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# Risk indicators of food insecurity in the CF population

By Semret Seyoum, Marsha Regenstein and Lea Nolan  
March 2021

## Introduction

Optimizing growth and weight, achieved by consuming sufficient nutrients, are important treatment goals for a person with cystic fibrosis (CF).<sup>1 2 3</sup> Most individuals with CF have pancreatic insufficiency, which hinders the absorption of essential nutrients and can impair weight gain and growth.<sup>4 5</sup> Many also have an increased metabolic rate. Suboptimal weight gain and growth is associated with worse pulmonary outcomes and decreased survival.<sup>6 7</sup> Although the majority of patients are prescribed pancreatic enzyme replacement therapy to improve nutrient absorption, achieving adequate weight gain can be challenging.<sup>4 5</sup> Most people with CF require a high calorie diet to reach their goals.<sup>2 3 4</sup> Understanding barriers to healthy nutritional intake is extremely important, especially in light of studies that many people with cystic fibrosis have trouble achieving and maintaining optimal weight gain and growth.<sup>1 5 8</sup>

According to the United States Department of Agriculture (USDA), food insecurity is defined as a household-level economic and social condition of limited or uncertain access to adequate food.<sup>9</sup> Food insecurity is a risk factor for inadequate nutritional intake among people with CF.<sup>5</sup> People with CF face unique financial challenges to afford their care.<sup>10</sup> Many people with CF need to consume more calories than the average person without CF, and spending on food is higher as a result. The financial challenges of this disease, including costly out-of-pocket expenses for services and therapies, impacts patient's ability to afford food and maintain a sufficient diet. Any financial barriers to food can have deleterious implications for the health of people with CF.<sup>5 8</sup>

*This issue brief focuses on food insecurity within the CF population, as well as risk indicators of food insecurity. Of all the risk indicators we evaluate, household income and the ability to generate income through work appear to have the strongest associations with food insecurity. Our findings suggest that people with CF in lower*

*income groups are much more vulnerable to not having enough money for food. It is the norm, rather than exception, for people with CF living in households with annual income below \$60,000 to experience food insecurity. More than twice as many people who do not have paid employment experience food insecurity compared to people with paid employment. Many of the people who are non-working are more likely to be sick or disabled compared to working people with CF.*

*Our findings also highlight how pervasive food insecurity is within the CF community, regardless of income level or employment status. In other words, while food insecurity is most common among lower income, non-working individuals with CF, it is also seen at higher income levels and among people working in paid employment.*

### **Methods**

Under contract from the Cystic Fibrosis Foundation, researchers from the Milken Institute School of Public Health at George Washington University developed an online survey, the 2019 Cystic Fibrosis Health Insurance Survey, to understand coverage, access to care, and financial hardship among people with cystic fibrosis in the U.S.<sup>11</sup> As part of the survey, participants were asked a variety of questions to determine if the person with CF has experienced food insecurity.

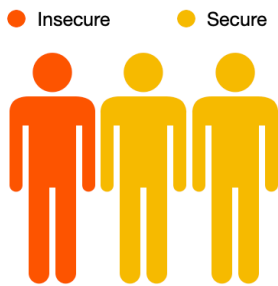
Survey participants were recruited with assistance from the CF Foundation. The Foundation shared the survey using social media and listservs, while also encouraging providers at the 133 accredited CF care centers across the United States to share the survey with their patients. All respondents represent a unique person with CF (even if the survey was filled out by a parent on behalf of their child). The cross-sectional survey was fielded from July to December 2019. The final sample includes 1,846 participants. The sample was weighted to reflect the parameters of the CF Foundation's 2019 Patient Registry Annual Data Report. The Registry is representative of the population of individuals in the U.S. who have CF and who seek care at an accredited care center.<sup>12</sup> Survey weights were applied to adjust for non-responses by age group and insurance type.<sup>13</sup>

Descriptive and bivariate quantitative analyses were conducted to explore the subpopulation with food insecurity and make comparisons to those who were food secure. Multiple logistic regressions were also utilized to examine the association between financial and coverage-related risk factors, or unmet medical need and food security.

The 2019 Cystic Fibrosis Health Insurance Survey was conducted before the COVID-19 outbreak. Any additional challenges with COVID-19 regarding access to care and financial hardship will not be captured in this issue brief. Likewise, the survey was conducted before the release of the highly effective modulator therapy elexacaftor/tezacaftor/ivacaftor (Trikafta<sup>®</sup>). This brief does not capture the impact of Trikafta<sup>®</sup> on nutritional needs and dietary intake, or any related effects on food security.

## Identifying Food Insecurity

Figure 1. Food Security Among People with CF



*Data from the 2019 CF Health Insurance Survey indicate that one in three people with CF (33%) in the U.S. have experienced food insecurity. This rate is triple the national average of 10.5%.<sup>9 14 15</sup>*

We identify people with CF as having “food insecurity” based on their responses to nine questions included in the survey (see Table 1). If the respondent answered “yes” to one or more of these questions, they were

categorized as experiencing food insecurity. Overall, one third of people with CF in the sample (33%) indicated some level of food insecurity in the year prior to the survey. The food security questions addressed three dimensions: problems affording food (i.e., the cost burden); changes in food intake; and use of supplemental resources to access food.

One out of five respondents (19%) indicated difficulty paying for food. The second dimension relates to the frequency in which people with CF altered their food consumption or behavior because they did not have enough money in the last 12 months. This includes if respondents often or sometimes were hungry and did not eat, ate less than they or their household should, or cut or skipped meals. People with CF most commonly reported that they often or sometimes couldn’t afford to eat balanced meals as recommended by their care team, or their groceries did not last because they didn’t have enough money to get more. Prevalence ranged from 10% to 20%, depending on the specific question asked. Lastly, we ask a series of questions about the use of supplemental resources to access food, such as Supplemental Nutrition Assistance Program (SNAP), a food bank, or a place of worship, in the last 12 months. About half of the respondents who indicated food insecurity turned to one or more of these supplemental services for support.

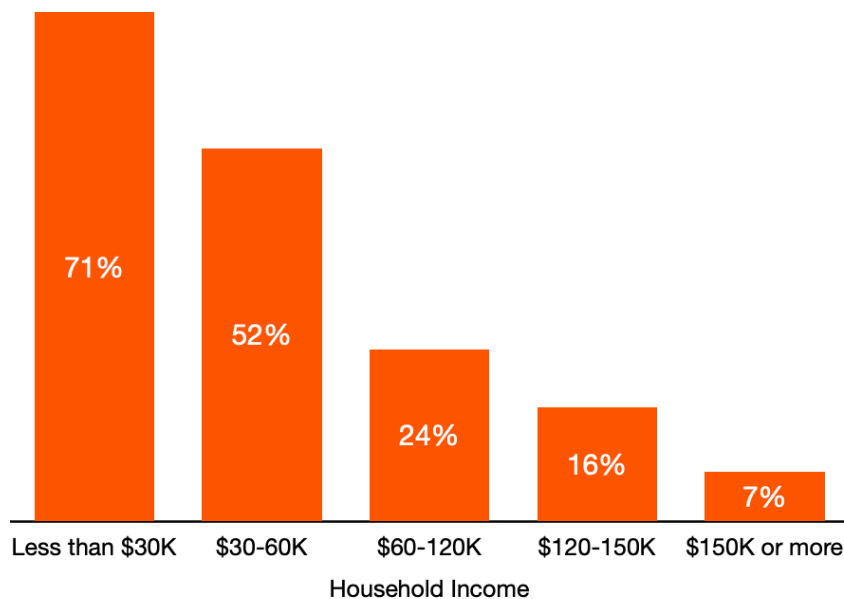
Table 1. Food Security Question Types		%
<b>Any food insecurity</b>		<b>33%</b>
You or your family faced an issue because of medical bills	Had difficulty paying for food	19%
You or your family “often” or “sometimes” altered intake because of cost (in the last 12 months)	Couldn't afford to eat balanced meals recommended by care team	20%
	Groceries didn't last and didn't have money to get more	18%
	Ate less than should because not enough money	15%
	Cut size or skipped meals because not enough money	14%
	Hungry but didn't eat because not enough money	10%
You or your family used supplemental resources (in the last 12 months)	Used the Supplemental Nutrition Assistance Program (SNAP)	12%
	Went to a food bank	8%
	Turned to a place of worship for food	4%

Several points are noteworthy in Table 1, including the substantial prevalence of food insecurity and the ways this plays out for people with CF. A noteworthy point revealed in the survey is that one out of five people with CF indicate say they could not afford to eat balanced meals because of limited resources. A sizeable portion are eating less of the foods than they should be eating or potentially going hungry. Only about half of the people who indicate food security say that they use a resource to help them shore up their nutritional needs. Despite the prevalence of food insecurity, only a quarter of the people who experience food insecurity used a food bank, and only 37% of people who experience food insecurity were able to access SNAP benefits. Our findings suggest that a gap exists between the resources available to support people with food insecurity and reported usage. People who are eligible for SNAP benefits and food banks may not be taking advantage of these resources, because of a negative associated stigma or a lack of awareness of the supports.<sup>16 17 18</sup> Additionally, some people who experience food insecurity do not qualify for SNAP benefits, and therefore are limited in the resources available to them. The potential stigma attached to utilizing food assistance may also act as a barrier for this group.

## Household Income

Income has a profound impact on food security among people with CF. In Figure 2, we examine how food security varies based upon the total household income of a person with CF.

Figure 2. Percentage of People With CF Who Experienced Food Insecurity by Household Income



*As annual household income increases for people with CF, the likelihood of food insecurity decreases. Across income categories, food insecurity is significantly more prevalent than in the general population. Seventy-one percent (71%) of respondents with less than \$30,000 in household income, and 52% of those with \$30,000 to \$60,000 have experienced food insecurity. While the majority of people with CF in lower income groups have experienced food insecurity, a substantial portion of higher income groups also have inadequate access to food. Almost a quarter (23%) of respondents in households with an income of \$120,000 to \$150,000 have also experienced food insecurity, which is twelve-fold the prevalence of food insecurity in the general U.S. population at or above 185 percent of the poverty line (in 2019).<sup>19</sup> As shown in a previous publication on the CF Health Insurance Survey, people with CF face numerous out-of-pocket expenses to manage their care, which can put serious financial strain on people with CF and their families regardless of household income.<sup>10</sup> They may not qualify for certain additional food supports available to others based on their family household income. Even in households with an income of \$150,000 or more, a nontrivial amount (7%) of people with CF still report food insecurity. The cost of insurance, in and of itself, is a significant household expense. The premiums, deductibles and copayments that people with CF pay can create financial challenges that impact getting health services they need, while also reducing available income for other family necessities such as food and rent. Insurance lowers the overall health care costs to the patient, but it can be a significant household expense.<sup>10</sup>*

Table 2 illustrates the odds of food insecurity across different ranges of household income, while controlling for differences in age and insurance. We control age to evaluate risk indicators for food security, while accounting for the differential impact of age any associated socio-economic factors on financial burden. We control for insurance because differences in coverage can also impact the financial burden experienced by people with CF, which we discuss later in this brief.<sup>20</sup>

**Table 2. Adjusted Odds Ratio of Food Insecurity by Annual Household Income**

Household Income	Adjusted Odds Ratio
\$150K or more	(Reference)
Less than \$30K	18.630***
\$30K-\$60K	10.719***
\$60-\$120K	3.830***
\$120-\$150K	2.681***
<i>Note:</i> Odds ratios are adjusted to hold insurance and age constant.	
* Denotes there is a statistically significant association between household income and food insecurity at a p-value <.05 ** Denotes a p-value<.01 *** Denotes a p-value<.001.	

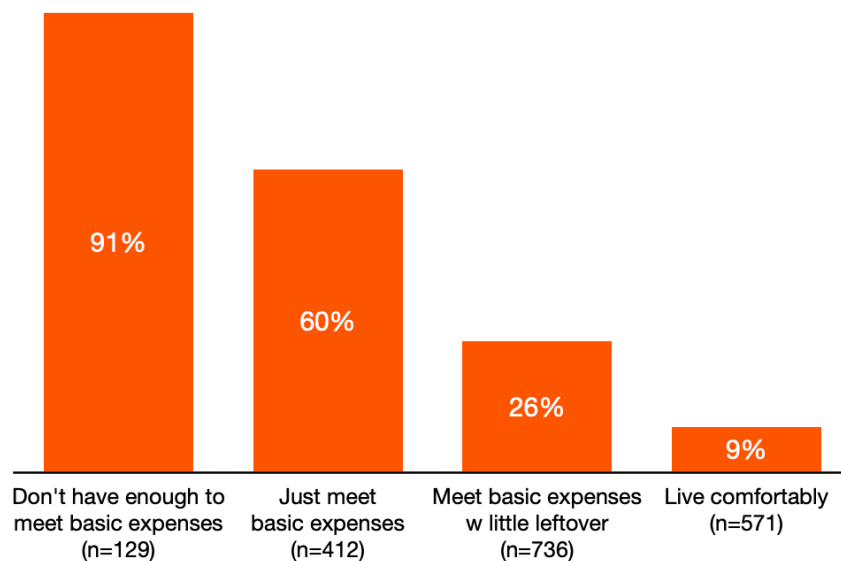
*The odds of food insecurity are 19 times higher for people with CF with a household income less than \$30,000 compared to those with an income of \$150,000 or more ( $p<.001$ ), while controlling for age and insurance. The odds of food insecurity are 11 times higher for people with CF with a household income \$30,000 to \$59,999 compared to those with an income of \$150,000 or more ( $p<.001$ ).*

The risk of experiencing food insecurity is significantly higher for people with CF with a lower income. *Our findings indicate that it is the norm, rather than exception, for low-income households with CF to experience food insecurity.*

## Household Finance

To estimate financial burden within a person with CF's household, we asked survey respondents to indicate which scenario best describes their household's financial situation: whether they live comfortably, meet basic expenses with a little leftover for extras, just meet basic expenses, or don't have enough to meet basic expenses (Figure 3). This question has been used in other national surveys to measure the financial status of those with medical bill problems.<sup>21</sup>

Figure 3. Percentage of People with CF Who Experienced Food Insecurity by Household Financial Situation



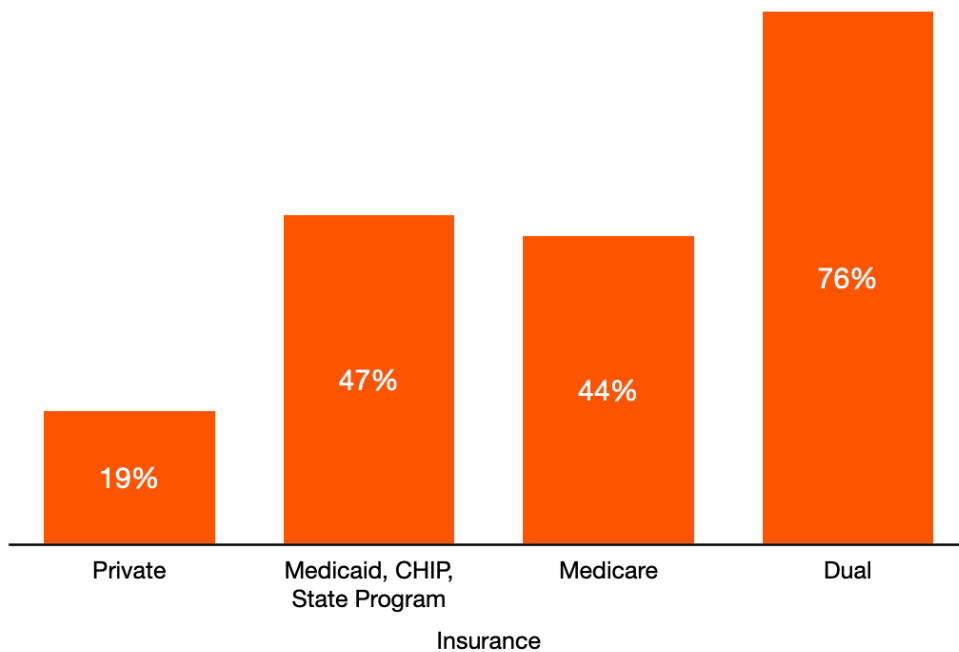
*As household financial situation worsens for people with CF, the risk of food insecurity increases.* Financially strapped households are at great risk of food insecurity. 91% of people with CF who do not have enough money to meet their basic expenses have experienced food insecurity. In comparison, 9% of people with CF who report that they live comfortably have experienced food insecurity. Among this group that lives comfortably, many are ineligible for food assistance, such as SNAP, and may feel reluctant to go to other food supports, such as food banks, to complement the food that they have. It is also possible that the stigma of not being able to provide for their family without food supports deters use of these supports.<sup>16 17 18</sup> Periodically people may feel that they are taking resources from others and therefore may not utilize other resources to supplement their food intake. The high prevalence of food insecurity for the entire CF population, across all income categories, should be something that care centers are aware of to help address the nutritional needs of their patients.

## Insurance

The majority of people experiencing food insecurity have some form of public insurance. As shown in Figure 4, 47% of Medicaid beneficiaries and 44% of Medicare beneficiaries have experienced food insecurity. People who are dually covered by Medicare and Medicaid are particularly vulnerable to food insecurity; three-quarters (74%) of so-called “duals” indicate that they have trouble affording food, alter their food intake because of cost, or use supplemental sources to obtain the food they need. This is a truly staggering statistic, indicating that the majority of people who depend on these dual supports for coverage are likely to face the added burden of access to a sufficient nutritional intake.

The factor most likely driving this extraordinarily high rate of food insecurity is a lack of resources to purchase food. The majority of duals (94%) are on disability, and therefore are restricted to income limits to qualify for benefits. The Social Security Administration places strict limits on how much income people can earn to retain eligibility for these disability programs. People who qualify for Supplemental Security Income (SSI) cannot earn more than \$1,260 per month.<sup>22 23</sup> Some people with CF who depend on these disability programs may be able to work additional hours when their health permits; however, the earnings from these extra hours may put their disability status at risk. In the context of food security, it could be that working additional hours would mitigate some of the challenges to accessing adequate food, but people may not have the option of earning additional income for fear of losing their benefits.<sup>13</sup>

Figure 4. Percentage of People with CF Who Experienced Food Insecurity by Insurance Type





People with CF covered through Medicaid may be at higher risk of experiencing food insecurity due to household income. Coverage thresholds for Medicaid vary by state but are generally limited to people with low or very-low household incomes. Given that income has a significant impact on food insecurity, it is unsurprising that Medicaid beneficiaries are more vulnerable to the risk of food insecurity. Moreover, dual eligibles, i.e., individuals who qualify for both Medicaid and Medicare on the basis of income and disability status, are especially vulnerable to health and social needs, regardless of whether they have CF. Those dually insured by Medicaid and Medicare who cannot work may be eligible for certain benefits, such as SNAP, but may still have trouble putting food on the table if SNAP or other benefits are not sufficiently high to cover their nutritional needs.

Table 3 showcases the odds of food insecurity by coverage, while controlling for differences in household income and age.

**Table 3. Adjusted Odds Ratio of Food Insecurity by Insurance of Person with CF**

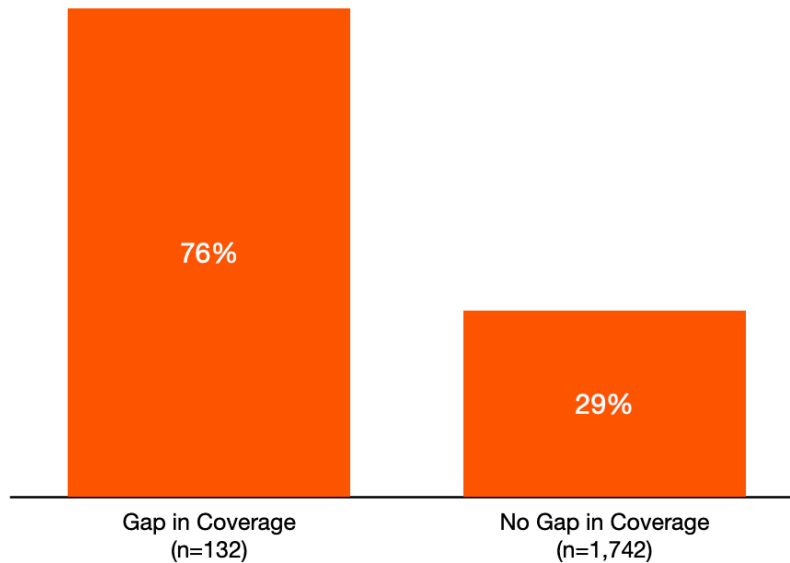
Insurance Type	Adjusted Odds Ratio
Private	(Reference)
Medicaid, CHIP, State Program	2.149***
Medicare	1.808**
Dual	3.503***

*Note:* Odds ratios are adjusted to hold age and household income constant. \* Denotes there is a statistically significant association between insurance type and food insecurity at a p-value <.05 \*\* Denotes a p-value<.01 \*\*\* Denotes a p-value<.001.

*The odds of food insecurity are 2 times higher for people with CF with Medicaid than those privately insured, while controlling for household income and age (p<.001). The odds of food insecurity are 3.5 times higher people with CF dually covered by Medicaid and Medicare than those privately insured, while controlling for household income and age (p<.001). While publicly insured individuals have significantly higher odds of food insecurity than those privately insured, 19% of privately insured people with CF experience food insecurity which is almost double the national average.<sup>15</sup>*

Fewer than 1 percent of respondents were uninsured at the point in time when they completed the Health Insurance Survey. However, we recognize that people can be uninsured at various times throughout a year, with gaps in coverage creating substantial barriers to accessing necessary health services and placing heavy burdens on household finances to be able to afford health care and other necessities of daily living. We asked insured survey respondents whether they were uninsured for any part of the previous 12 months. While the majority of respondents (93%) had coverage for the entire 12-month period, some respondents (7%) did not. As shown in Figure 5, our data indicates people with CF experiencing any gap in coverage are more likely to experience food insecurity than those with consistent coverage.

Figure 5. Percentage of People with CF Who Experienced Food Insecurity by Gap in Coverage

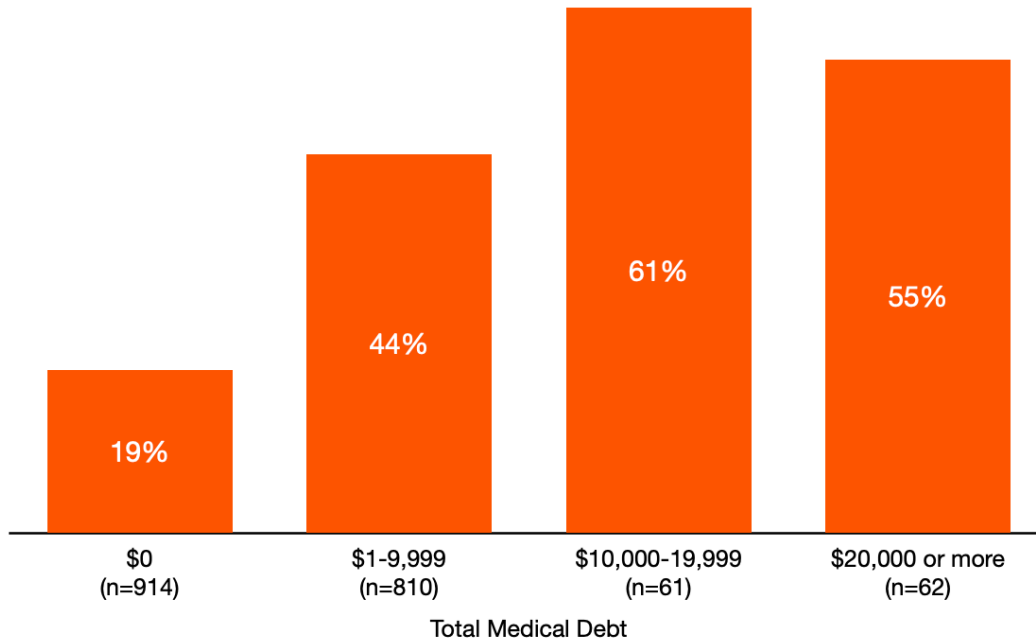


*Three-quarters of people with CF who have had a gap in coverage experienced food insecurity (76%). This reinforces the importance of insurance for people with CF and suggests that a gap in coverage makes people with CF more vulnerable to food insecurity.* We surmise that a gap in coverage places a sufficiently high burden on people with CF to afford medications and other health services, thus leaving less money available to maintain adequate food intake. Looking more closely at the group of people with CF who had a lapse in coverage and experienced food insecurity, 51% have a household income less than \$60,000. This provides further support of the link between income and food security.

## Medical Debt

Carrying medical debt can also serve as a barrier to financial security, which is in turn associated with food insecurity. This can be particularly challenging for people with CF who are faced with a new or unexpected financial burden, while already carrying debt from a previous financial challenge. To better understand the debt people with CF hold related to their health care, we asked survey respondents to report the total amount of medical debt they currently had. Half of people with CF (51%) reported that they have medical debt.

Figure 6. Percentage of People With CF Who Experienced Food Insecurity by Total Medical Debt



*As shown in Figure 6, people with CF with higher amounts of medical debt are more likely to have experienced food insecurity.* For example, 61% of those with \$10,000 to \$20,000 in medical debt, and 55% of those with \$20,000 or more in medical debt, have experienced food insecurity. This compares to about one out of five people with CF who indicate that they have no medical debt. In the debt-free group, those who are food insecure tend to have a lower income than those who are food secure: 77% of those who are food insecure have a household income less than \$60,000 compared to 18% who are food secure. Income, again, stands out as a key indicator of food insecurity. As shown in previous publications on the results from the CF Health Insurance Survey, the financial burden of paying for care can lead to underuse of medications.<sup>10</sup> While insurance is critical to easing the burden of overall health care costs to the patient, the patient’s share of costs can still be quite substantial. A person with CF may be debt-free, but significant copayments and other costs to the patient may constrain their income available to pay for food.

#### *Additional Financial Issues*

In the survey, respondents were also asked a series of questions that address financial issues people with CF or their families have ever faced because of medical bills. As shown in Table 4, people with CF were asked if they have ever been forced to move or were evicted, filed for bankruptcy, had difficulty paying for rent mortgage or utilities, borrowed money from family or friends, or took out money from long-term savings. Eight percent of people

with CF reported that they were forced to move or evicted because of the costs of their CF care. Among those who faced eviction or were forced to move, nearly all (97%) reported food insecurity. Among the 19% of people with CF who had difficulty paying their mortgage or utilities, 73% have experienced food insecurity. Our data suggest that when housing issues impose a financial burden on people with CF, they are much more vulnerable to experiencing food insecurity.

**Table 4. Percentage of People with CF Who Food Insecurity Among Those Who Face A Financial Issue**

	Percentage Who Faced Financial Issue	Percentage Who Experienced Food Insecurity, Among Those Who Faced Financial Issue
Forced to move or evicted?	8%	97%
Filed for bankruptcy?	7%	81%
Had difficulty paying rent/mortgage or utilities?	19%	73%
Borrowed money from friends or family?	30%	71%
Took money out of retirement, college, long-term saving?	39%	50%

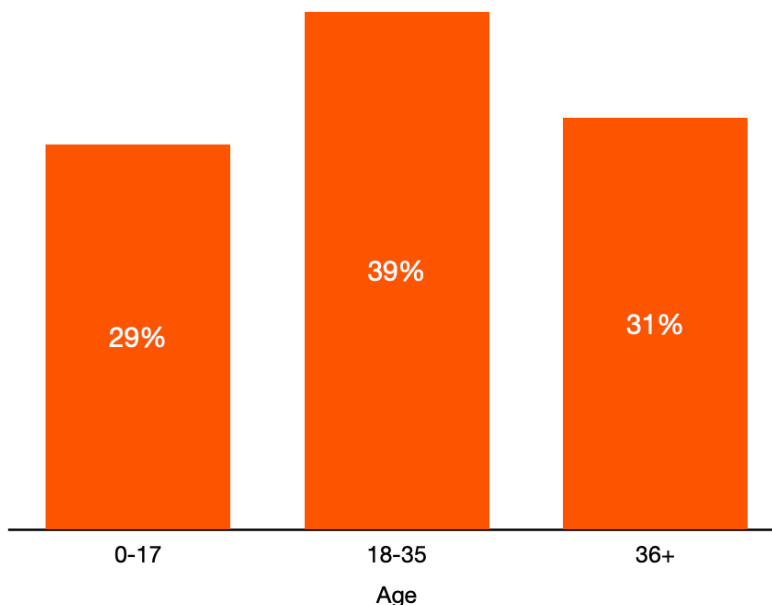
## Demographics

Food security varies depending on the demographic characteristics of the person with CF. In the following section, we examine how food insecurity varies based upon the age, education, race, ethnicity, and employment of the person with CF.

### Age

Figure 7 showcases the percentage of people with CF who are food insecure by three categories of age: children (0-17 years old), young adults (18-35 years old), older adults (36 years old and above). Our data indicate that food insecurity is common across all age groups. Young adults are most likely to report food insecurity, with 39% of 18-35 year olds experiencing food insecurity. About three in ten children (29%) and adults age 36 and older (31%) with CF reported food insecurity. Parents who filled out the CF HIS on behalf of their child were asked to report their child/family’s experiences related to food security. Therefore, reports of food insecurity among children also capture the families’ access to food. Family members, such as the parents, may potentially limit their own access to food in order to protect and better support the child’s nutritional intake.

Figure 7. Percentage of People with CF Who Experienced Food Insecurity By Age



In Table 5, we examine the odds of food insecurity across different age groups, while controlling for differences in household income and insurance.

**Table 5. Adjusted Odds Ratio of Food Insecurity by Age of Person with CF**

Age	Adjusted Odds Ratio
0-17	(Reference)
18-35	1.401*
36+	1.104

*Note:* Odds ratios are adjusted to hold household income and insurance constant.  
 \* Denotes there is a statistically significant association between the age group and food insecurity at a p-value <.05 \*\* Denotes a p-value<.01 \*\*\* Denotes a p-value<.001.

*The odds of food insecurity are 1.4 times higher for younger adults (18-35 years old) than children with CF (p<.05), controlling for household income and insurance.*

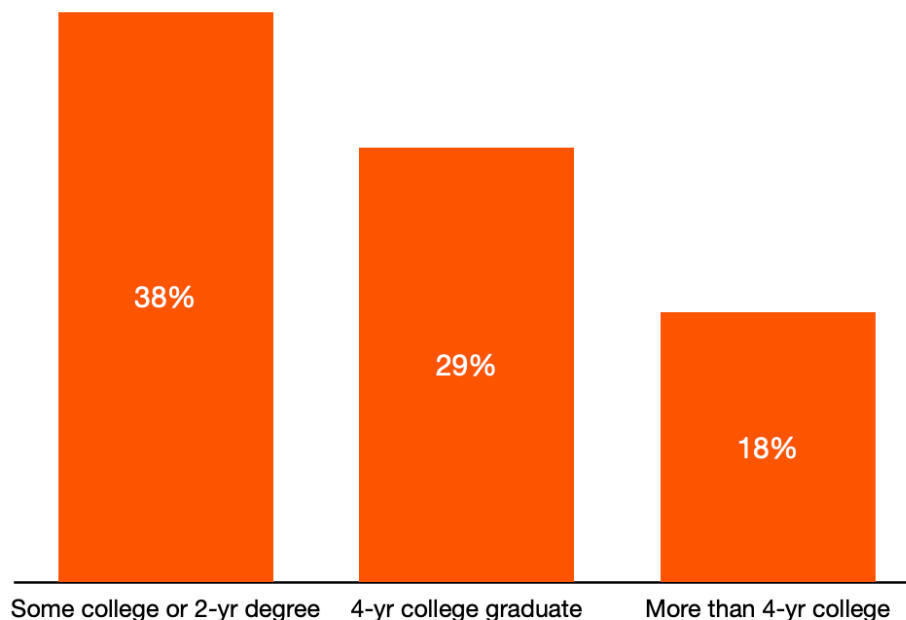
Younger adults may be more likely to experience food insecurity because they have not established financial stability that protects them from food insecurity, and they may not receive as much financial support from parents or partners within the household as children or older adults. Many of them have not been in the workforce for long periods of time and their salaries may reflect lower levels of work experience.

#### *Education among older adults*

In Figure 8 we showcase the percentage of older adults (ages 36 and above) who are food insecure by the amount of higher education they have completed. *The more education an older adult with CF has completed, the less likely they are to have experienced food insecurity.* There is ample evidence that higher education is associated with better

employment and/or higher wages.<sup>24</sup> As we will show in the following sections, higher household income and employment correlate with increased food security. Despite these protections, however, food insecurity is not a rare occurrence in this age group: 18% of adults age 36 and above with more than four years of college education have experienced food insecurity.

Figure 8. Percentage of Adults (36+) with Food Security or Insecurity by Higher Education



### Race and ethnicity

As shown in Table 6, 95% of the people with CF in the sample are white, 2% are Black or African American, and 7% are Latinx.<sup>25</sup> Food security varies substantially by race and ethnicity, though these findings must be interpreted with caution since the number of Black/African American respondents in the survey is small. *One-third of white respondents reported food insecurity (32%). In contrast, two-thirds of Black or African American respondents reported food insecurity (66%).* When we examine differences in food security by ethnicity, we find 41% of Latinx respondents are food insecure, compared to 32% of non-Latinx respondents.

Table 6. Percentage of People with CF Who are Food Insecure by Race and Ethnicity

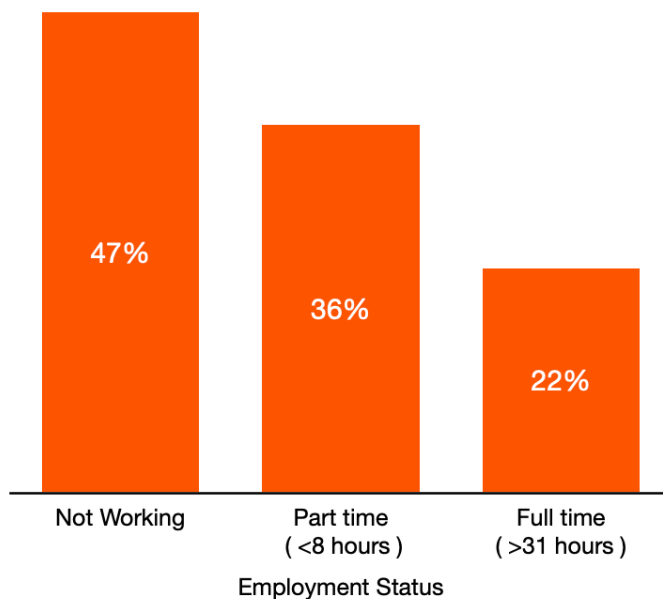
Race or Ethnicity	Race/Ethnicity	Percentage Who Experienced Food Insecurity by Race/Ethnicity
White (n=1,757)	95%	32%
Black or African American (n=32)	2%	66%
Latinx (n=127)	7%	41%

Looking more closely within these smaller subpopulations, it is important to consider the impact of household income on food security. About three-quarters of Black respondents (76%) have an income lower than \$60,000; this compares to 48% of Latinx respondents and 34% of white respondents. It can be hard to draw conclusions based on the small sample size of Black and Latinx respondents. However, our findings indicate that food insecurity may be more prevalent within Black and Latinx CF communities, signaling the need for more research to better understand the risk factors for food insecurity among these subgroups.

### Employment

A significant proportion of people with CF face food insecurity regardless of employment status (see Figure 9). Our data indicate, however, that employment status may be an important risk factor for food insecurity.

Figure 9. Percentage of People with CF Who Experienced Food Insecurity by Employment Status



*The risk of food insecurity increases if a person with CF works less than full time or is not working. Nearly half of people with CF who are not working have faced food insecurity (47%). This is more than twice the rate of full-time workers, though it is noteworthy that even one out of five full-time workers experienced food insecurity in the previous 12 months. This suggests that employment alone does not protect a person with CF from the risks of food insecurity. When we examine the household income of full-time workers, we find that 61% of those who are food insecure have an income below \$60,000, compared to 17% of full-time workers who are food secure. This reinforces that household income is a key indicator of food security and suggests that significant food insecurity challenges remain despite families working.*

## Disability

Disability status is also associated with food insecurity. We asked survey respondents if they receive disability payments as a way to identify the percentage of people with CF who are disabled. Our survey indicates that one-fifth of respondents receive some form of disability benefits. *Among this group, 59% are food insecure compared to 26% who do not receive disability payments (shown in Figure 10).* Our data indicate that there is a greater risk of food insecurity among people who are sicker and less able to work.

Figure 10. Percentage of People With CF Who Experienced Food Insecurity by Disability

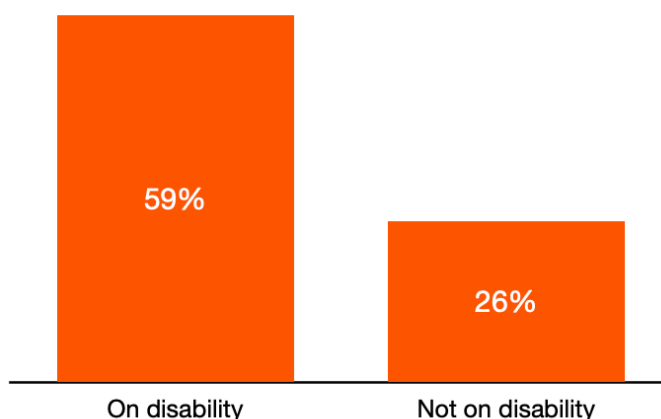


Table 7 showcases the odds of food insecurity by disability payment status, while controlling for household income, insurance, and age.

**Table 7. Adjusted Odds Ratio of Food Insecurity by Disability Payments of Person with CF**

Disability	Adjusted Odds Ratio
Do not receive disability payments	(Reference)
On disability payments	1.594*

*Note:* Odds ratios are adjusted to hold household income, insurance and age constant.  
 \* Denotes there is a statistically significant association between disability payments and food insecurity at a p-value <.05 \*\* Denotes a p-value<.01 \*\*\* Denotes a p-value<.001.

*The odds of food insecurity are 1.6 times higher for people with CF on disability than those not on disability (p=.015), while controlling for household income, insurance, and age.* People on disability have a fixed income that may place them at a greater risk or may make them more vulnerable to experiencing food insecurity. They also are by definition more likely to have greater health care costs or other needs for social supports which can limit the amount of money available to maintain sufficient nutrition.



## Use of Therapies

We believe that it is important to understand the relationship between utilization of specific CF therapies and limited access to adequate food. With input from the CF Foundation, we identified common therapies for CF care management, such as CFTR modulators, G-tube equipment and formula, and diabetes related medications and supplies. This data was collected prior to the availability of Trikafta®. Table 8 shows some of the therapies that are associated with the substantial food insecurity. The left column in Table 8 shows the percentage of people with CF who utilize each therapy. The right column shows the percentage of people with CF who – in addition to using the medication or supplies– *also* have experienced food insecurity. For example, 86% of people with CF in the sample utilize Pulmozyme. Among this group that uses Pulmozyme, 34% had food insecurity. A startling finding of the survey is that nearly half of people who use G- tube or NG-tube formula feeds or equipment to supplement nutrition, experience food insecurity. *As identified in previous publications on the results from the CF Health Insurance Survey, people with CF have significant problems affording these therapies. **Error! Bookmark not defined.** If a person has difficulty affording CF-related therapies, they are more likely to also experience food insecurity. This holds true for the different types of CF therapies.*

**Table 8. Percentage of People with CF With Food Insecurity Among Those Who Use CF-Related Therapies**

Therapy	Percentage Who Use Therapy	Percentage Who Experienced Food Insecurity, Among Those Who Use Therapy
G-tube or NG-tube formula feeds	30%	48%
G-tube or NG-tube equipment	31%	47%
Transplant services and medications	27%	46%
Insulin	38%	45%
Diabetes supplies	41%	44%
Mental health care	48%	43%
CFTR modulators (Kalydeco, Orkambi, Symdeko)	63%	35%
Pulmozyme	86%	34%

## Delayed Care

Survey respondents also provided information about unmet medical need due to cost. People with CF were asked if they delayed CF care center visits when they did not feel well because of cost. Underuse of care center visits associates with poorer health outcomes for people with CF.<sup>26</sup> As shown in Table 9, 10% of people with CF in the sample delayed a visit to their care center when they did not feel well. Among this group of people with unmet need for care center visits, 76% have experienced food insecurity. Respondents were also asked if they delayed or shortened a hospitalization. Twelve percent (12%) of people with CF have delayed a hospitalization; two-thirds of these individuals have experienced food

insecurity. Lastly, respondents were asked if they delayed or skipped prescription medications in the last 12 months. Twenty-four percent (24%) of the sample delayed or skipped medications because of cost. Among this group, 58% have experienced food insecurity. *If patients have some unmet medical care need then the likelihood of food insecurity increases substantially.*

**Table 9. Percentage of People with CF Who Food Insecurity Among Those Who Had Unmet Medical Need**

Unmet Medical Need Due to Cost	Percentage Who Had Unmet Medical Need	Percentage Who Experienced Food Insecurity, Among Those Who Had Unmet Medical Need
Delayed CF care center visit when didn't feel well	10%	76%
Tried to delay or shorten a hospitalization	12%	64%
Delayed or skipped medications	24%	58%

In Table 10, we examine the odds of food insecurity by unmet medical need, holding income, insurance, and age constant.

**Table 10. Adjusted Odds Ratio of Food Insecurity Among Those with Unmet Medical Need**

Unmet Medical Need	Adjusted Odds Ratio
Care Center Visit	
Did not delay visit when didn't feel well	(Reference)
Delayed visit when didn't feel well	7.642***
Hospitalization	
Did not delay or shorten a hospitalization	(Reference)
Tried to delay or shorten a hospitalization	4.001***
Prescription Medications	
Met Rx Need	(Reference)
Unmet Rx need	5.222***

*Note:* Odds ratios are adjusted to hold household income, insurance and age constant.  
 \* Denotes there is a statistically significant association between the unmet medical need and food insecurity at a p-value <.05 \*\* Denotes a p-value<.01 \*\*\* Denotes a p-value<.001.

*The odds of food insecurity are 8 times higher for people with CF who delayed or skipped a CF care center visit when they didn't feel well than those did not skip a care center visit, while controlling for household income, insurance, and age (p<.001).*

*The odds of food insecurity are 4 times higher for people with CF who delayed a hospitalization than those who did not, while controlling for household income, insurance, and age (p<.001).*

*The odds of food insecurity are 5 times higher for people with CF who had some unmet Rx need than those who did not have unmet Rx need, while controlling for household income, insurance, and age ( $p < .001$ ).*

A person with CF who experiences some unmet medical need related to care center visits, hospitalizations, or prescription medications is more vulnerable to experience food insecurity.

## Conclusion

One out of three people with cystic fibrosis are food insecure, compared to one out of ten people in the general population.<sup>15</sup> The alarming presence of food insecurity is seen across all age groups, regardless of income. However, it is clear that income is the most critical factor associated with food insecurity. Our findings indicate that the odds of being food insecure are 19 times higher for people with CF with a household income less than \$30,000 compared to those with an income of \$150,000 or more.

Without question, a lack of resources is the most significant factor associated with food insecurity among the population of people with CF. Nevertheless, we add a cautionary note that focusing only on income to identify food insecurity can overlook pockets of need across all income categories.

The 2019 CF Health Insurance Survey reveals that people with CF with the following characteristics are at highest risk of food insecurity:

- Income and employment:
  - Lower income (less than \$60,000 annually)
  - Not employed for pay
- Financial challenges:
  - Unable to or just meet basic living expenses
  - Have \$10,000 or more in medical debt
  - Have faced a financial issue because of medical bills, e.g., eviction or bankruptcy
- Insurance:
  - Dually covered by Medicaid and Medicare, or covered by Medicaid
  - Interruptions in health insurance coverage
- Vulnerable population groups:
  - Black or African American
  - On disability
- Health care utilization:
  - Use G-tube or NG-tube therapies, transplant services and medications, or insulin
  - Delayed or skipped care center visit, hospitalization, or prescription medications in the last 12 months

While these groups are certainly at greater risk of food insecurity, our data indicate that nearly all of these indicators are related to financial resources. Low household income and barriers to generating income through work appear to be the key indicators for food insecurity among people with CF. More than twice as many non-workers experience food insecurity compared to workers. And the people who aren't working are more likely to be sick or disabled. Even among higher income groups and full-time workers, food insecurity is not uncommon. One in ten respondents with an income greater than 120,000 and 22% of full-time workers have faced food insecurity. The cost burden of CF makes even the most financially secure individuals in the community vulnerable to food insecurity.

Given that people with CF need a sufficient nutritional uptake to optimize their growth and weight, the consequences of food insecurity are likely to be more harmful for a person with CF than someone who does not have CF. Despite the prevalence of food insecurity in the CF population, only about half of food insecure individuals utilize a resource, such as SNAP benefits and food banks, to access their nutritional needs.

It is disheartening to see the extent to which people experience food insecurity, especially when they are also challenged with managing life-long chronic conditions. Vast expansions in programs like SNAP and new programs to address a growing epidemic of food insecurity in the country should be available for people with chronic conditions, and others who are resource constrained. To the extent possible, insurance programs need to address burdensome out-of-pocket expenses, especially among those on Medicare due to disability. Health costs that accrue to patients due to out-of-pocket requirements compete with the costs of basic needs of daily living, like food and shelter. This is especially true for people with CF who face a plethora of costs to maintain and manage their health. No one should ever be forced to make a decision to buy the food they need or medication that they require due to the cost. It appears that people with CF are making decisions about whether to get food, in addition to many other decisions related to care management, given the resources available to them.

Effective and sustainable programs and policies are needed to reduce this gap between food insecure individuals and supportive resources. Screening for food security and providing options for community resources to supplement food intake should be a routine part of care.

This survey was conducted prior to the outbreak of COVID-19. To the extent that people with CF have faced increased financial and coverage-related barriers to accessing food due to circumstances related to COVID-19, the findings presented in this brief are likely to underestimate food security within the CF population.

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## Endnotes

- <sup>1</sup> Kalnins, D., & Wilschanski, M. (2012). Maintenance of nutritional status in patients with cystic fibrosis: new and emerging therapies. *Drug design, development and therapy*, 6, 151–161. <https://doi.org/10.2147/DDDT.S9258>
- <sup>2</sup> MacDonald A. (1996). Nutritional management of cystic fibrosis. *Archives of disease in childhood*, 74(1), 81–87. <https://doi.org/10.1136/adc.74.1.81>
- <sup>3</sup> Van der Haak, N. et al. (2020). Highlights from the nutrition guidelines for cystic fibrosis in Australia and New Zealand. *Journal of Cystic Fibrosis*, 19(1), 16-25. <https://doi.org/10.1016/j.jcf.2019.05.007>
- <sup>4</sup> The Cystic Fibrosis Foundation. Healthy High-Calorie Eating. <https://www.cff.org/Life-With-CF/Daily-Life/Fitness-and-Nutrition/Nutrition/Getting-Your-Nutrients/Healthy-High-Calorie-Eating/>
- <sup>5</sup> Brown PS, Durham D, Tivis RD, et al. Evaluation of Food Insecurity in Adults and Children with Cystic Fibrosis: Community Case Study. *Front Public Heal*. 2018;6:348. doi:10.3389/fpubh.2018.00348
- <sup>6</sup> Sullivan, J. S., & Mascarenhas, M. R. (2017). Nutrition: Prevention and management of nutritional failure in Cystic Fibrosis. *Journal of Cystic Fibrosis*, 16, S87–S93. <https://doi.org/10.1016/j.jcf.2017.07.010>
- <sup>7</sup> Sheikh, S., Zemel, B. S., Stallings, V. A., Rubenstein, R. C., & Kelly, A. (2014). Body composition and pulmonary function in cystic fibrosis. *Frontiers in pediatrics*, 2, 33. <https://doi.org/10.3389/fped.2014.00033>
- <sup>8</sup> Charkhchi, P., Fazeli Dehkordy, S., & Carlos, R. C. (2018). Housing and Food Insecurity, Care Access, and Health Status Among the Chronically Ill: An Analysis of the Behavioral Risk Factor Surveillance System. *Journal of general internal medicine*, 33(5), 644–650. <https://doi.org/10.1007/s11606-017-4255-z>
- <sup>9</sup> United States Department of Agriculture, Economic Research Service. Definitions of Food Security. <https://www.ers.usda.gov/topics/food-nutrition-assistance/food-security-in-the-us/definitions-of-food-security.aspx>
- <sup>10</sup> Seyoum, Semret; Regenstein, Marsha; and Nolan, Lea, "Cost, coverage, and the underuse of medications among people with CF" (2020). Health Policy and Management Issue Briefs. Paper 57.
- <sup>11</sup> The survey used previously validated questions from national surveys related to unmet medical need, coverage, access to care, and financial hardship. Some questions were modified to fit the CF population's experience, and developed new CF-specific questions about services, treatments, and supplies with input from CF Foundation staff and advisors. The survey also included questions on socio-demographic characteristics, general health, CF-related illness and challenges, insurance benefits and coverage, access to care, and costs of CF care.
- <sup>12</sup> Cystic Fibrosis Foundation (2019). Cystic Fibrosis Foundation Patient Registry 2019 Annual Data Report.
- <sup>13</sup> People with CF were categorized into three age groups- children 0-17 years old, young adults 18-35 years old, and older adults 36 years and above. For insurance, we identified

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six unique categories- private, Medicaid, Medicare, Duals, other, and uninsured. To account for people with multiple insurance types we identified respondents as belonging to one insurance category, using the following decision criteria:

- Medicaid: Respondents whose coverage is Medicaid, CHIP, or a state program. The Medicaid category includes respondents with any of these programs or respondents with other sources of coverage in addition to Medicaid, CHIP or a state program, except for respondents with Medicare, who are otherwise categorized (see below).
- Medicare: Respondents whose coverage is Medicare. The Medicare category includes respondents with Medicare alone or with any additional sources of coverage, except for respondents with Medicaid.
- Duals: Respondents whose coverage includes Medicare and Medicaid. The Duals category includes respondents with Medicare and Medicaid only, or respondents with Medicare, Medicaid and additional sources of coverage.
- Private: Respondents whose coverage is private. The private category includes participants with any other additional sources of coverage, except for Medicaid and/or Medicare.
- Other: Respondents whose coverage is not private, Medicaid, Medicare, or uninsured.
- Uninsured: Respondents who report they do not have insurance.

<sup>14</sup> The national average is based on measurements that very closely align with the measures utilized to define food insecurity in this brief. The questions related to food security in the CF Health Insurance Survey are based on validated national surveys. The USDA definition utilized the same questions to measure food insecurity, as well as some additional questions. The food insecurity defined in this brief is therefore very similar to the USDA measurement, and any discrepancies would underestimate the potential food insecurity in the sample.

<sup>15</sup> United States Department of Agriculture, Economic Research Service. Key Statistics and Graphics. <https://www.ers.usda.gov/topics/food-nutrition-assistance/food-security-in-the-us/key-statistics-graphics.aspx>

<sup>16</sup> Tianna Gaines-Turner, Joanna Cruz Simmons, and Mariana Chilton, 2019: Recommendations from SNAP Participants to Improve Wages and End Stigma. *American Journal of Public Health* 109, 1664-1667, <https://doi.org/10.2105/AJPH.2019.305362>

<sup>17</sup> Wilde, P., & Ranney, C. (2000). The Monthly Food Stamp Cycle: Shopping Frequency and Food Intake Decisions in an Endogenous Switching Regression Framework. *American Journal of Agricultural Economics*, 82(1), 200-213. Retrieved February 2, 2021, from <http://www.jstor.org/stable/1244489>

<sup>18</sup> Reppond, H.A., Thomas-Brown, K., Sampson, N.R. and Price, C.E. (2018), Addressing Food Insecurity in College: Mapping a Shared Conceptual Framework for Campus Pantries in Michigan. *Analyses of Social Issues and Public Policy*, 18: 378-399. <https://doi.org/10.1111/asap.12161>

<sup>19</sup> United States Department of Agriculture, Economic Research Service. (2019). *Prevalence of food insecurity by selected household characteristics, 2019* [Data file]. Retrieved from <https://www.ers.usda.gov/webdocs/charts/80061/insecurity.png?v=7069.2>

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<sup>20</sup> In Table 3, we control age and household income to evaluate risk indicators for food security, while accounting for the differential impact of these socio-economic factors on financial burden. In Table 5, we control household income and insurance to account for differences in coverage and socio-economic status. In subsequent regression analyses, we control for age, household income, and insurance in order to account for differences in coverage, age and socio-economic status.

<sup>21</sup> Hamel, L., Norton, M., Pollitz, K., Levitt, L., Claxton, G., & Brodie, M. (2016). The Burden of Medical Debt: Results from the Kaiser Family Foundation/New York Times Medical Bills Survey, (January), 1–29. Retrieved from <https://kaiserfamilyfoundation.files.wordpress.com/2016/01/8806-the-burden-of-medical-debt-results-from-the-kaiser-family-foundation-new-york-times-medical-bills-survey.pdf>

<sup>22</sup> Social Security Administration. Understanding Supplemental Security Income SSI Work Incentives. <https://www.ssa.gov/ssi/text-work-ussi.htm>

<sup>23</sup> Linebaugh, M. (2020, January 31) How Much Can You Work While Receiving SSI Disability Benefits? *Nolo*. <https://www.nolo.com/legal-encyclopedia/how-much-can-you-work-while-receiving-ssi-disability-benefits.html>

<sup>24</sup> United States Bureau of Labor Statistics, Current Population Survey. (2019). *Unemployment rate and earnings by educational attainment* [Data file]. Retrieved from <https://www.bls.gov/emp/chart-unemployment-earnings-education.htm>

<sup>25</sup> This is similar to the demographics reported in the 2019 Patient Registry Annual Data Report. The Registry reports 93% of people with CF are white, 5% are Black or African American, and 9% are Latinx.

<sup>26</sup> Mogayzel PJ Jr, Dunitz J, Marrow LC, Hazle LA. Improving chronic care delivery and outcomes: the impact of the cystic fibrosis Care Center Network. *BMJ Qual Saf*. 2014;23 Suppl 1:i3-i8. doi:10.1136/bmjqs-2013-002363