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journal homepage: www.elsevier.com/locate/jcfTelehealth use in cystic fibrosis during COVID-19: Association with race, ethnicity, and socioeconomic factors[☆]

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ABSTRACT

Background: Due to the COVID-19 pandemic, there was an uptake of telehealth in cystic fibrosis care. Previous studies show disparities in telehealth use based on socioeconomic status (SES). We aimed to: (1) understand telehealth use and perceptions and (2) identify the facilitators and barriers to telehealth use among people with CF and their families (PwCF) from diverse racial/ethnic and socioeconomic backgrounds.

Methods: We conducted an analysis of the 2020 Cystic Fibrosis State of Care surveys completed by PwCF (PFSoc), CF Care Programs (SoC1) and the CF Foundation Patient Registry (CFFPR).

Results: A total of 424 PwCF and 286 programs responded to the PFSoc and SoC1. Among PwCF, 90% self-identified as White, 6% as Hispanic/Latino, and 2% as Black. Racial/ethnic minorities were less likely to have had a telehealth visit ($p=.015$). This difference was pronounced among the Hispanic/Latino population ($p<.01$). Telehealth use did not differ by health insurance and was similarly offered independent of financial status. Compared to PwCF who denied financial constraints, those who reported financial difficulties found telehealth more difficult to use ($p=.018$) and were less likely to think that their concerns ($p=.010$) or issues that mattered most to them ($p=.020$) were addressed during telehealth. Programs perceived lack of technology, language barriers, and home conditions as barriers to telehealth in vulnerable populations.

Conclusion: PFSoc and SoC1 identified differences in telehealth use and care perceptions by ethnicity, race, and socioeconomic characteristics. Further studies are needed to understand how telehealth can change access to CF care in diverse subpopulations.

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Abbreviations: CF, Cystic Fibrosis; CFCP, CF Care Program; CFF, Cystic Fibrosis Foundation; CFFPR, Cystic Fibrosis Foundation Patient Registry; CFTR, Cystic fibrosis transmembrane conductance regulator; PFSoc, Patient and Family CF State of Care Survey; PwCF, People with CF and families of patients with CF; SoC1, CF Care Program State of Care Survey Version 1 2020; TDI, The Dartmouth Institute for Health Policy & Clinical Practice; SARS-CoV-2, Severe Acute Respiratory Syndrome Due to Coronavirus 2; SES, Socioeconomic Status; TH, Telehealth.

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1. Introduction

As the cystic fibrosis (CF) care center network rapidly adopted telehealth during the COVID-19 pandemic [1], concerns were raised regarding further exacerbation of racial/ethnic and socioeconomic status (SES) disparities [2–10]. In the general population, racial/ethnic minorities and people with low SES experience decreased access to health care and are more likely to report lower satisfaction with the health care system [11–13]. While telehealth does not universally address all issues related to healthcare access

in these populations [14,15], it may increase access by eliminating travel time and cost and may improve patient satisfaction [16] if critical constraints are addressed to prevent telehealth from further decreasing access to care.

The 2019 CF Foundation Patient Registry (CFFPR) reports that 9.4% of people with CF (PwCF) identify as Hispanic/Latino, 4.7% as Black, and 3.8% as other non-White race [17]. PwCF from racial/ethnic minority backgrounds and/or low SES experience greater burden of disease, increased health care utilization, and worse outcomes that parallel those in the general population [2,5,6,18–20]. Socioeconomic inequities (e.g., access to financial resources, household income, parental education, social support) and adverse environmental exposures (smoking) in the CF population have been previously associated with lung function decline and increased infection rates [21,22]. In addition, survey data shows that PwCF from racial/ethnic minority backgrounds and/or low SES report lower quality of life even after adjusting for disease severity [23]. Care experience and quality of care have been previously described in PwCF, but there are limited reports that examine care delivery and experience among PwCF from minority backgrounds or those with low SES, particularly in telehealth [24].

Our objective was to understand access to and experiences with telehealth among PwCF from diverse racial/ethnic and/or socioeconomic backgrounds, as well as facilitators and barriers to use of telehealth services during the COVID-19 pandemic in these vulnerable populations. Specifically, we sought to identify whether differences in telehealth use, care quality, and barriers or facilitators are associated with racial/ethnic and socioeconomic characteristics of PwCF.

2. Methods

2.1. Data sources

Three data sources were used: (a) the Patient and Family CF State of Care Survey (PFSoc) distributed to PwCF via care programs, Community Voice newsletter, and CF Foundation (CFF) Facebook page between August 24 and October 30, 2020; (b) the CF Program State of Care Survey Version 1 (SoC1) distributed to CFF accredited centers between July 29 and September 18, 2020 [1]; and (c) the CFFPR [17]. Community Voice is a network of PwCF created by CFF. Through Community Voice PwCF can connect with each other virtually and actively shape research and programs for the CF community [25].

The PFSoc data was not linked to the SoC1 or CFFPR. SoC1 and CFFPR were linked at the program level. Information related to the racial/ethnic/socioeconomic breakdown of program respondents was not captured. Respondents of SoC1 are physician program directors.

Human subjects approval was granted by a central institutional review board (Advarra), protocol (Marshall, Pro00045302).

2.2. Variables

Independent PFSoc variables included self-identified racial or ethnic minority status and financial struggles during the COVID-19 pandemic, as defined by reported concerns paying for one or more of the following essentials: co-pays, food, housing, utilities, transportation, medication, or other care, and reported insurance status, categorized into (a) Medicare (alone or with any other insurance); (b) Medicaid (alone or with other insurance, excluding Medicare); or (c) other insurance (private, military or other insurance, excluding Medicare or Medicaid). PwCF who selected no insurance ($n=1$), preferred not to answer ($n=4$), or did not answer the question related to insurance ($n=86$) were excluded. For consistency,

we use the terms “Black” for Black or African American and “Hispanic/Latino” for Hispanic, Latino/a, or the gender-neutral Latinx. The term vulnerable population was used to include racial/ethnic minorities and/or people of low SES. We used the term minority for race and ethnicity other than non-Hispanic white. Telehealth was defined as a virtual visit conducted by phone or internet connection, with or without a video component.

Dependent PFSoc variables focused on four telehealth areas: access, quality, interest, and barriers. Telehealth access was surveyed by questions related to receipt of telehealth, mode of meeting with care team, and ease of access. Telehealth quality was surveyed by questions related to overall quality relative to in-person care; proportion of top-box responses to questions asking about concerns, shared decision-making as measured by collaboRATE [25,26], and perceptions of adequate time with provider; scheduling at a time that worked, telehealth coverage by insurance, need for a co-pay, and ability to find a quiet, private place to participate. Telehealth interest was defined as a desire for future telehealth and preference for in-person versus telehealth care. PwCF who identified lower quality of care for telehealth relative to in-person care were asked to answer another set of questions to further describe barriers of telehealth care, which included difficulty using the technology, unclear instructions, unstable connection, inability to find a quiet/private space, inability to schedule at a time that worked, visit too short, questions unanswered, lack of physical exam, lack of pulmonary function test, and lack of sputum or throat culture. Some questions overlapped with but were more detailed than previous questions asked under quality of care.

SoC1 responses were assessed across programs. Free-text responses to the question, “Sometimes a crisis creates both positive and negative effects. What effect has the use of telehealth had on disadvantaged populations?” were analyzed to identify barriers and facilitators using qualitative analysis methods.

2.3. Analytic approach

Data were summarized with descriptive statistics. Relationships between variables were determined with chi-square tests for categorical data (and, where appropriate, Fisher’s exact tests to account for small sample sizes), and Kruskal Wallis H tests for ranked data. Analyses were conducted with SPSS (version 26.0). Qualitative analyses for free-text responses were conducted with Atlas.ti (version 8.4.5). We used inductive thematic analysis to identify themes and sub-themes. All qualitative data were independently coded by two reviewers (AVC and PS). Responses between reviewers were evaluated for consensus, and discrepancies were resolved via conversation.

3. Results

3.1. Sample characteristics

The PFSoc was completed by 424 patients and the SoC1 by 286 programs. Complete demographics of PFSoc responders are reported elsewhere in this issue [1].

The characteristics of the sample are summarized in Table 1. More than 10% ($n=35$) of PFSoc respondents identified as a racial or ethnic minority, nearly 27% ($n=109$) had financial concerns as a result of the COVID-19 pandemic, and 34% ($n=116$) had public insurance. People who reported financial concerns due to the COVID-19 pandemic were more likely to identify as a racial or ethnic minority (43%, $n=15$ vs. 24%, $n=73$; $p=.017$), and were more likely to have Medicaid (41%, $n=29$) compared to Medicare (29%, $n=13$) or all other insurance types (20%, $n=40$) ($p<.001$). There was no difference in insurance type by racial/ethnic minority group. When compared to the 2020 CFFPR, PFSoc responders were more likely

Table 1
Characteristics of SoCs respondents and the 2020 CF Foundation Patient Registry.

Characteristics of SoCs responders	PFSOCs n (%)	CFFPR n (%)	p-value
Race/ethnicity SoCs			
Any racial or ethnic minority	35 (10.4%)	5270 (16.4%)	0.003*
Hispanic/Latino	22 (6.5%)	3049 (9.5%)	0.062
Black	8 (2.4%)	1434 (4.5%)	0.062
American Indian / Alaskan Native	3 (0.9%)	195 (0.6%)	Not calc.
White (excluding any racial or ethnic minority)	303 (89.6%)	26825 (83.6%)	0.003*
Concerns about paying for necessities, as a result of the COVID-19 pandemic¹			
Any financial concerns (yes)	109 (26.8%)	N/A	
Food	49 (12.1%)	N/A	
Housing	44 (10.8%)	N/A	
Utilities	47 (11.6%)	N/A	
Transportation	28 (6.9%)	N/A	
Medication	50 (12.3%)	N/A	
Co-pays	41 (10.1%)	N/A	
Other care	50 (12.3%)	N/A	
Insurance status			
Medicare	45 (13.2%)	3285 (10.2%)	0.070
Medicaid	71 (20.9%)	10707 (33.4%)	<0.001**
Other insurance	224 (65.9%)	17845 (55.6%)	<0.001**

¹ Example question: As a result of the coronavirus/COVID-19 pandemic, have you had any concerns about paying for food? See appendix for full questionnaire details.

* statistically significant p<0.05,

** p<0.01 See Methods.

to be White; in addition, PFSOC responders were less likely to have Medicaid and more likely to have private insurance than CFFPR participants (Table 1). While the PFSOC responders are a subgroup of CFFPR participants, they do not entirely represent the CFFPR population.

3.2. Racial/ethnic characteristics as a predictor of telehealth access, quality, interest, and perceived barriers

Access to telehealth: PwCF from a racial or ethnic minority group were significantly less likely to have had a telehealth visit, compared to people who identified only as White (69%, n=24 vs. 85%, n=257, p=.015). Within the Hispanic/Latino subgroup (n=22), differences in telehealth utilization were more pronounced wherein only 54% (n=12) had a telehealth visit. Within the Black subgroup (n=8), differences in mode of telehealth existed, as Black responders were less likely to have a video component of their visit compared to all others (57%, n=4 vs. 89%, n=250 p<.05). We found no statistically significant difference in the proportion of PFSOC respondents that cited that “the care team has not been in contact to schedule a telehealth visit” or “I did not want to receive care in this way”. Reasons cited by racial /ethnic minorities for no telehealth visit included: in-person visits during that time (n=5), care team has not been in contact to schedule a telehealth visit (n=3), I did not want to receive care in this way (n=3), I do not know if telehealth visits are covered by insurance (n=1), concerns about co-pays and other costs (n=1), language barriers (n=1), no health concerns (n=1), six responders did not provide an answer.

Quality of telehealth: There were no differences between reports based on race or ethnicity.

Interest in telehealth: There were no differences between reports based on race or ethnicity with respect to future desire for telehealth.

Barriers to telehealth: Two respondents (29%) who identified as a racial/ethnic minority and one (1%) who identified as White felt that their questions were not answered by the care teams (Fig. 1).

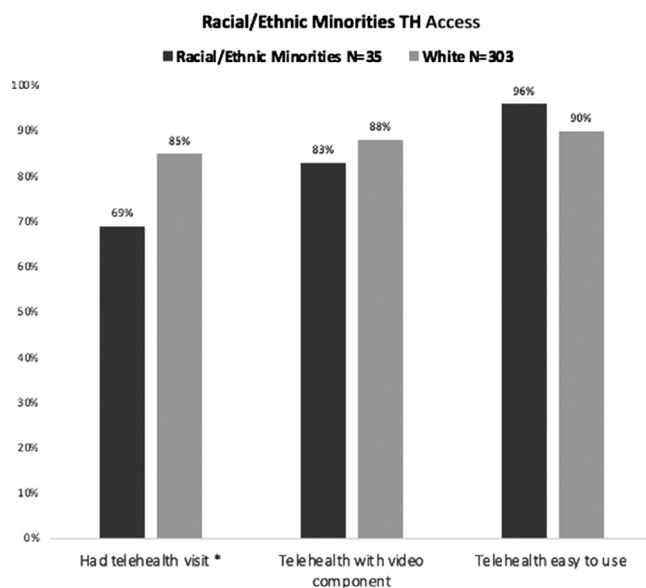


Fig. 1. Racial/Ethnic group telehealth access. TH=Telehealth, *statistically significant p<0.05

3.3. Financial impact of the pandemic as a predictor of telehealth access, quality, interest, and perceived barriers

PwCF experienced financial adversities due to COVID-19. While 28% (n=118) of respondents noted no change in employment, nearly one quarter (24%, n=102) had switched to working from home, and 20% (n=60) had reduced or eliminated their work hours (e.g., hours/salary reduced, laid off, furloughed, retired, quit, or leave of absence). One quarter of respondents (27%, n=109) reported concerns paying for essentials due to the COVID-19 pandemic, including paying for medication, other care, food, utilities, housing, and co-pays (10-12% each). There was less concern about paying for transportation (7%).

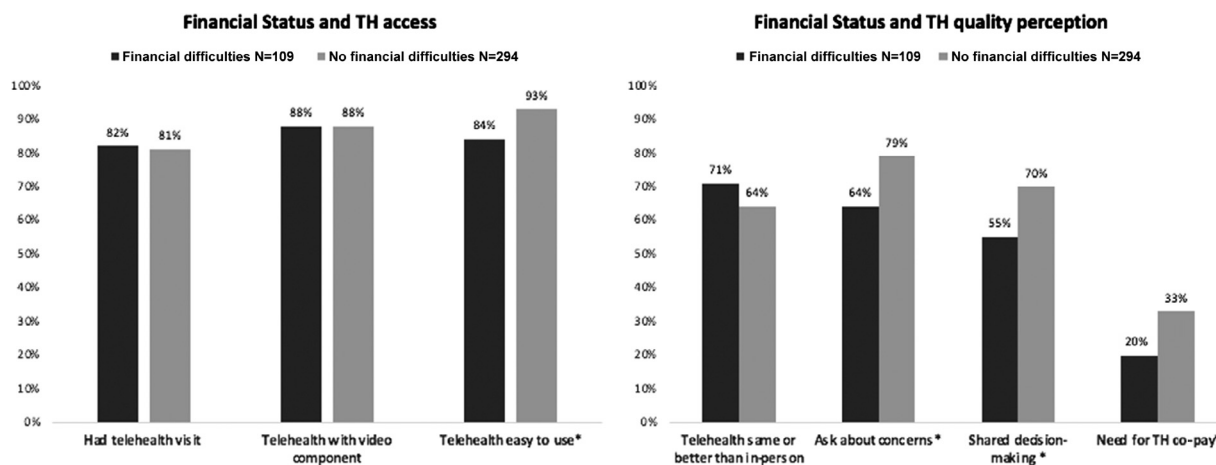


Fig. 2. PwCF financial status and telehealth access and quality perception. TH=Telehealth, *statistically significant p<0.05.

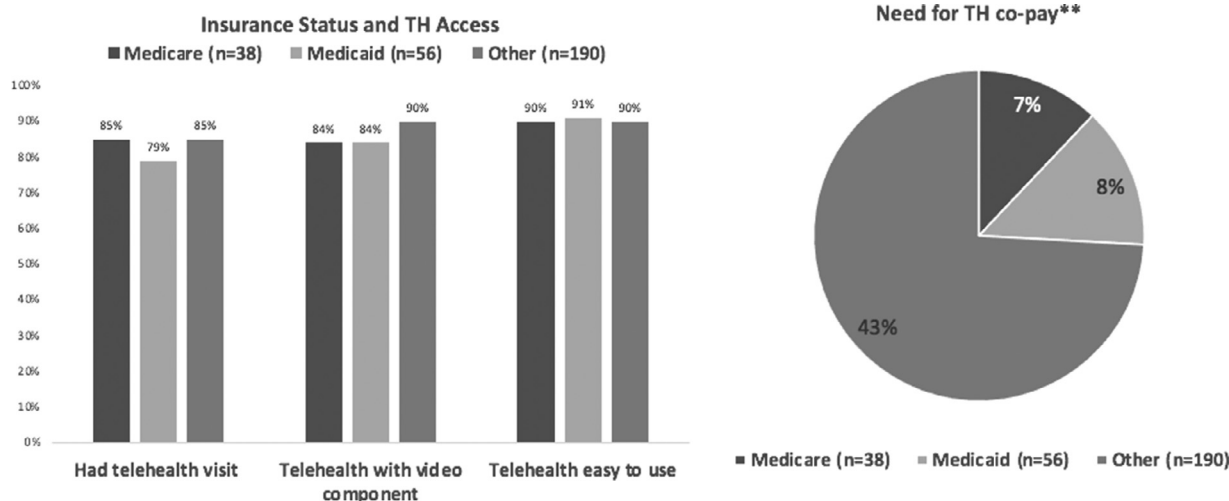


Fig. 3. Insurance Status and Access and Need for a Co-pay to TH TH=telehealth; **statistically significant p<0.01

Access to telehealth: PwCF with financial concerns were less likely to think that telehealth was easy to use than those without financial concerns (84%, n=74 vs. 93%, n=219; p=.018) (Fig. 2).

Quality of telehealth: PwCF who reported financial difficulties were less likely to think their care team asked about their concerns (64%, n=54 vs. 79%, n=177; p=.010) or included them in shared decision-making (55%, n=45 vs. 69%, n=154; p=.02). In addition, they were less likely to have paid a co-pay or other cost for telehealth services compared to those with no reported financial difficulties due to COVID-19 (20.0%, n=14 vs. 33%, n=60; p=.045).

Interest in and barriers to telehealth: There were no differences between PwCF who reported financial difficulties and those who did not with respect to future desire for or barriers to telehealth.

3.4. Insurance type as a predictor of telehealth access, quality, interest, and barriers

Access to, interest in, quality and barriers to telehealth: Insurance type was not associated with differences in access, interest, quality or barriers to telehealth services.

Few PwCF with Medicare (6.7%) or Medicaid (8.0%) reported having a co-pay for telehealth services. Almost half of the PFSoc responders with other insurances (43%) had a co-pay with telehealth (Fig. 3).

3.5. Facilitators and barriers to telehealth among vulnerable populations as reported by CF care programs

Programs provided free-text responses to the question, “Sometimes a crisis creates both positive and negative effects. What effect has the use of telehealth had on disadvantaged populations?” The answers were classified as shown in Fig. 4 (detailed listings of themes are available in Appendix Table 2). According to CF care programs, telehealth had a mixed impact on vulnerable populations. While half of programs (48%, n=134) indicated that telehealth made care less costly or more convenient or otherwise improved access to care, half of the programs (49%, n=136) indicated that telehealth limited access to care among PwCF from vulnerable populations. The programs identified travel cost, work, and child care as major facilitators of telehealth compared to in-person care. A quarter of programs identified barriers to telehealth associated with lack of technology/equipment (24%, n=66) or inability to connect to the Internet (23%, n=65). Fourteen percent of programs (n=40) indicated challenges associated with socioeconomic/home factors. In addition, 13 programs (5%) identified language barriers as a challenge to telehealth. A small proportion of programs indicated the positive impact of telehealth on psychosocial well-being (6%, n=17) and infection prevention (5%, n=14) among vulnerable populations.

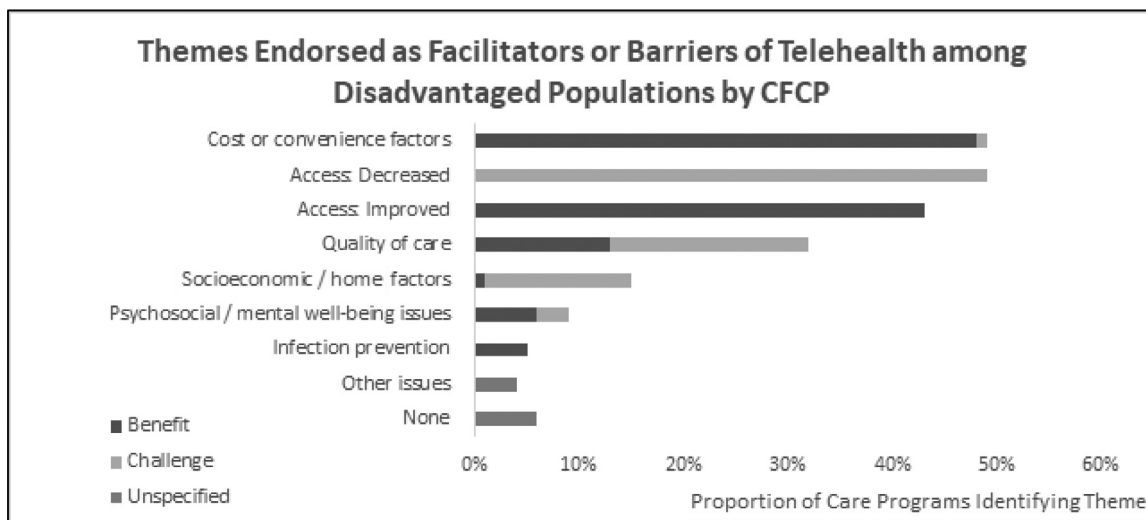


Fig. 4. Facilitators and barriers of CF care centers regarding the effect of telehealth on vulnerable populations: Qualitative summary from CF care programs (n=280)

4. Discussion

We describe important differences in access to and experiences with telehealth among PwCF who identified as a racial/ethnic minority or were socioeconomically disadvantaged.

Financial constraints were not associated with decreased use of telehealth and PwCF who reported financial difficulties associated with COVID-19 did not endorse increased cost of care due to co-pay or other costs for telehealth services. Responses to the PFSoc indicated that telehealth use during the COVID-19 pandemic did not differ by health insurance status, and insurance type was not associated with reported differences in access, quality, interest in, or barriers to telehealth services. Unsurprisingly, PwCF with public insurance were less likely to have paid a co-pay for telehealth services compared to those with other insurances. These findings suggest that the interventions implemented by the state and federal agencies and private insurers to support telehealth coverage, eliminating co-pays and similarly reimbursing telehealth visits with in-person care, were successful and suggest that telehealth may provide a mechanism for reducing socioeconomic barriers to accessing care.

PwCF from minority groups who responded to the PFSoc were less likely to have had a telehealth visit than respondents identifying as White. This difference was more pronounced in the Hispanic/Latino subgroup. Black respondents were less likely to have a video component of their telehealth visit compared to all others. Limited video use among racial and ethnic minorities in the general population has been attributed to decreased access of devices, broadband access, and reliable cellphone data plans [27]. Furthermore, data in the general population show that when racial/ethnic minorities are offered telehealth, they are as likely as the white population to utilize it [28]. The data were obtained in the middle of the pandemic, so we are unable to discern if there were group differences in the rate of uptake as the pandemic progressed.

The SoC1 responses identified language barriers as a challenge to telehealth, which may explain the lower utilization in Hispanic/Latino PwCF. Including an interpreter synchronously as part of the multidisciplinary telehealth visit may increase access to telehealth in the Hispanic/Latino group. Other reasons for the apparent access disparity to telehealth for PwCF from racial/ethnic minority, cannot be determined from our surveys; it is important, in the interest of equity, to understand if these differences are related to decreased interest or lack of opportunity to telehealth care.

Care programs were split on the merits of telehealth for vulnerable populations: whereas half indicated that telehealth improved

access to care another half indicated that telehealth limited access to care for these populations. These results may suffer from provider perception and personal bias. It is also noteworthy that PwCF from minority groups and who reported financial difficulties were more likely to think that their questions were not fully answered during telehealth visits, a perception that calls for further investigation. Overall, the different perceptions and experiences of the vulnerable populations with CF with telehealth, present important challenges and opportunities for self-examination. Previous studies on implicit bias in health care have found evidence of racial/ethnic and class bias among health care providers. Implicit bias influenced patient-provider interactions, treatment decisions, and patient health outcomes in the vulnerable populations [29,30]. Exploring implicit bias among providers may be important for reducing inequities in CF care.

We believe that important conclusions can be drawn from our data, but there are some weaknesses to our study. This study is limited by the relatively small number of respondents who represent racial/ethnic minorities. The proportion of minority PFSoc respondents was slightly lower than the proportion of minority patients in the CFFPR, so the total number of minority respondents was smaller than we would have liked. The PFSoc was intended for distribution to the general CF population, and an interest in comparing the experience of low SES and minority groups was developed after the survey had been distributed, no attempt was made to purposefully sample these groups and the PFSoc was distributed in English without a Spanish version.

5. Conclusion

PFSoc, SoC1, and program surveys identified differences in telehealth use and care perceptions by ethnicity, race, and socioeconomic characteristics. In order for telehealth to be part of an equitable CF care model, further studies are needed to better understand barriers and facilitators of telehealth use among PwCF from diverse ethnic, racial, and socioeconomic backgrounds.

CRedit author statement

All authors should have made substantial contributions to all of the following: (1) the conception and design of the study, or acquisition of data, or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content, (3) final approval of the version to be submitted.

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Declaration of Competing Interest

While I received grant support from CFF and private pharmaceutical companies, I have no conflict of interest to report related to this manuscript.

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Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:[10.1016/j.jcf.2021.09.006](https://doi.org/10.1016/j.jcf.2021.09.006).

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