



# Cystic Fibrosis Research News

## **Title:**

Cost burden among the CF population in the United States: A focus on debt, food insecurity, housing and health services.

## **Lay Title:**

People with CF face high costs of CF care which have implications for debt, access to health care, adequate food, and other necessities of life.

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## **What was your research question?**

CF is a very expensive condition to treat and manage. What do patients say are the financial challenges they face because of the costs of CF care, including covered and non-covered supplies and services? Do patients with CF experience debt, difficulties getting adequate food, and financial barriers to health care?

## **Why is this important?**

Most people with CF have health insurance, which means that a lot of the costs of CF, such as doctor visits and medications, are mostly covered. But even with insurance, people with CF face co-payments, deductibles, and expenses that are not covered at all by insurance, leading to difficulties paying other bills. This also can create challenges in terms of keeping up with the full range of CF and other health care that is necessary for optimal CF management. Being in debt and having barriers to purchasing adequate food have implications for overall health and quality of life.

## **What did you do?**

We developed a patient survey for people with CF and parents of children with CF. The Cystic Fibrosis Foundation used its patient and affiliate networks to advertise the online survey. We surveyed over 1800 people with CF in 2019 (pre-COVID-19) to learn about their insurance coverage, the financial challenges they faced in getting CF care, whether they were or had

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been in debt because of their medical bills, and if they experienced difficulties accessing the food they needed. We created a measure of “financial burden” that indicated a person had debt, housing or food challenges, or some combination of these.

## **What did you find?**

The vast majority of people with CF are covered by some form of health insurance. Yet two-thirds of people with CF face financial burdens, with more than half of respondents reporting debt issues. About a quarter of respondents face housing issues and a third face challenges obtaining adequate food for themselves or their families. Importantly, financial burdens are associated with unmet medical needs, such as not having prescriptions filled, delayed or forgone CF care center visits, and delayed hospitalizations. Income is the biggest risk factor for financial burden for people with CF with levels of burden highest among lower-income groups.

## **What does this mean and reasons for caution?**

Financial burden is widespread among the CF population, with serious implications for their ability to take full advantage of the recommendations of their care team. Health insurance shields against some but not all CF costs, with many the responsibility of the person with CF or a family member. The CF care team should be aware of the challenges people face on a routine basis accessing the services, medications, supplies and other supports that are so important to optimal management of CF.

## **What's next?**

Policy change is needed to protect people with CF from financial burdens through health insurance or other supports. More research needs to address the coverage implications of an aging CF population, who will qualify for Medicare coverage by virtue of disability or age. Medicare requires substantial out-of-pocket payments from beneficiaries.

## **Original manuscript citation in PubMed**

<https://pubmed.ncbi.nlm.nih.gov/36710098/>