were interviewed during clinic visits. The parent of one patient with cognitive impairment completed the questionnaire on behalf of the patient.

Of 76 patients who responded to the questionnaire, 22 (28.9%) answered at least one question affirmatively. Multiple affirmative answers were endorsed by 10 patients (13.2%); eight of these patients reported that they lost their job, lost Table 3. SDH questionnaire items and responses.

Questions	Affirmative answers (N = 76) n (%)
Housing	4 (5.3)ª
Has your housing situation changed due to COVID-19?	4 (5.3)
Employment security	20 (26.3)
a. Have you lost your job due to COVID-19?	9 (11.8)
b. Are you concerned about losing your job due to COVID-19?	11 (14.5)
Insurance security	6 (7.9)
a. Have you lost your insurance as a result of COVID-19?	1 (1.3)
b. Are you concerned about losing your insurance due to COVID-19 job loss or other financial reasons?	5 (6.6)
Transportation	2 (2.6)
Has your transportation been affected due to COVID-19?	2 (2.6)
Utilities	5 (6.6)
Are you concerned that your utilities (gas, water, electricity) will be shut off in the next few weeks?	5 (6.6)
Food security	13 (17.1)
a. Are you able to afford enough food to feed yourself and your family?	6 (7.9)
b. Are you concerned that in the next few weeks you will no longer be able to afford food?	7 (2.6)
Medication access	5 (6.6)
Are you concerned that you will not be able to afford or access your CF medications in time for your next refill?	5 (6.6)
Any affirmative answer	22 (28.9)
CF, cystic fibrosis; SDH, social determinants of health. ªBold italic font represents cumulative affirmative answers for each domain.	

insurance, or were concerned about losing their insurance and reported either housing or food insecurity or both. The other two patients who answered affirmatively to more than one question were only concerned about future possible impacts. The domains most endorsed were employment and food security; over a quarter of respondents (26.3%) reported that they either lost their job or were concerned of losing their job and 17.1% reported concerns related to affording food at the time of administration of questionnaire or after. Fewer patients reported concerns regarding insurance coverage (7.9%), medication access (6.6%), utilities (6.6%), and transportation (2.6%). All patients unemployed prior to the COVID-19 pandemic had health insurance; five out of nine (55.6%) had private insurance and four out of nine (33.3%) had Medicaid/Medicare (Table 4). Most were married or in a stable relationship and had additional financial family support. Their social situation did not change significantly during the COVID-19 pandemic, with most change and hardship being related to partner/family social stability. All patients receiving disability prior to COVID-19 also had health insurance coverage (18.2% private insurance, 81.8% Medicaid/Medicare) and thus less likely to report insurance instability.

	Unemployed (<i>N</i> = 9) <i>n</i> (%)	Employed (N = 40) n (%)	Disability (N = 22) n (%)	Retired (N = 3) n (%)	Student (N = 2) n (%)
No insurance	0 (-)	2 (5.0)	0 (-)	0 (-)	0 (-)
Medicare/Medicaid	4 (44.4)	2 (5.0)	18 (81.8)	3 (100)	1 (50.0)
Private	5 (55.6)	36 (90.0)	4 (18.2)	0 (-)	1 (50.0)

 Table 4. Pre-COVID-19 employment status categorized by health insurance status.

Table 5. SDH questionnaire affirmative responses categorized by pre-COVID-19 status of employment, health insurance, and education level.

	Employment					Health insurance			Education	
	Unempl (N = 9) n (%)	Empl (N = 40) n (%)	Disability (N = 22) n (%)	Retired (N = 3) n (%)	Student (N = 2) n (%)	No ins (N = 3) n (%)	Mcare/ caid (N = 27) n (%)	Private (N = 46) n (%)	HS or less (N = 35) n (%)	College+ (N = 41) n (%)
Q1 (<i>N</i> = 4)	1 (11.1)	0 (-)	3 (13.7)	0 (-)	0 (-)	0 (-)	3 (11.1)	1 (2.2)	2 (5.7)	2 (4.9)
Q2a (N = 9)	0 (-)	5 (12.5)	3 (13.7)	0 (-)	1 (50.0)	0 (-)	4 (14.8)	5 (10.9)	6 (17.1)	3 (7.3)
Q2b (N = 13)	0 (-)	10 (25.0)	2 (9.1)	0 (-)	1 (50.0)	0 (-)	1 (3.7)	12 (26.1)	5 (14.3)	8 (19.5)
Q3a (N = 1)	0 (-)	1 (2.5)	0 (-)	0 (-)	0 (-)	0 (-)	1 (3.7)	0 (-)	1 (2.9)	0 (-)
Q3b ($N = 5$)	0 (-)	4 (10.0)	1 (4.5)	0 (-)	0 (-)	0 (-)	0 (-)	5 (10.9)	2 (5.7)	3 (7.3)
Q4 (N = 2)	1 (11.1)	0 (-)	1 (4.5)	0 (-)	0 (-)	0 (-)	1 (3.7)	1 (2.2)	2 (5.7)	0 (-)
Q5 (N = 5)	0 (-)	2 (5.0)	3 (13.7)	0 (-)	0 (-)	0 (-)	4 (14.8)	1 (2.2)	4 (11.4)	1 (2.4)
Q6a (N = 6)	1 (11.1)	2 (5.0)	3 (13.7)	0 (-)	0 (-)	0 (-)	4 (14.8)	2 (4.3)	5 (14.3)	1 (2.4)
Q6b (N = 7)	1 (11.1)	3 (7.5)	3 (13.7)	0 (-)	0 (-)	0 (-)	5 (18.5)	2 (4.3)	6 (17.1)	1 (2.4)
Q7 ($N = 5$)	0 (-)	4 (10.0)	1 (4.5)	0 (-)	0 (-)	1 (33.3)	2 (7.4)	2 (4.3)	3 (8.6)	2 (4.9)

Empl, employed; HS, high school; ins, insurance; Mcare/caid, Medicare/Medicaid; Q, question; SDH, social determinants of health; Unempl, unemployed.

Patients who were employed prior to COVID-19 were more likely to answer affirmatively to the SDH screening in all domains, as 37.5% responded affirmatively to at least one question versus 25.0% of unemployed patients and 21.1% of patients receiving disability. Affirmative answers endorsed by patients employed prior to COVID-19 were more likely to be related to loss of employment, concern for loss of employment, insurance security, and access to medications (25.0%, 12.5%, 10%, and 10.0%, respectively) (Table 5). Patients receiving disability were more likely to report hardship related to ability to afford utilities (13.7%) and food security (15.8%) when compared with patients employed prior to COVID-19 (5.0% and 7.5%, respectively) or unemployed (11.1% and 11.1%, respectively) (Table 5). One patient enrolled in school reported loss of employment and concern for employment. No retired patients reported social hardship in context of COVID-19.

Patients insured by Medicaid/Medicare were more likely to report a change in housing, and financial hardship in relationship to utilities and food stability, while patients insured by private payors prior to COVID-19 were more likely to report concern related to losing employment and

	Table 6.	Social	work	response	to	undesired	change	in SDH.
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Domain	Response or resource provided by social worker
1. Housing	 Housing stability was assessed for all patients Discussed available resources/currents laws and policies that protect patients from eviction Information on regional shelter availability was provided to homeless patients
2. Employment	 Unemployment application and stimulus package forms were made available for patients Letters for support for work from home were made available
3. Insurance	 Provided assistance with Medicaid, COBRA, and alternative insurance plan application and federally supported insurance Compass^a information was made available to inquire for additional support
4. Transportation	 Transportation assistance discussed with patients who could become ensured through Medicaid Compass^a information was made available to inquire for additional support, as limited transportation assistance exists in the community
5. Utilities	 Letters for support offered for electricity maintenance <i>Compass</i>^a information was made available to inquire for additional support
6. Food security	 Supplemental Nutrition Assistance Program (SNAP) resources were provided Regional resources provided depending on patient residence
7. Medication access	 Patient assistance forms for medications were offered to patients who could no longer afford CF-specific therapies
CE cyctic fibrocic, COBRA	Consolidated Omnibus Rudget Reconstitution Act, SDH, social determinants of health

CF, cystic fibrosis; CUBRA, Consolidated Umnibus Budget Reconciliation Act; SDH, social determinants of health. *Compass* is the Cystic Fibrosis Foundation's patient assistance service offered free of charge for persons with CF. Additional information can be found at https://www.cff.org/Assistance-Services/About-Compass/What-Is-Compass/.

health insurance (Table 5). Only one patient who was uninsured reported social hardship (CF-specific medication access).

Patient employment status was affected by the COVID-19 pandemic similarly across education level, as patients with both some high school education (14.3%) and some college education (19.5%) reported employment insecurity and patients in both education levels lost employment (Table 5).

Regarding age, employed patients had a mean age of 35.1 (n = 40, SD = 10.5), compared with 28.8 for unemployed (n = 9, SD = 7.2), 39.7 for those receiving disability (n = 22, SD = 12.4), 63.7 for retired (n = 3, SD = 6.1), and 21.5 for student patients (n = 2, SD = 2.1). Uninsured patients had a mean age of 31.3 (n = 3, SD = 3.5), compared with 39.4 for those with Medicaid/Medicare (n = 27, SD = 15.3) and 35.0 for private insurance (n = 46, SD = 10.6). The CF team social worker attempted to contact all patients who answered affirmatively to any question to provide support and resources (Table 6) and was able to reach 21 of 22 patients (95.5%). The social worker contacted 4 patients by phone (18.2%), spoke in clinic with 5 patients (22.7%), and shared resources via MyChart with 12 patients (54.5%) who answered any question affirmatively. One patient (4.5%) could not be reached by phone or MyChart after multiple attempts. No patient previously on cystic fibrosis transmembrane conductance regulator (CFTR) modulators, a CF-specific medication, lost access to these medications.

Discussion

There are increasing calls for consideration and examination of SDH during COVID-19. Sharma and colleagues¹⁴ surveyed the effect of COVID-19 on low-income households with children and found that over half reported concerns about financial stability, food availability, and food insecurity; almost half reported employment concerns; and approximately one-third endorsed housing and health care access concerns. Associations between race or ethnicity and low SES and increased occurrence of COVID-19 and related hospitalizations have been found,¹⁵ as well as higher occurrence of COVID-19, increased mortality, and a higher prevalence of

chronic health conditions in economically vulnerable areas.^{16,17}

While research on the impact of COVID-19 on SDH has increased, little is known regarding effects on specific patient populations, including chronic disease. A survey by Singh and colleagues¹⁸ found that the COVID-19 pandemic severely impacted people with chronic health conditions in India, including difficulty accessing health care and medications, loss of income, and loss of employment. Although our findings also indicated an impact on SDH during COVID-19, it is difficult to compare the two results due to significant differences in the health care systems and governments of India and the United States. While this existing research is much needed and highlights the socioeconomic and health vulnerabilities of chronic disease populations, there is no research to date examining the impact of COVID-19 on SDH in specific chronic disease populations, including CF.

As of 24 June 2021, the Cystic Fibrosis Foundation (CFF) reported 1542 known cases of COVID-19 in patients with CF in the United States (1097 adult, 445 pediatric; Bruce C. Marshall, M.D., CFF Executive Vice President and Chief Medical Officer, email communication, 24 June 2021). The socioeconomic stability of patients with chronic disorders like CF is threatened by the need for social distancing and economic changes in the era of COVID-19; however, social distancing is paramount in protecting the health of those with chronic disorders who are at higher risk of morbidity and mortality due to infections. In addition, patients with CF have increased risk of complications if they develop a pulmonary exacerbation related to respiratory viruses, including COVID-19. Some of the adults with CF followed up in our clinic were not provided the ability to work from home to observe social distancing and as a result, were either released from their duties or quit their jobs to avoid unnecessary exposure to COVID-19. A total of nine patients (11.8%) reported job loss at the time of the questionnaire and an additional 11 (14.5%) reported concern about losing their job in the near future. Patients with both high school and college levels of education reported similar concerns related to job security in the context of COVID-19.

Workers across the United States have experienced furloughs and unemployment during COVID-19. As of May 2021, there were 9.3 million unemployed persons in the United States (in February 2020 prior to COVID-19, there were 5.7 million unemployed persons).¹⁹ Over 25% of the patients who responded to the questionnaire endorsed loss of employment or concern for loss of employment. It is not surprising that we identified high unemployment rates in our patient population; however, unemployment for people with CF can quickly lead to uncontrolled respiratory disease, decline in lung function, and increased exacerbation rates when associated with loss of insurance benefits and access to health care and medications. This area is a priority for interventions to assist this population.

Most of the patients with CF who reported changes in housing were able to maintain stable housing by moving in with family or friends. However, for the few patients who experienced homelessness, affordable housing resources were scarce and social distancing in shelters was difficult to achieve. Multiple interventions were implemented by local organizations and coalitions to support the people who experience homelessness in urban areas. However, for patients who reside in rural areas and depend on family for emotional and social support, moving to a nearby city for shelter is not feasible.

This CF team's goal is to provide equitable care to all patients with CF and to identify early barriers to health care that can be overcome with assistance from the team and CF community. Through this questionnaire, we were able to identify social changes and rapidly intervene for mitigation of social hardship, providing resources to over 95% of the patients who endorsed risk of socioeconomic hardship. The CFF has also provided people with CF with multiple resources and programs that address social issues. However, some patients have not yet returned to clinic since the onset of COVID-19 and have not answered multiple contact attempts to schedule a clinic visit either through telemedicine or in person. There is concern that these patients are undergoing social hardship that prohibits them from reaching out for health care. In addition, these patients may not be aware of existing resources or feel comfortable asking for help. It is unclear how to reach these patients or how to identify if help is needed. This was a limitation of the study, and additional research in this area is greatly needed.

A quality improvement process for delivery of an SDH screening questionnaire was designed and successfully implemented in our clinic, and we continue to offer the questionnaire during patient visits. This questionnaire has the potential to impact health care beyond this clinic, as it can be utilized by other CF centers, clinics who deliver care for patients with other chronic conditions, and in the primary care setting. This was a singlecenter quality improvement project, and future research should include multicenter and long-term data collection regarding impact of COVID-19 on SDH in patients with CF and other chronic disease populations. In addition, future research should include a focus on programs and public policies that may be beneficial in mitigating the effects of changes in SHD on vulnerable populations, including patients with chronic diseases such as CF; the use of control groups; and comparison of CF patients to the general population's experience during COVID-19 to better understand the impact on SDH specific to the CF population.

Conclusion

Screening for social hardship in chronic disorders like CF is feasible and important in the context of COVID-19 socioeconomic changes. Understanding the disruptions in patients' SDH during the pandemic allows for early interventions and mitigation to minimize disruptions in health care and ensure continuity in health insurance, access to health care, housing, and food stability.

Conflict of interest statement

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Supplemental material

Supplemental material for this article is available online.

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