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Evaluating Differences in the Disease Experiences of Minority Adults With Cystic Fibrosis

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Abstract

Extensive research has demonstrated disparities in health outcomes and survival between non-Hispanic Caucasian (NHC) and non-Caucasian or Hispanic (minority) persons with cystic fibrosis (CF) in the United States (US). However, very little research has been done to explore the disease experiences of racial and ethnic minority persons with CF. Adult subjects with CF were approached for study participation and to characterize their experiential disease perceptions. Survey data were analyzed using Chi-Square tests and Mann-Whitney *U*-test for basic categorical and continuous variables, and Kruskal-Wallis one-way ANOVA using ranks for Likert scales. Minority persons reported significantly lower scores (more negative experience) when comparing themselves to others with CF (15.18 ± 2.89 vs 18.40 ± 3.18, $P < .01$), particularly in the areas of representation in research, experience, and support. We were able to identify the unique experiences of minority persons with CF, including perceived lower disease understanding and poorer representation compared to most others with CF. Further large studies are needed to develop and assess interventions that may be useful for serving these diverse populations.

Keywords

Culture/diversity, outpatient satisfaction data, patient feedback, patient perspectives/narratives, relationships in healthcare

Background

Cystic fibrosis (CF) is a genetic condition caused by mutations in the CF transmembrane conductance regulator (CFTR*)* gene (1). Dysfunction of this gene results in a buildup of mucus in the airways, pancreatic insufficiency, and other co-morbidities (1). CFTR carrier rates are highest amongst non-Hispanic Caucasians (NHC). However, CF is by no means racially unique (1). CF affects approximately 1 in 3000 individuals of Caucasian descent, 1 in 8000 individuals of Hispanic descent, 1 in 15 000 individuals of African American descent, and 1 in 30 000 individuals of Asian American descent (1). Within the United States in 2020, there were 31 411 individuals with CF accounted for in the national CF registry. Of these, 93.4% identified as White, 4.7% identified as African American, 3.9% identified as "Other Race," and 9.6% identified as Hispanic (2). As new research has developed more effective treatments, the median survival of persons with CF has steadily improved to 50.0 years by 2020 (2). While CF survival has increased overall, equal improvements have not been observed within non-Caucasian or Hispanic (racial and ethnic minority) populations, and exciting new therapies such as CFTR modulators appear to disproportionately benefit NHC persons with CF due to their more common mutations (3–6). Private or rare mutations, which are more commonly seen in racial and ethnic minority persons with CF, often do not have approved modulators.

Previous research has explored differences between Hispanic and non-Hispanic persons and found that disparities in survival and lung function between these groups exist even after accounting for typical morbidities (6,7). In a 2018 retrospective cohort analysis of over 26 000 persons with CF, Rho et al (6) found that Hispanic persons had lower survival overall, with a mean age at death of 22.4 ± 9.9 years

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compared to a mean age at death of 28.1 ± 10.0 years for non-Hispanic persons. McGarry et al (7) found that across the United States, Hispanic persons with CF had lower lung function, with a forced expiratory volume in one second (FEV_1) 4.0% to 9.0% lower than non-Hispanic persons with CF, depending on the region in the United States. Outside of objective disease outcomes, non-Caucasian persons with CF had a poorer quality of life after accounting for socioeconomic status and other co-morbidities (8). Despite research demonstrating differences in quantifiable health outcomes and health-related quality of life, very little research has been done to explore the disease experiences of racial and ethnic minority persons with CF. Multiple studies have demonstrated patients' adherence to chronic disease management is directly correlated to their perceptions of disease and cultural experience (9,10). For example, studies such as Adzika et al (11) show the strong influence that supportive familial and social environment plays on the health-related quality of life of sickle cell anemia patients. Further research is needed in this area to explore if there are differences in cultural and disease perceptions between Caucasian and non-Caucasian persons with CF, and if there are, to ultimately optimize disease experience and health outcomes for all peoples.

The goal of this study was to comparatively explore disease-specific experiences and cultural contributions for racial and ethnic minority persons with CF. Identifying factors that contribute to a more negative disease experience among racial and ethnic minority persons will establish a basis for further research that could quantify the differences and promote better healthcare practices for physicians and other allied health clinicians. To our knowledge, this is the first study to comparatively explore the more subjective disease experiences of NHC and racial and ethnic minority persons with CF.

Methods

Participants and Data Collection

Subjects met inclusion criteria if they were 18 years of age or older, previously diagnosed with CF, and were a patient at the local academic adult CF care center. Participants were excluded if they were incarcerated or if they could not read English. The study protocol was reviewed and approved by the local institutional review board (IRB00117205). Participants were recruited via email from the clinic mailing list in an open-recruitment style. Following informed consent, subjects completed an online survey to assess self-perception of disease, experiences with healthcare, family, culture, and community support, and self-comparison to others with CF (Supplemental Document 1). The survey was distributed 3 times between January 2020 and December 2020, and took 5 to 10 min to complete. If participants self-identified as White and Non-Hispanic they were included in the NHC cohort. Participants were included in the racial and ethnic minority cohort (minority) if they identified as either Hispanic and/or American Indian or Alaska Native, Asian, Black, or African American, Native Hawaiian, or Pacific Islander, "Mixed" or "other" race.

Measures

Several questions in the survey were selectively drawn from the Illness Perceptions Questionnaire-Revised (IPQ-R), a survey validated for several chronic diseases, including CF (12). These Likert-type questions were scored consistently with the IPQ-R methodology. Survey questions also included multiple-choice Likert-type questions and open-answer questions. Likert-type items were scored 1 to 5, with 1 being "strongly disagree" and 5 being "strongly agree." Within the survey, 8 questions were reverse scored. Higher scores indicate more positive experiences, while lower scores indicate more negative experiences. A score of 3.5 or higher was considered a "positive" response and reflects the subject general agreement with the Likert-question statement. Open-ended questions were included in each section to allow participants to expand upon their experience of CF illness including diagnosis, perception of family/culture/community influences, quality of CF care, and comparisons of their disease experience compared to others with CF.

Statistical Analyses

Survey data were analyzed using several statistical tests. Data was evaluated for normality using kurtosis and skewness. Shapiro-Wilk analysis was utilized to assess the normality of continuous data. For nonparametric data, categorical and continuous variables were compared using Chi-square and Mann-Whitney *U*-test, respectively. The median age of diagnosis was further compared by independent samples median analysis. Kruskal-Wallis one-way ANOVA using ranks for Likert scales was performed to compare experiences between the groups. Each individual Likert-type question was compared between the minority and NHC populations, as were the Likert scales for the 4 primary evaluation areas: self-perception of disease, experiences with healthcare, families, cultures, communities, and self-comparison to others with CF. Correction for multiple pairwise comparisons was performed. In order to compare the frequency of emotions reported by participants, Fisher's exact test was utilized as more than 20% of the cell counts were less than 5. Subsequent post-hoc analysis was performed between groups further divided based on gender (ie, minority male, minority female, NHC male, NHC female). Between group and gender comparisons of Likert-scale data were analyzed by Kruskal-Wallis one-way ANOVA with subsequent Bonferroni correction for multiple-comparison correction. A $P \leq .05$ was set to determine significance. Open answer questions from this survey are considered pilot data and therefore did not receive complete thematic analysis. All statistical analyses were conducted using IBM SPSS version 27.

Results

Participant Demographics

Of 330 possible subjects, 82 completed the survey (24.8% response rate). The characteristics of survey respondents are shown in Table 1. Of participants, 85.4% were NHC, which is consistent with the demographics of the clinic from which the participants were recruited. Of respondents, 63.4% were assigned female at birth, with one respondent identifying as nonbinary or transgender. The median age at diagnosis was 1.0 years for NHC and 2.5 years for minorities. There was no significant difference in income or age at diagnosis between NHC and minority subjects. There was a significant difference in education level, with NHC participants reporting higher rates of some tertiary education or higher. Additionally, there were differences in self-reported parental income, with NHC reporting a higher percentage of parents earning an annual income of $50 000 or more ($P < .01$). Supplemental Table 1 displays the specific racial and ethnic characteristics of the minority respondents. Hispanic or Latinx participants made up 16.7% of the minority sample. Black or African American and Asian participants made up 66.7% and 8.3%, respectively. No participants self-identified as Native American or Alaska Natives, and 2 participants reported being "other" or mixed race.

Table 1. Participant Demographics (N = 82).

	Non-Hispanic Caucasian (NHC)	Minority	*P*-value
Total (n)	70	12	
Age at diagnosis (years)			
Mean (± standard deviation)	10.17 ± 18.76	4.56 ± 6.33	.645
Median	1.00	2.50	.447
Range	0-63	0-22	
Sex n (%)			.873
Female	44 (62.9%)	8 (66.7%)	
Education n (%)			**.038**
Secondary education or less	11 (15.7%)	7 (58.3%)	
Undergraduate education	38 (54.3%)	3 (25%)	
Graduate education	21 (30%)	2 (16.7%)	
Annual income n (%)			.109
Less than $50 000	34 (50.00%)	9 (75.00%)	
$50 000 or more	34 (50.00%)	3 (25.00%)	
Parental education n (%)			
Mother[a]			.391
Secondary education or less	17 (25.8%)	5 (45.5%)	
Undergraduate education	38 (57.6%)	5 (45.5%)	
Graduate education	11 (16.7%)	1 (9.1%)	
Father[b]			.494
Secondary education or less	15 (22.7%)	4 (40%)	
Undergraduate education	32 (48.5%)	4 (40%)	
Graduate education	19 (28.8%)	2 (20%)	
Parental annual income n (%)[c]			**.005**
Less than $50 000	10 (17.5%)	5 (62.5%)	
$50 000 or more	47 (82.5%	3 (37.5%)	

[a]NHC n = 66, minority n = 11.
[b]NHC n = 66, minority n = 10.
[c]NHC n = 57, minority n = 8.

Perception of Illness

Minority participants rated themselves significantly lower in their understanding of CF than NHC participants (3.67 ± 0.99 vs 4.37 ± 0.85, $P < .01$). Minority participants also had lower overall scores on the entire perception of illness scale (29.58 ± 4.81 vs 32.97 ± 4.47, $P < .05$) (Table 2).

Emotions Associated With Disease

On average, a higher percentage of minority subjects reported more negative (4.08 vs 2.81, $P < .05$) and approximately the same amount of positive (0.67 vs 0.74, $P = .668$) emotions

Table 2. Perception of Illness.

Perception of illness statement	Non-Hispanic Caucasian (NHC) (n = 70)	Minority (n = 12)	*P*-value
*My illness strongly affects the way others see me	3.36 ± 1.13	2.67 ± 1.16	.055
*My illness has serious financial consequences	2.23 ± 1.18	1.75 ± 0.97	.166
*My illness causes difficulties for those close to me	2.71 ± 1.12	2.17 ± 1.12	.095
What I do can determine whether my illness gets better or worse	4.17 ± 0.85	3.83 ± 1.03	.270
The course of my illness depends on me	3.81 ± 0.97	3.58 ± 1.24	.546
The negative effects of my illness can be prevented (avoided) by my treatment	3.51 ± 0.93	3.50 ± 0.67	.818
*Nothing I do will affect my illness	4.37 ± 0.80	4.17 ± 0.72	.246
*My actions will have no effect on the outcome of my illness	4.43 ± 0.67	4.25 ± 0.75	.408
I have a clear picture or understanding of my condition	**4.37 ± 0.85**	**3.67 ± 0.99**	**.009**
Perception of illness total score	**32.97 ± 4.47**	**29.58 ± 4.81**	**.021**

Scores are reported as a mean ± standard deviation, and *P*-value was calculated using Kruskal-Wallis one-way ANOVA with ranks. Higher scores indicate a more positive experience range = 1–5. Asterisks (*) indicate questions that were reverse scored. Statements were selectively drawn from the IPQ-R.

when thinking about their CF than did NHC subjects (Table 3). Specifically, minority subjects were significantly more likely to endorse experiencing both depression and anxiety compared to the NHC group (83.3% vs 31.4%, $P < .001$, 83.3% vs 48.6%, $P < .05$, respectively). The most commonly reported emotions among NHC participants were worry/concern, anxiety, gratitude, and depression. Minority participants commonly expressed these as well, in addition to fear and anger.

Quality-of-Care

There were no significant differences reported on quality-of-care measures between NHC and minority participants (Supplemental Table 2). Overall, both minority and NHC participants expressed satisfaction with their current CF care. Statistically, there were no differences between groups in their perceived appropriateness for their timing of diagnosis, with similar percentages endorsing that their diagnosis was made either earlier or later than expected ($P = .391$, Supplemental Figure 1). However, in open-ended questioning, several minority participants believed they were diagnosed later due to healthcare providers not suspecting CF because of their ethnicity. One participant of self-reported Asian ancestry shared: "They didn't think to test me for CF because of my ethnicity. One doctor had to convince the others to test me and they thought she was crazy for it."

Table 3. Self-Reported Emotions Associated With Cystic Fibrosis.

Emotion	Non-Hispanic Caucasian (NHC) (n = 70) n (%)	Minority (n = 12) n (%)	*P*-value
Depression	**22 (31.4%)**	**10 (83.3%)**	**.001**
Anger	18 (25.7%)	6 (50.0%)	1.00
Loss	11 (15.9%)	2 (16.7%)	1.00
Worry/concern	51 (72.9%)	12 (100%)	.722
Anxiety	**34 (48.6%)**	**10 (83.3%)**	**.031**
Fear	245 (35.7%)	6 (50%)	.356
Disgust	10 (14.3%)	1 (8.3%)	1.00
Guilt	16 (2122.9%)	2(16.7%)	1.00
Shame	10 (14.3%)	2 (16.7%)	1.00
Gratitude	31 (44.3%)	4 (33.3%)	.543
Pride	16 (22.9%)	2 (16.7%)	1.00
Joy	5 (7.1%)	2 (16.7%)	.271
Total negative	**197 (31.2%)**	**49 (45.4%)**	**.025**
Total positive	52 (24.7%)	8 (22.2%)	.668

Family, Culture, and Community Support

There were no statistically significant differences identified between minority and NHC persons in familial/community support (Supplemental Table 3). In the survey comments, many subjects recounted a lack of public familiarity with CF, support from family members, and familial education levels and how they contributed to support.

Comparison to Others With CF

Minority persons reported significantly lower scores on the Likert scale when comparing themselves to others with CF (15.18 ± 2.89 vs 18.40 ± 3.18, $P < .01$), with lower scores indicating their experience was perceived as worse than most others with CF (Table 4). This was significantly different in the areas of representation in research (1.91 ± 1.38 vs 3.09 ± 1.27, $P < .01$) and support from family and community (3.18 ± 1.08 vs 4.03 ± 1.12, $P < .05$). One participant shared: "I hate to say this but I am black and not [too] many of us have CF so I don't get any influence." Both minority and NHC participants shared that while they felt that they may not be represented as well in research due to their race, ethnicity, or milder clinical presentation, most did not express distress over this. Rather, they expressed hope for future research or that existing research will equally benefit them.

Gender Differences Between Groups

Further comparisons between groups separated by gender demonstrated significant differences. Within the category of "perceptions of illness," minority females were much less likely to agree with the statement "I have a clear picture or understanding of my condition" than their NHC female peers (Figure 1A). This difference amongst females was the primary driver of the difference between the racial groups in

Table 4. Comparison to Others With CF (N = 80).

Comparison to others statement	NHC (n = 68)	Minority (n = 12)	*P*-value
Representation of people like me in CF research and campaigns is … (better/same/worse)	**3.09 ± 1.27**	**1.91 ± 1.38**	**.006**
My personal benefit from CF research and campaigns is … (better/same/worse)	3.21 ± 1.15	3.18 ± 1.40	.980
My experience of CF is … (better/same/worse)	4.32 ± 1.01	3.73 ± 1.35	.122
My treatment by healthcare professionals is … (better/same/worse)	3.75 ± 1.03	3.18 ± 0.60	.066
My support from my family/community is … (better/same/worse)	**4.03 ± 1.12**	**3.18 ± 1.08**	**.023**
Comparison to others total	**18.40 ± 3.18**	**15.18 ± 2.89**	**.004**

Abbreviations: NHC, Non-Hispanic Caucasian; CF, cystic fibrosis.
Scores are reported as a mean ± standard deviation, and *P*-value was calculated using Kruskal-Wallis one-way ANOVA with ranks. Higher scores indicate a more positive experience.

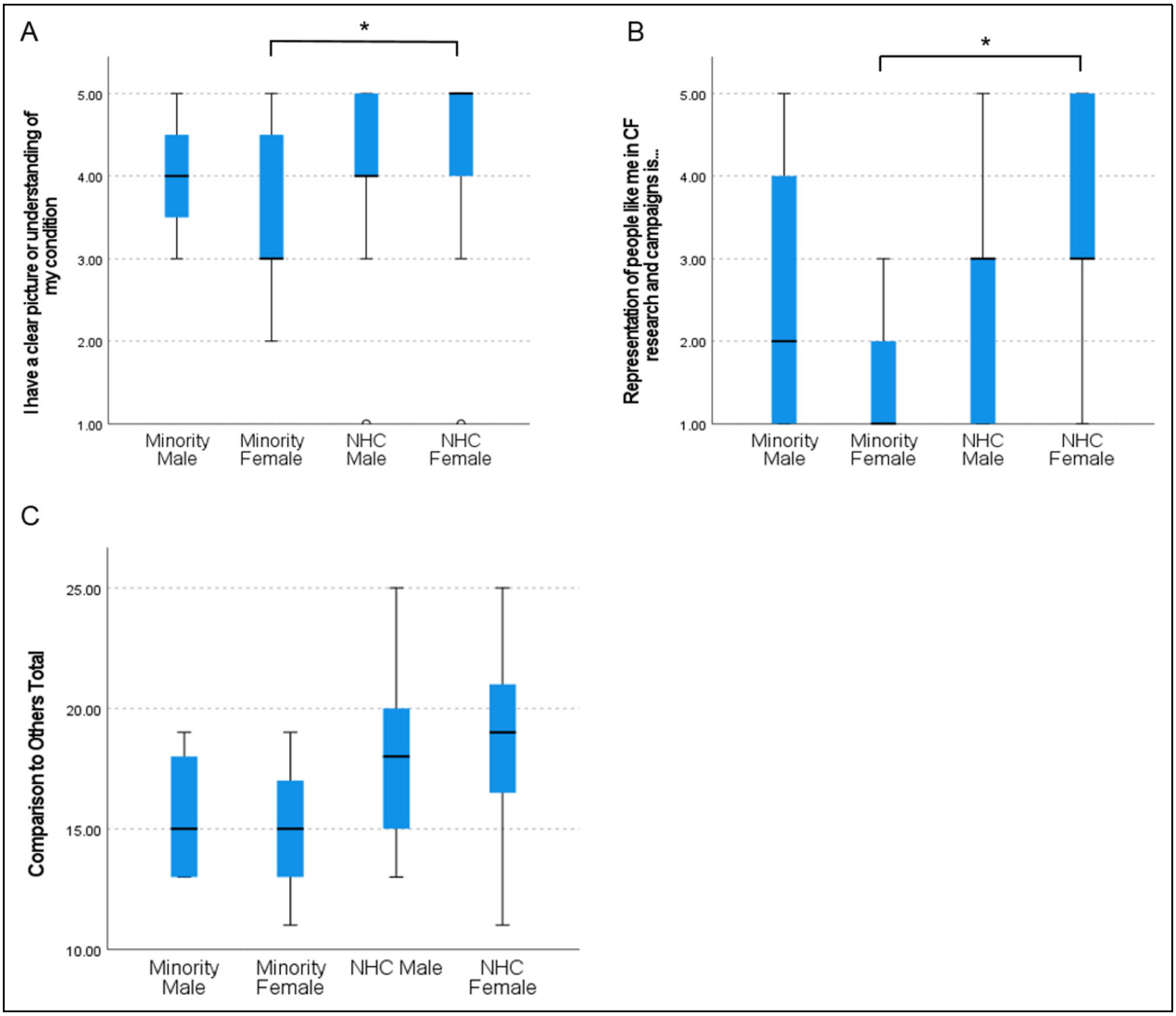

Figure 1. Gender difference between groups. (A) Degree of agreement with the statement "I have a clear picture or understanding of my condition" within the category of perception of illness. There were significant differences between minority female subjects and NHC subjects (3.5 ± 1.07 vs 4.47 ± 0.81, $P < .05$). (B) Degree of agreement with the statement. "Representation of people like me in CF research and campaigns is" with the comparison to others with the CF category (1.57 ± 0.98 vs 3.32 ± 1.22, $P < .01$). (C) Total scores of agreement in the comparison to others with the CF category. There were trends toward differences between female minority subjects compared to female NHC subjects, but these did not meet statistical significance following Bonferroni correction for multiple analyses (15.0 ± 3.06 vs 18.57 ± 3.32, $P = .067$).
Abbreviations: NHC, Non-Hispanic Caucasian; CF, cystic fibrosis.

this category. Female minority subjects were also significantly less likely to agree that they were well represented in CF research compared to their NHC counterparts (Figure 1B). There were trends toward female minority subjects reporting worse experiences in general when compared to both male and female NHC subjects, but these did not meet statistical significance when corrected for multiple comparisons.

Discussion

This study is the first to document the subjective and perceived disease experiences of NHC and racial and ethnic minority persons with CF in the areas of disease perception, quality of care, cultural and community support, and comparison of others with CF. The most notable differences between racial groups were found in the perception of illness, endorsement of negative emotions associated with their disease, and comparison to others with CF, particularly in regards to representation in CF research.

Minority persons with CF reported feeling they had a significantly lower understanding of their disease and more negative perceptions of their illness overall when compared to NHC participants. This was most prevalent in females between racial groups. Previous data has demonstrated limited understanding of disease manifestations is a significant source of mental distress for both patients and their

caregivers (13). These perceptions may be related to several complex factors. One possibility is that this difference may be related to a limited understanding of CF by family and community members, as the cultural or community support of persons with CF may play a large role in their management of care and experience of their illness (14,15). While no significant differences were noted in the cultural and community support portion of the survey, in the comparison to others section, minority participants perceived their support from family and community as significantly lower than NHC participants. Several participants expanded upon this in the survey comments section. One topic broached across both minority and NHC participants was unfamiliarity with CF within their communities. This experience may be particularly exacerbated within minority communities due to the lower prevalence of CF (2). As one participant wrote: "I am Black with what is known as white people's disease. So, not many people knew or cared what was going on with me. I got a lot of 'eww, why does she keep coughing', as if I had something that they could catch." Several minority participants expressed that while they received support, they felt that their families and communities had insufficient understanding of their condition: "African Americans are rarely affected by CF. Therefore, my circle of family and friends are not very knowledgeable of the illness, and white Americans in my circle tend not to believe that I have the illness."

Another possible explanation for the perceived lower understanding may be the limited representation of minority individuals in CF research and campaigns. Minority participants, particularly females, were significantly less likely to agree that representation of people similar to them was the same or better in CF research and/or campaigns. These results are unsurprising, as the underrepresentation of minorities in CF drug trials has been documented previously (16). This may lead to some disconnect from the community and distance from ongoing CF research, causing feelings of decreased understanding about the disease and new treatments. The CF foundation has begun prioritizing research for communities of color to begin to rectify the disparities outlined above (5,17). What is perhaps more surprising is that while minority participants reported poorer representation, further elaboration revealed a sense of survivor's guilt and gratitude for how existing research does benefit them: "I … often feel as though I am far healthier than others with CF. I have survivor's guilt sometimes, especially when I think about those I've lost … makes me feel an odd sense of guilt for being so healthy." Acknowledgment of disparities and empathy for those who research does not currently benefit, however, is not a substitute for research that better represents all individuals affected with CF. These contradictory findings suggest that future research is needed to clarify the nuances of this complex experience.

It is important to note that these differences in understanding of CF are perceived differences. As objective knowledge was not assessed, there may or may not be a true difference in disease knowledge/understanding between these groups. However, we believe it is important to explore the implications of a perceived lack of knowledge and the possible impact it may have on disease experience.

Both NHC and minority subjects reported frequent negative emotions associated with their CF illness including depression, fear, and worry. However, minority participants were significantly more likely to express anxiety and depression in regards to their illness and were more likely in general to endorse negative emotions than their NHC counterparts. It is possible these emotions are associated with worse physical health outcomes as multiple studies have demonstrated worse clinical outcomes in minority persons with CF, even after adjusting for socioeconomic status (3,6,18). However, specific cultural experiences may also be exacerbating this difference. Unsurprisingly, experiential racism has been significantly associated with mental health outcomes in a large meta-analysis (19). Along these lines, some minority participants acknowledged that their personal life experiences deeply influenced their experience with CF. "I am from a family that has suffered a lot in this country, cycles of poverty, violence and abuse are all parts of my lineage … Food shelters, homelessness, and turmoil formed my childhood … My life is different now, I am a high earner and live in a very stable environment but, it took me getting here to really see how bad it was." Intergenerational and personal trauma are more prevalent in minority individuals, and can influence mental health concerns to which individuals with chronic illnesses like CF may already be prone (20,21). Both minority and NHC participants expressed a sense of lack of control they feel over their CF: "I feel like no matter what I do far as taking my meds I have no control with the outcome of my condition. I feel like I do everything right and sometimes the doctor still tell me bad news … Hard to deal with at times, when you do your treatments and still feel like it isn't enough." There is growing recognition of the importance of resilience in chronic disease management (22). These data would suggest that a better understanding of the emotions and disease experience of persons with CF are important when conceptualizing approaches to bolster resiliency and improving the entirety of their disease management.

While no differences were apparent in the quality-of-care quantitatively, some nuanced topics emerged in the survey comments. The first being delayed diagnosis due to clinician biases: "the rarity of African Americans having CF made the diagnosis come later. No one suspected me to have it [because] of my ethnicity." Because all participants are over the age of 18, it is unlikely that they went through a newborn screening (NBS) program for CF. While a few states performed NBS for CF before 1997, NBS for CF was not adopted in all 50 states until 2007, after all, participants were born (23,24). While NBS has improved the identification of affected individuals and reduced diagnostic bias from healthcare providers, studies have shown that due to the limited nature of CF NBS in many states, and the wider genotypic heterogeneity among minority persons with CF, screening disproportionately fails to pick up CFTR mutations in minorities (25,26). One way to decrease the diagnostic disparity among these groups may be to move towards

sequencing *CFTR* rather than common variant panels (27). This is in addition to broad educational initiatives to the general population to dispel the myth that CF is racially unique.

By exploring the potential cultural and disease experiential differences between Caucasian and non-Caucasian persons with CF, some insight can be gleamed for interventions or development of support structures focused on attenuating negative psychosocial experiences. This may help improve clinical outcomes of minority persons with CF. For example, this study demonstrated there is a significantly higher endorsement of anxiety and depression associated with disease experience in minority persons with CF. Given this, regular mental health screening with simple clinical screens such as the Generalized Anxiety Disorder – 7 and the Personal Health Questionnaire – 9 should be performed on all persons with CF (28). Special attention to offering resiliency training to cultivate mindfulness and self-care would be important for any person with CF, but particularly minorities. This study also found that minority persons with CF were significantly less likely to feel represented in research. It is critically important that research be inclusive and representative of the whole CF population (5,16). To this aim, it is important to recruit diverse patient partners to participate on research development committees and make special efforts to attenuate any social or economic barriers that may inadvertently discriminate and preclude minority persons with CF from participating in research. Finally, while there were no quantitative differences in perceived quality of healthcare between groups in this study, open-ended survey question responses suggested minority persons experience healthcare struggles both before and after their CF diagnosis. Previous studies have demonstrated implicit biases do exist in healthcare professionals at low to moderate levels (29). Instituting implicit bias training as well as cultural competency training is an important measure to take among healthcare professionals to lessen the effect of bias and hopefully reduce harm.

This study has several limitations. One shortcoming is the small sample size, which in part resulted from difficulties with recruitment due to COVID-19. Minority persons are a small, but important portion of the CF population, and sampling from a single CF center limited the number of potential participants. Additionally, it is possible that the patients at the CF care center we recruited from may not be representative of the larger CF population. The inability to separate out individuals of different minorities is also a limitation, as there are unique differences that can be lost when grouped together. The COVID-19 pandemic and a limited survey collection period may have created barriers for individuals with limited access to technology or the internet when clinic visits were moved virtually. Future studies should implement a similar approach on a larger scale, collecting participants from across the country and internationally.

We believe that this study is an important addition to the limited existing literature regarding the subjective experiences of minority persons with CF. It is effective in highlighting the experiences of minority persons with CF, including their self-reported perception of less understanding when compared to NHC, a more negative experience compared to others with CF, and complex emotions surrounding those disparate experiences with a higher endorsement of anxiety and depression. This study has revealed the need to foster education surrounding CF in minority communities, open and continuous communication and education between patients and providers, and the importance of increasing representation of minorities in CF research. Further research studies will be needed to evaluate these questions on a larger scale and to develop and assess interventions that may be useful for serving these populations. In particular, qualitative comments from participants suggest there is more to the story than was captured by quantitative data alone. The future qualitative investigation would be helpful to enrich our understanding of the present data.

Author Contributions

Kia Hutchins—Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Writing, original draft, review & editing. **Eileen Barr**—Conceptualization, Methodology, Formal analysis, Writing – review & editing. **Cecelia Bellcross**—Conceptualization, Project administration, Resources, Supervision, Writing–original draft, Writing–review & editing. **Nadia Ali**—Formal analysis, Methodology, Project administration, Resources, Supervision, Validation, Writing–review & editing. **William R. Hunt**—Conceptualization, Formal analysis, Investigation, Methodology, Project administration, Resources, Supervision, Visualization; Writing–review & editing.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethics Approval

This study was performed in line with the principles of the Declaration of Helsinki. The study protocol was reviewed and approved by the Emory University institutional review board (IRB00117205). Informed consent was obtained from all individual participants in the study.

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Statement of Human and Animal Rights

All procedures in this study were conducted in accordance with the Emory University institutional review board (IRB00117205) approved protocols.

Statement of Informed Consent

Written informed consent was obtained from the patients for their anonymized information to be published in this article.

Supplemental Material

Supplemental material for this article is available online.

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