

Food and Transportation Disparities



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Real World Health Care

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Food and transportation insecurity can lead to poor health outcomes among underserved populations.

Food and Transportation Disparities is a recently published series of articles that spotlights the organizations and efforts dedicated to lessening and removing these disparities so patients can focus on their health.

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Social Determinants of Health Create Barriers to Care

Social determinants of health (SDOH) are the non-medical factors that influence health outcomes. They are the conditions in the environment where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.

SDOH contribute to wide health disparities and inequities. For example, people who don't have access to grocery stores with healthy foods are less likely to have good nutrition. That raises the risk of health conditions and even lowers life expectancy relative to people who do have access to healthy foods.

This year, Real World Health Care will focus on two key SDOH issues: food insecurity and transportation insecurity. We'll share insights and practical solutions from organizations working to break down these barriers to care and create more equitable conditions for patients.

What is Food Insecurity?

Food insecurity is defined as a household-level economic and social condition of limited or uncertain access to adequate food. In 2021, 13.5 million households comprising 33.8 million people were food insecure at some time during the year. Food insecurity may be long-term or temporary and can be influenced by neighborhood conditions, physical access to food, and lack of transportation. It has increased dramatically since the start of the COVID-19 pandemic.

Impact of Food Insecurity on Cancer Management

Studies have suggested that food insecurity likely contributes to the development of chronic disease in some cases (through nutritional and behavioral pathways), whereas chronic disease likely contributes to the development of food insecurity in other cases (by increasing health care expenditures and decreasing employability). A 2022 study found that 32% of cancer survivors (those with a self-reported cancer diagnosis) were food insecure.

Health researchers, in a recent commentary in the journal *Cancer*, reviewed numerous studies about the link between cancer and food insecurity, several of which found that the prevalence of cancer increases as the severity of food insecurity increases. The studies they reviewed also found:

- Diets high in animal fat increase the risk of breast, colon, pancreatic and prostate cancer, whereas diets high in fruits, vegetables and whole grains may be protective.
- Severely constrained food budgets in food-insecure households may complicate the cachexia and anorexia experienced by patients with cancer.
- Individuals in food-insecure households prioritize foods with refined grains and added sugars, salts and fats because they are generally less expensive than healthier foods and their longer shelf life protects against the expense of food spoilage.

- When healthy foods are available in low-income communities, they often are of poorer quality.
- Food insecurity can be a significant driver of cancer distress, which can lead to treatment non-adherence, increased use of outpatient and emergency department care, greater difficulty in decision making, and poorer quality of life.

When cancer patients experience food insecurity and cannot adhere to their medication regimen, the risk for disease complications increases. In one study, 55% of patients with food insecurity did not take their medications because they were unable to afford them, compared to 12% of their peers that were food secure.

In the Cancer commentary, the researchers note that no formal recommendations for food insecurity screening exist in the oncological clinical setting. However, they point to the Hunger Vital Sign™ (HVS), a two-question screening tool that has been validated in both adult and pediatric patients. (Editor’s Note: The USDA also offers the U.S. Household Food Security Survey Module developed by the National Center for Health Statistics.)

The researchers also point to several resources and interventions for food-insecure patients, including the Supplemental Nutrition Assistance Program (SNAP), local food banks, home-delivered meals and community programs that may mitigate food insecurity by providing food or money for food. They also note that non-food resources, such as prescription payment assistance programs, can help to relieve food budgets by allowing for the shifting of household expenses.

What is Transportation Insecurity?

Transportation insecurity can be defined as a condition in which one is unable to regularly move from place to place in a safe and timely manner because one lacks the material, economic or social resources necessary for transportation.

According to research from the University of Michigan, one in four adults in the U.S. experience transportation insecurity, making it difficult for them to hold a job, get to the grocery store or child care, and conduct other daily activities. The researchers note that problems with transportation are commonly cited as a primary reason people miss or delay medical appointments or leave prescriptions unfilled, with consequences for individual health outcomes.

Impact of Transportation Insecurity on Cancer Treatment Adherence

In 2021, the National Cancer Policy Forum of the National Academies of Science, Engineering, and Medicine sponsored a series of webinars addressing key social determinants of health, including food, housing, and transportation among patients with cancer. In a commentary article summarizing the webinar series, experts noted several reasons that transportation insecurity is an acutely important problem for patients with cancer:

- Patients with cancer are particularly susceptible to transportation as a barrier to medical care, with higher rates of transportation insecurity relative to similar patients without a history of cancer.
- Transportation insecurity among patients with cancer is common.

- The consequences of transportation insecurity among patients with cancer are substantial and may result in patients forgoing, missing, delaying and/or altering necessary clinical care.
- Transportation insecurity has the potential to increase rates of cancer recurrence and mortality as well as exacerbate disparities in cancer incidence, severity, and outcomes.

In an effort to gain insights into who experiences transportation insecurity and help others determine which interventions can improve transportation insecurity, the University of Michigan researchers developed and validated a Transportation Security Index, the first tool to measure transportation security. Modeled after the Food Insecurity Index, the Transportation Security Index is a 16-question survey composed of items that focus on the symptoms of transportation insecurity.

Among many potential uses for the Transportation Security Index, the researchers suggest that health providers and social workers use the tool to screen patients to identify whether they need transportation-related assistance. Such assistance may be available through local transportation authorities or via grants from non-profit organizations like the HealthWell Foundation, which offers transportation assistance through several travel funds.

Food Insecurity in America

Most of us are taught from an early age that to be healthy, we must eat healthy foods. Poor diets – those in which people consume excess fat, sugar and calories – are linked to a range of health problems including obesity, high blood pressure, diabetes and hypertension.

For some Americans, however, easy access to healthy food is not a given. An estimated 23.5 million live in food deserts, meaning that a supermarket offering a selection of healthy foods is more than one mile away in an urban area or more than 10 miles away in a rural area. Compounding the problem, over two million Americans live in food deserts and don't have a car or public transportation, making it nearly impossible to get to a supermarket.

The Intersection of Food Insecurity and Health

Beyond those who live in food deserts, many more Americans are considered food insecure, meaning they can't always afford sufficient food, regardless of its easy availability or nutritional value. Hunger Free America estimates that 54 million Americans are food insecure, a number that increased dramatically upon the start of the COVID pandemic.

Food insecurity has a direct impact on health. A recent study found that food insecure families have 20 percent greater health care expenditures than food-secure families, for an annual difference of \$2,456. A different study found that 54 percent of older adults who are food insecure have multiple (two or more) chronic conditions, compared with 41 percent of food secure individuals.

Before the COVID pandemic, the University of Michigan National Poll on Healthy Aging surveyed a national sample of U.S. adults age 50-80 about household food insecurity. The poll found:

- 45 percent of adults who were food insecure rated their physical health as fair or poor, compared to 14 percent of those who were food secure.
- 24 percent of those who were food insecure reported fair or poor mental health, compared to five percent of those who were food secure.
- 43 percent of those who were food insecure rated their diets as being fair or poor quality compared to 20 percent of those who were food secure.

Who is Food Insecure?

"Hunger and food insecurity exist in every state in the nation – in inner cities, rural areas and even the suburbs, where the problem is growing rapidly" said Joel Berg, CEO, Hunger Free America, pointing to recent USDA data indicating that the Southeast and Southwest suffer the highest rates of food insecurity. "The mental image that most people have of who is hungry – the homeless person or panhandler on the street – is not accurate. Less than five percent of food insecure people are homeless."

Instead, said Berg, food-insecure Americans are most often lower-income wage earners who haven't seen a cost-of-living increase in over a decade and who often must juggle affording food with affording housing, health care, childcare and transportation.

"They may be forced to ration food, eat less frequently, buy less costly and therefore less healthy food, and even forgo food themselves to feed their children," Berg said.

Berg noted that it may surprise some people to know that the largest number of people who are hungry and food insecure are white, “although people of color are more likely to live in poverty and suffer from food insecurity.”

Households headed by single mothers, he said, have about three times the food insecurity as two-parent households.

Falling into Poverty: The Erosion of the Middle Class

Berg debunked another myth about intertwined poverty and food insecurity: that it is primarily cultural and inherited – the same people facing the problem year in and year out. Instead, he said the number of people who are sometimes poor and hungry is ten times greater than that of people who are always poor and hungry.

“Most people who suffer from food insecurity do so episodically, when they are down on their luck,” he said.

“Perhaps they’ve been treading water in the middle class

and their car breaks down. They can’t get to work and therefore lose their job. Or they get sick and need to take time away from work. Or their workplace shuts down or has layoffs. Suddenly, they have fallen out of the middle class and into poverty.”

Hunger Free America’s philosophy believes that ending poverty is the key to ending hunger and food insecurity.

“Until workers are paid higher wages, the government expands the federal food safety net, and there are more living wage jobs, there will continue to be hunger in America even if we produce enough food to feed all 330 million of us,” Berg said.

Hunger Free America: A Lean Organization with a Mighty Presence

Hunger Free America partners with hundreds of organizations nationwide to inspire change through a combination of advocacy and direct service designed to help people receive the assistance they need.

Hunger Free America’s AmeriCorps VISTA (Volunteers in Service to America) program works on the frontlines of hunger at partner organizations around the country. Year-long VISTA members help build the capacity of food pantries, soup kitchens and other groups by recruiting volunteers, conducting research and supporting benefits outreach.

Hunger Free America also operates the National Hunger Hotline (1-866-3-HUNGRY/1-866-348-6479) on behalf of the U.S. Department of Agriculture. The hotline directs callers from all 50 states and territories to their local SNAP (Supplemental Nutrition Assistance Program) offices, provides information about federal benefits programs, and lets callers know where they can find food immediately through a national database of food resources.

Hunger Free America also conducts advocacy at the local, state and federal levels; conducts original research on federal nutrition programs, child hunger, and the challenges facing low-income Americans; and publishes groundbreaking reports that provide data to support its concrete yet realistic solutions to poverty and hunger.



Joel Berg

“We also operate a strategic volunteer program that connects individuals and groups with skills-based and high-impact volunteer opportunities,” Berg concluded. “It’s these opportunities that make the biggest difference in the national fight against hunger.”

CancerCare: Barriers to Proper Nutrition are Both Financial and Physical

As part of our series on Food and Transportation Disparities, *Real World Health Care* reached out to Leeann Medina-Martinez, LCSW, CancerCare’s Disparities Program coordinator. CancerCare is the leading national organization providing free, professional support services and information to help people manage the emotional, practical and financial challenges of cancer.

We asked Medina-Martinez about the nutrition-related barriers cancer patients face when being treated for cancer and where they can seek help.

Importance of Proper Nutrition for Cancer Patients

Real World Health Care: Why is proper nutrition so important for people living with cancer?

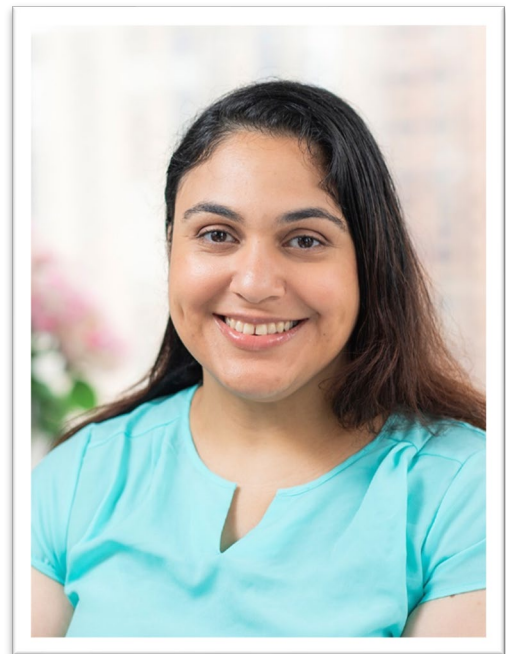
Leeann Medina-Martinez: Nutrition is an important part of maintaining strength and weight. It helps patients keep their bodies fueled and better manage treatment side effects. Lack of proper nutrition can impact treatment plans. For example, if a patient who is on chemotherapy loses too much weight and isn’t able to maintain weight, there is a possibility the oncologist might decide to stop chemotherapy.

Barriers to Proper Nutrition

RWHC: What are some of the common barriers cancer patients face in terms of getting the proper nutrition?

LMM: The barriers cancer patients face in getting proper nutrition are usually financial and physical. On the physical side, it can be difficult for some cancer patients to stomach certain foods. Depending on the specific cancer diagnosis and treatment, patients may experience a change in appetite – typically a decreased or complete lack of appetite that leads them to skip meals. Some cancer treatments create food aversions, dry mouth and mouth sores that make eating a challenge. Nausea, fatigue and pain can also serve to dampen appetite or create an aversion to food.

The financial barrier is not having enough money to purchase recommended foods, such as fresh fruits, vegetables and lean proteins. Or, these foods may not be readily available to them at their local store. Getting to a grocery store with nutritious and affordable food is especially a barrier for patients living in “food deserts” (urban areas without close access to



Leeann Medina-Martinez

affordable and healthy foods) or even rural areas, when patients lack access to public transportation, a car, or family and friends who can help with grocery shopping.

RWHC: How are those barriers compounded if the patient lives with food insecurity?

LMM: If a patient lives with food insecurity, the barriers I mentioned earlier are intensified because they are less likely to be able to travel to get food. Patients may not be able to afford food that is both palatable and provides the nourishment their bodies need. Moreover, they might not want or be able to eat the foods that are available because of the side effects of treatment on their body.

Better Nutrition Starts with a Conversation

RWHC: How can cancer patients improve their nutrition? Are there any common tips for increasing their appetite or finding foods that will be more palatable?

LMM: Patients should discuss their nutrition needs with their oncology team, including the nutritionist on the team. These discussions are important because there are medications and recommendations (including taking vitamins and supplements) that can be made based on the patient's health history that may assist in increasing appetite. Most suggestions are to eat fresh vegetables, whole grains, fruit, and protein with a focus on high-protein snacks, and sufficient hydration. Some tips for increasing appetite or finding foods more palatable are to eat favorite foods at any time of the day – having breakfast food for dinner as an example, or adding lemon juice or fresh fruit to water to improve its taste.

If their care team does not include a nutritionist, patients may want to start by reaching out to their insurance company to find an approved provider. If that is not an option, patients can reach out to CancerCare for help finding a nutritionist, identifying a nutritionist at their hospital or provider, and connecting them with nutrition-related educational resources. Another avenue is to try [Ina®](#), the [Intelligent Nutrition Assistant](#). A partnership with CancerCare and Savor Health, Ina provides nutritional support and guidance 24/7 through text messaging.

Financial Assistance May be Available

RWHC: What can cancer patients or their loved ones do if they are having problems affording nutritious food during their treatments?

LMM: Nutrition plays an important role in the patient's well-being. Patients and caregivers should put a plan into place for finding, accessing and affording nutritious food. If they find themselves in a situation where they are deciding on whether to go without certain foods, or food in general, then they might be facing some food insecurity. Patients who are food insecure may be eligible for financial assistance for food and transportation services, including Meals on Wheels, food pantries, government benefits and other community groups available to help. The financial cost of cancer treatment may also create additional financial burdens for patients who can no longer afford, or have the energy to buy and prepare, nutritious foods. They should know support is available and there is no shame in asking for assistance.

RHWC: What services and support does CancerCare offer to help people who are concerned about their nutrition or having nutrition-related problems during their cancer treatments?

LMM: CancerCare offers several services such as publications, Connect Education Workshops, resource navigation services, as well as A Helping Hand resource database. CancerCare also offers limited financial assistance that can assist with transportation concerns. In addition, CancerCare has partnered with Magnolia Meals at Home, a meal delivery program that aims to help patients by providing nourishing meals to households affected by cancer available in a few states. We also offer My Cancer Circle, a free, private community for caregivers to organize support, including meal deliveries and transportation, for their loved ones with cancer.

Don't Let a Tank of Gas Stand in the Way of Needed Medical Treatment

The diagnosis can be frightening enough. Hearing you or your child has cancer, a rare disease or other chronic health condition can send the heart sinking and the mind spinning. Is the condition treatable? What do treatments entail? How will your quality of life be impacted?

Then comes the financial concerns. Will you be forced to miss work, take a leave of absence or quit your job while you or your child copes with the effects of the disease? How costly are the treatments? How much will insurance cover?

Transportation Insecurity Is a Nationwide Problem

These concerns are very real for Americans with chronic and life-altering illnesses. And for many, they are compounded by an additional practical and financial worry: how to get to their doctor's appointments and treatments.

- About 8.5 percent of Americans don't have access to a car, according to recent U.S. Census Bureau data, although that percentage climbs to 30-35 percent in areas like New York and the District of Columbia.
- According to the American Public Transportation Association, more than two in five Americans have no access to public transportation.
- Affording gasoline or other transportation costs is now a top concern for U.S. adults, with about 71 percent polled by Kaiser Family Foundation in March 2022 noting that they are either "very worried" or "somewhat worried" about being able to afford these costs (up from 40 percent who said the same in February 2020).

Transportation insecurity – defined as a condition in which one is unable to regularly move from place to place in a safe and timely manner because they lack the material, economic or social resources necessary for transportation – is a key measure of poverty and a social determinant of health. It affects people in large cities, small towns, suburbs and rural areas across the country and prevents 3.6 million Americans from receiving medical care each year.

Patients facing transportation insecurity should discuss their concerns with their health care team. Often a care team's social worker or patient navigator can help them find local services or volunteers to assist. Several national charitable organizations also provide assistance.

Compass to Care: Built from Personal Experience

Michelle Ernsdorff-May is the founder and CEO of [Compass to Care](#), a 501(c)(3) organization that provides free, non-emergency medical transportation (NEMT) solutions to access lifesaving cancer treatment and clinical trials for children fighting cancer and facing poverty or cancer-related financial toxicity.

Ernsdorff-May knows all too well the impact a cancer diagnosis can have on a family because she experienced it herself. She was diagnosed with a rare form of kidney cancer at 14 months, and there were no pediatric oncologists in her hometown of Dubuque, Iowa. Her family, forced to seek treatment for Ernsdorff-May at a clinic 200 miles away from home, soon discovered the financial burden of a year and a half of back-and-forth travel.

“One time, I was hospitalized unexpectedly,” she says. “My mother stayed with me in the hospital, but my father had to get back home to work. He ended up hitchhiking home because he didn’t have the money for a bus ticket or car rental. Later in life, I found out this type of extreme scenario is all too common.”

According to Ernsdorff-May, only about 200 pediatric cancer centers exist in the U.S., and 30 percent of children have to travel at least 60 miles to reach an oncologist. This travel can be particularly burdensome in the early stages of cancer diagnosis, when frequent trips to the doctor are needed for testing and treatment planning.

“Because parents can’t take short- or long-term disability to care for a child, they have no choice but to reduce their work hours or take unpaid Family & Medical Leave,” she says, noting that one in four families lose 40 percent of their household income when a child is diagnosed with cancer. “They quickly find themselves on the slippery slope of having to pay for increased medical and non-medical expenses with reduced or no income.”



Michelle Ernsdorff-May

Read how [Compass to Care](#) helped Amy and her son Codey receive the experimental treatment he needed to fight the neuroblastoma he’s been living with for 16 years.

Fighting Cancer One Trip at a Time

Today, Compass to Care helps pediatric cancer patients and their families by providing financial assistance for airfare, gasoline, lodging, parking fees, taxi or ride share services, and train fare. Patients, their loved ones, or care team can [apply online](#) and receive assistance in as little as 24-48 hours.

“A tank of gas, a train ride or even a plane ticket may seem like a minor issue in the face of medical costs that can run thousands or tens of thousands of dollars,” Ernsdorff-May says. “However, research points to a risk of relapse when a child misses just one daily dose of chemotherapy in a two-week course. That’s why we want to help ensure that children arrive on time, every time treatment is scheduled.”

Mercy Medical Angels Restores Hope and Health

[Mercy Medical Angels](#) also helps to remove barriers to medical care through air and ground transportation assistance. Since 1972, it has provided more than 300,000 trips for patients who can’t afford to travel to long-distance health care, with 35,000 trips just last year.

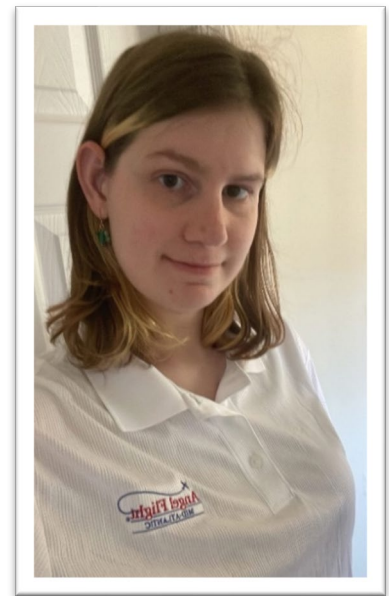
Mercy Medical Angels provides transportation assistance through several affiliated organizations:

- Angel Flight Mid-Atlantic: a network of experienced volunteer pilots who generously donate their time, private airplane and resources to transport patients to medical care.
- Angel Wings for Veterans: provides flights to veterans and their families to vital health care resources they can't otherwise afford.
- Angel Canines and Wounded Warriors: provides transportation to vetted service dog organizations for veterans with post-traumatic stress or depression.
- Angel Wheels: provides ground transportation with gas cards and bus or train tickets to non-local medical care more than 50 miles away.

"Our volunteer pilots are the most wonderful people on the planet," says Stephanie Singer, communications specialist, Mercy Medical Angels. "If for some reason, we can't fly a patient on a general aviation aircraft, the pilot will drive the patient to the airport for a commercial flight."

Singer notes that the organization is always looking for volunteer pilots, "If you enjoy flying and want to make a difference in the lives of others doing something you love, please contact us."

In addition to volunteer pilots, Mercy Medical Angels works with commercial airlines to provide charitable flight assistance. Read how they partnered with one airline to help 14-year-old Emma and her mother get from Arkansas to New York for treatment of several life-altering medical conditions.



Stephanie Singer

Unexpected Financial Burdens

To help people understand the role that transportation insecurity has, Mercy Medical Angels points to stories like Emma's and to Liliana's, whose sudden diagnosis of a rare kidney disease created an unexpected financial burden for her family.

"Transportation insecurity can happen to anyone, not just those who have had long-term financial problems," she explains. "Often, it happens to families in which one or both parents have worked and built their savings over the years. A sudden diagnosis can wipe out those savings pretty quickly."

Singer invites families who need assistance traveling to health care treatments to apply online for help from Mercy Medical Angels.

Travel Assistance Available from the HealthWell Foundation

The HealthWell Foundation (publisher of *Real World Health Care*) currently offers several assistance funds designed to help patients with transportation-related costs:

- The Cancer-Related Behavioral Health Fund offers assistance with transportation needed to manage cancer-related behavioral health issues.

- The [Emergency/Medical Workers Behavioral Health Fund](#) offers assistance with transportation needed to manage behavioral health issues affecting emergency and medical workers.
- The [Gout Travel Fund](#) provides assistance for travel related to obtaining treatment for gout.

“Financial and transportation insecurities can create long-lasting effects,” says Krista Zodet, president & CEO, HealthWell Foundation. “We are honored to help patients access the treatments they need for life-altering illnesses.”

No One Left Alone Addresses Cancer Health Disparities at the Local Level

As the president of the Community Oncology Alliance (COA) in 2021, during the height of the COVID-19 pandemic, Kashyap Patel, MD, was troubled by the significant health care disparities faced by racial and ethnic minorities. He started to investigate how where someone lives – down to their individual zip code – affects their ability to access quality health care.

“I was intrigued by a 2013 study from the Robert Wood Johnson Foundation, which found that life expectancy of people born in different neighborhoods in New Orleans varied up to 25 years,” he says. “People born in the French Quarter had an average life expectancy of 55 years, while those born just 10 miles northwest of that lived an average of 80 years.”

Dr. Patel saw parallels in his own practice, Carolina Blood and Cancer Care Associates (CBCCA), which serves patients in two clinics – one in a relatively affluent suburb of Charlotte and the other in the heart of rural South Carolina, where a faltering industrial-based

economy led to sharp decreases in education and income levels. Many residents in that part of the state lack easy access to transportation, nutritious food and safe housing as well, making them some of the most vulnerable and marginalized patients by cancer health disparities.

These social determinants of health (SDOH) are risk factors for early mortality, says Dr. Patel, pointing to an American Association of Cancer Research study that found 34% of all cancer deaths could be prevented if socioeconomic disparities were eliminated.

“Advances in science over the past few decades have been significant and have taken us far in reducing cancer mortality, but unfortunately, not everyone can benefit from those advances,” he says. “If a patient doesn’t have something as basic as a reliable ride to and from the doctor’s office, they may miss a blood check, putting them at risk for infection. If they live in a food desert, they can’t access the healthy food they need to support their nutritional requirements. If they live in an area underserved by technology infrastructure, telehealth visits are impossible.”

Ensuring Equitable Access to Care

To address these SDOH issues, Dr. Patel launched a program called No One Left Alone (NOLA). In its pilot stage at CBCCA, NOLA focused on addressing patients’ financial insecurity and hired a new staff member to match financially needy patients with free drugs through patient assistance programs. Dedicated financial counselors completed required paperwork on behalf of patients, often applying to multiple foundations to ensure the patient had no or minimal out-of-pocket costs.



Kashyap Patel

“Not a single patient was turned away for treatment regardless of their ability to pay,” says Dr. Patel.

NOLA’s second step was to improve access to biomarker and germline testing – an important indicator of the root cause of a patient’s cancer – by working with testing labs to cover the procedures as a component of their research. This alleviated the need for patients to cover out-of-pocket costs for the expensive tests. NOLA’s efforts resulted in an increase in biomarker testing from about 30-40 percent of CBCCA patients to 80+ percent.

“The need for this is critical, because only one in four eligible patients with cancer receives biomarker testing, which can help determine the most effective course of treatment,” adds Dr. Patel.

In February 2022, NOLA started to collect extensive SDOH data. They developed a detailed patient intake form to evaluate patients’ access to transportation, literacy, mental health, food insecurity, social support, and housing security. Working through a local consortium of 15 non-profit organizations, NOLA refers patients to needed services for food, housing and transportation, along with cancer screening services.

“Intervention at the local level, with social safety net solutions, is critical,” Dr. Patel says. “In fact, global studies show that countries investing in providing healthy food and accessible transportation have higher life expectancies than here in America. Our goal with NOLA is to not only serve our patients locally, but also to provide a replicable road map that can be shared with other practices around the country.”

NOLA’s next focus is building a fund to cover insurance copays for hospital visits, to further alleviate the financial toxicity facing cancer patients. Equitable access to clinical trials is another key goal. As NOLA tackles these new goals, Dr. Patel says they will continue to foster partnerships with multiple stakeholders, including local non-profits, congressional offices, the state Department of Health and Human Services and Medicaid teams, and others to create a collaborative effort.

Community Practices Drive Action

CBCCA is a model for independent oncology practices, with five physicians, four mid-level providers and eight research staff who see about 1,500-1,900 new patients annually. The practice benefits from its membership in COA, which is helping to drive action with a NOLA-like program in Texas and other initiatives.

According to a COA position statement, “COA and its members strive to recognize disparities whenever possible and are committed to being leaders in collective efforts to end them.” To that end, COA established a Health Equity Committee in 2022 to lead its efforts to address cancer and other health disparities through research and projects.

“Taking action and tackling problems like cancer care disparities at a local level is a hallmark of what the COA does,” says Dr. Patel, who is working on a cancer disparities playbook to help other community providers address equitable cancer care delivery locally. “System-level changes are important, but they take time and funding. Patients with cancer cannot wait for macro-level changes to take place.”

People with Cystic Fibrosis at Higher Risk for Food Insecurity

Proper nutrition is crucial for everyone. Healthy foods fuel our bodies and minds, help us grow and thrive, and can even play a role in warding off disease. Unfortunately, millions of Americans don't get proper nutrition because they are food insecure, meaning they can't access or afford sufficient nutritious food.

Food insecurity is a particular problem among people with cystic fibrosis because their nutritional requirements are more challenging than the general population's. Many with CF need to take in double the amount of food and calories as others due to an increased metabolic rate and pancreatic insufficiency, which hinders the absorption of essential nutrients. Spending on food is higher as a result.

"People with CF produce a thick, sticky mucus throughout the body," explained Kim Reno, senior manager of Health Systems Innovation and Navigation, Cystic Fibrosis Foundation (CF Foundation). "That mucus keeps the digestive tract from absorbing the nutrients needed to maintain and gain weight. As a result, patients may be at risk for poorer health outcomes and decreased survival."



Kim Reno

Affording Care and Affording Food

Reno joined CF Foundation five years ago after spending 23 years as a clinical social worker in a CF care center. She was tasked with helping the organization tackle the issue of food insecurity and learned that food insecurity is a challenge for a number of reasons.

A 2019 study supported by CF Foundation and conducted by researchers from the Milken Institute School of Public Health at George Washington University found up to 33 percent of CF patients faced food insecurity and 20 percent were unable to afford the balanced meals recommended by their CF care team. While food insecurity was found to be most common among lower-income, non-working individuals with CF, it was also seen at higher income levels and among people working in paid employment.

"Even before the COVID-19 pandemic, when fresh fruits and vegetables started to become more expensive for everyone, we heard from CF clinicians that access to food was a problem for people with CF across all income levels," Reno said. "Between out-of-pocket costs associated with frequent doctor appointments, and expensive medications and treatments, people with CF are often forced to make tradeoffs between their medical care and basic needs like food, rent and utilities."

Screening for Food Insecurity

One of CF Foundation's first initiatives to help reduce food insecurity among the CF population focused on increasing awareness of the issue among CF care providers. CF Foundation created a Food Security Committee comprised of doctors, dietitians, nurses,

social workers, CF patients and family caregivers from around the country and began to collect data about how patients are screened for food insecurity.

They found that only about half of CF care centers were screening patients for food insecurity and that there were no formal or standard screening tools being used. The committee therefore focused their initial efforts on educating clinicians about the importance of food security and how to have probing, yet compassionate conversations with their patients about the issue. The goal was to have every CF patient asked about food security at every visit, using an evidence-based tool like the Hunger Vital Sign.

“Screening tools like the Hunger Vital Sign often ask patients to rate changes in their food security ‘in the last year,’” Reno elaborated. “But food insecurity can change on a dime. Food that is affordable and accessible one month may not be the next month. That’s why these conversations are so essential at every quarterly appointment, and why we need to collectively erase the stigma associated with food insecurity, because it can happen to anyone at any time. The clinic should be a safe space where patients feel comfortable answering questions honestly.”

As a result of its education efforts, CF Foundation has seen an increase in food security screening, with over 90 percent of care centers now conducting regular screening.

Pilot Program Gets Nutritious Food to Those in Need

As CF Foundation continues to conduct additional food insecurity research, it also is tackling the issue on the ground. In 2021, CF Foundation partnered with Food & Friends, a Washington, D.C.-area non-profit that provides home-delivered, medically tailored meals and nutrition therapy, as well as groceries and nutrition counseling, to people living with life-challenging illnesses.

Registered dietitians on the Food & Friends staff work in partnership with registered dietitians at CF Care Centers to design a diet high in calories, especially protein and fat, to address the complex nutritional needs for people with CF. The partnership focused on serving three targeted groups of CF patients, including pediatric patients, patients discharged from the hospital, and patients who are awaiting a lung transplant and are unable to shop and prepare food.

According to Reno, since the partnership started, referring CF care centers have reported a decrease in food insecurity and family stress among participants. CF Foundation is currently working to expand the program to other states.

“We also are compiling some out-of-the-box ideas from CF care centers to share with the provider community,” she said. “For example, one center helps its patients obtain hunting and fishing licenses. Others are creating food pantries in their centers and participating in ‘food gleaning’ programs that make imperfect produce – so-called ‘ugly’ fruits and vegetables that are considered not pretty enough for retail sale – available to patients at no cost.”

One-On-One Help

In addition to its work educating the provider community, CF Foundation provides one-on-one help to patients and their families through its Compass program. Accredited case managers – available by calling 844-COMPASS (844-266-7277), emailing compass@cff.org

or submitting an [online request form](#) – help with complex challenges, including food insecurity; understanding insurance basics; troubleshooting insurance coverage issues; seeking financial assistance for medical care and other living expenses; finding answers to legal questions related to work, school, and disability/government benefits; and more.

“Health insurance can be particularly complex and challenging,” Reno said. “We help to make sure that patients are maximizing their benefits, so they don’t pay more than needed for their health care. This, in turn, frees money to use for food and other necessities.”

While the CF Foundation does not provide direct financial support to patients, it does refer patients to outside organizations that have support programs in place. One example of such an organization is the HealthWell Foundation, which provides financial grants to eligible patients to assist with out-of-pocket costs associated with [CF treatments](#) and [CF vitamins and supplements](#).

“Many CF patients turn to liquid supplements to boost their caloric intake,” Reno said. “These products can be very expensive. In fact, during my days as a clinical social worker, it was not uncommon for me to see patients ‘hoard’ the shakes they received in the hospital to take home for later.”

Reno said she is proud of the work the CF Foundation has done to address food insecurity among its patient population, but that their work is just beginning and there’s a lot left to do.

“We’re in the process of expanding the initial focus of our Food Security Committee to other social determinants of health such as access to affordable transportation, housing and internet broadband,” she said. “We plan to launch a new committee this summer and will include people with CF and their families.”

Food as Medicine: Free Program Provides Medically Tailored Meals to People Living with HIV, Cancer in the St. Louis Region

Swamps. Deserts. Mirages. The terms refer to more than just our geographic environment. They also can be used to refer to our food environment or the food that is available to us day-to-day.

Food deserts are geographic areas in which residents have limited access to healthy food, such as fresh fruits, vegetables, and lean protein. Food swamps have adequate access to healthy food at retail, but also feature an overabundance of exposure to less healthy food and beverages typically found at fast food outlets and convenience stores. Food mirages are barriers low-income individuals face when trying to access healthy, affordable food in their neighborhood. For example, stores selling healthy food are available, but the food is out of reach financially.

In the St. Louis region, these food environments have led to nutrition insecurity among many residents. Those living with chronic illnesses like HIV and cancer are at particular risk from the negative health and quality-of-life effects of nutrition insecurity.

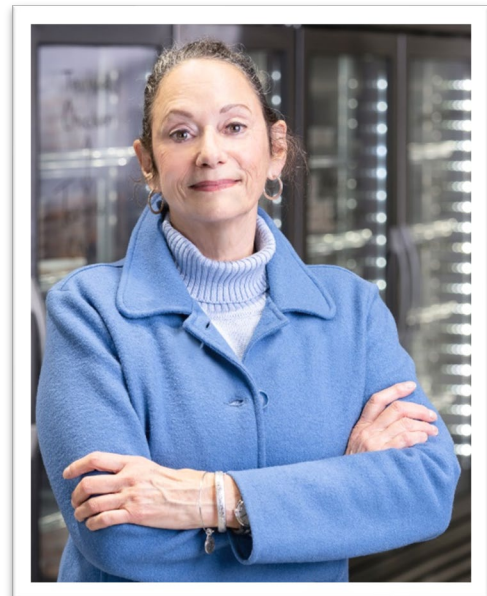
Food Outreach is working to change that paradigm. Founded in 1988 by a group of caring individuals cooking meals for seven of their friends living with HIV/AIDS, Food Outreach is the only community-based organization in Missouri and western Illinois that prepares and delivers medically tailored meals (MTMs) for individuals living with chronic illnesses, including HIV and cancer. The organization also has a pilot program to serve people with type 2 diabetes.

“Nutrition insecurity and related disparities have left under-invested communities at greatest risk for chronic illness and death,” said Julie Lock, executive director, Food Outreach. “For more than 35 years, we have been at the forefront of advancing the idea that nutrition can be a vital and holistic part of an individual’s wellness and medical treatment plan.”

Battling Hunger While Battling Cancer

Lock said that proper nutrition – including lean proteins, fresh fruits and vegetables – is important for everyone, but it is particularly important for people with life-altering illnesses such as cancer.

“Battling cancer increases the body’s need for protein,” Lock said. “When someone with cancer doesn’t get enough protein-dense calories through their diet, their body copes by breaking down tissue in order to survive, resulting in unintentional weight loss and loss of muscle mass.”



Julie Lock

Without proper nutrition, Lock said cancer patients may experience waning energy and strength, poor sleep, and nausea. They also may have problems tolerating their cancer treatment, which can lead to treatment side effects or even the inability to complete treatment as prescribed.

The Medically Tailored Meal Program

Food Outreach is part of a national coalition of non-profit, medically tailored food and nutrition providers called the Food is Medicine Coalition (FIMC). FIMC defines medically tailored meals as “meals approved by a registered dietitian nutritionist (RDN) that reflect appropriate dietary therapy based on evidence-based practice guidelines. Diet/meals are recommended by an RDN based on a nutritional assessment and a referral by a health care provider to address a medical diagnosis, symptoms, allergies, medication management and side effects to ensure the best possible nutrition-related health outcomes.”

“Medically Tailored Meals are one of the least expensive and most effective ways to improve our health care system in an equitable way,” noted FIMC Executive Director, Alissa Wassung, in a statement on the organization’s website.

Food Outreach builds its MTM program around healthy entrees and side dishes that are protein-, vegetable-, and fruit-forward, with a focus on whole foods instead of heavily processed foods. Their Registered Dietitians (RDs) work together with their chefs and volunteers to plan, cook and flash-freeze over 6,000 meals every week, from menu selections that change every two weeks.

Clients receive two meals a day, matched to dietary restrictions and personal and cultural preferences. The scratch-prepared meals are supplemented with a variety of fresh, frozen and shelf-stable proteins, fruits, and vegetables, along with complex carbohydrate foods such as oatmeal, beans, and brown rice. Some clients, including those with swallowing or chewing disorders and severe nausea, receive protein shake supplements.

“Our RDs work with each client to assess their current nutritional status, their treatment plan and any side effects they are experiencing so we can match the meals we prepare with what the client can eat and digest,” Lock said. “They also delve into bigger issues around hunger by asking how recently the client had a scratch-prepared meal, whether they have food in their refrigerator and whether the client actually has a refrigerator and a way to prepare fresh food.”

For clients who lack some of these basic food preparation appliances, Food Outreach will supply a microwave and/or a blender at no charge. All of the agency’s services are provided at no charge to its clients.

Meeting Clients Where They Are

Many of Food Outreach’s clients pick up their meals at the organization’s midtown St. Louis Nutrition Center, where they can order off a “menu” of options, watch their meals be hand-packed by volunteers, and get help carrying their meals to the parking lot, if needed.

“They enjoy being with others and sharing the experiences they are going through,” Lock said. “The personal touches our friendly, respectful, and caring staff and volunteers provide help to nourish their souls as well as their bodies.”

Editor's Note: Listen to three-time cancer survivor, Sandra, tell her story about her experiences with the caring individuals at Food Outreach.

Clients who are too weak or ill to pick up their food have meals delivered to their home, a service made possible due to the generous support of corporations and foundations, which allowed Food Outreach to significantly expand its pool of delivery vans and drivers.

"Our home delivery program gained traction during the COVID pandemic," Lock said. "But it's also an integral part of our strategy to meet our clients where they are and address adjacent issues like transportation insecurity."

As in the old "give a man a fish/teach a man to fish" proverb, Food Outreach's goal is to help its clients transition from its services by learning where and how to access healthy food, and how to prepare and cook that food in a way that fits their culture and lifestyle.

"We teach them how, even on a very limited budget, they can use the power of healthy foods to meet their physical and nutritional needs and advance their wellness journey," Lock concluded.