

# Barriers To Care



A Series by:

*Real World Health Care*

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For many Americans, significant costs and other barriers keep them from accessing life-changing, and oftentimes lifesaving, health care.

***Barriers to Care*** is a recently published series of articles that spotlights the organizations and efforts dedicated to removing barriers to care and making treatments within reach.

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# Financial Toxicity Across the Cancer Care Continuum

**By Patricia Falconer, Strategic Advisor, Atlas Health**

Financial toxicity describes the problems cancer patients experience related to the cost of treatment. Medical financial hardship is increasingly common with many cancer patients due to the difficulty of paying medical bills, high level of financial distress and need to delay or forgo care altogether because of cost. The economic burden is highest for patients in the first 12 months after diagnosis and at end of life or last 12 months before death. Additionally, out-of-pocket costs are generally higher for younger patients and patients diagnosed with later stage disease.<sup>1</sup>

## **Financial Toxicity Impacts Patients Throughout Their Care Journey**

Spending on cancer care has increased in recent years due in part to targeted therapies, immunotherapies, advanced imaging, supportive care, longer treatment durations and more treatment combinations.<sup>2</sup> Multidisciplinary cancer care often includes surgery, radiation therapy, systemic therapy and in some cases, clinical trials.



*Patricia Falconer*

## **Surgery**

Half of surgical patients report either financial strain or unaffordable care, especially surgical patients with a family income between 50 and 150% of the Federal Poverty Level. Surgical patients may have unmet medical needs, choose to alter their medications and delay or defer care due to cost. Financial toxicity may lead to worse post-operative outcomes, especially for patients with complications driven by cost-reducing behaviors such as medication non-adherence or not showing up for post-operative appointments.

## **Radiation Therapy**

Radiation therapy is an important and routinely used modality to treat cancer. Forty percent of patients faced financial distress as a result of radiation treatment alone or as part of a multimodal treatment regimen, and 10% of patients had a loss or decrease in income as an indirect consequence.<sup>3</sup> In another study, 22% of patients experienced financial toxicity related to radiation treatment. They attributed financial distress to the loss of their job, reduced income and/or difficulty paying their rent/mortgage, transportation and food.<sup>4</sup>

## **Systemic Therapy**

Patients receiving systemic therapy are more likely to experience financial toxicity than patients receiving only radiation therapy or surgery due to the greater duration of therapy and the high cost of cancer drugs. There are more individuals with larger out-of-pocket expenditures based on their insurance plan. Since 2016, the number of US workers covered by high deductible insurance plans, defined as out-of-pocket costs greater than \$1,000, increased by 50%. Compared to a decade ago, cancer patients are receiving increasingly expensive chemotherapy and biologics, both alone and in combination. For example, oral cancer drug-based treatment regimens, covered under patients' pharmacy benefits and including expensive specialty drugs, have the highest tier cost sharing.<sup>5</sup>

## **Clinical Trials**

Clinical trials are vital to the development of novel therapies for patients with cancer, yet less than 7% of eligible patients take part. Elderly, uninsured and minority patients, all of whom have limited financial resources, are underrepresented in cancer clinical trials. Although the Affordable Care Act requires coverage of routine costs for patients taking part in clinical trials, patients experience additional financial burden due to the costs of frequent clinical visits, added tests, distant travel and loss of income due to missed work. Many clinical trial participants have costs associated with their insurance, deductible, co-insurance, added travel, meals, lodging and other incidental expenses.<sup>6</sup>

## **Impacts of Financial Toxicity**

In the US, approximately 17 million people are cancer survivors, many of whom have lasting adverse effects of their disease and associated cancer treatment. Compared with individuals without a history of cancer, cancer survivors are at a greater risk for new cancers, disease progression, chronic conditions, out-of-pocket health care expenditures and work limitations. Thirty percent of adult cancer survivors report medical financial hardship as measured by an inability to afford health care services or delaying or forgoing medical care because of cost during the previous 12 months.<sup>7</sup> These results amplify the need for providers, hospitals, health systems and policy makers to implement solutions that will protect cancer patients from financial harm.

Additionally, cancer patients are too afraid or overwhelmed to ask for financial help and are hesitant to raise financial concerns. It is important to build patient trust and ensure that the purpose of financial hardship screening is to help patients receive the best care and not to ration care or provide unequal care based on the ability to pay.<sup>8</sup> Financial toxicity has been linked with several clinically relevant patient outcomes, including health-related quality of life, symptom burden, compliance and survival.<sup>9</sup> Given the important relationship between financial toxicity and poor outcomes, all cancer patients will benefit from early and continuing assessment of financial distress and access to interventions that will reduce financial burden.

## **Diagnosing Financial Toxicity**

Several validated screening tools are available to assess patients' financial toxicity. Financial distress assessment can be done using the Comprehensive Score for Financial Toxicity (COST) patient reported outcome survey. COST proved reliability and validity in measuring financial toxicity in a study including 233 patients with advanced disease who had been

receiving chemotherapy for at least 2 months. Patients with worse financial toxicity were correlated with higher psychological distress, lower income and lower quality of life.<sup>10</sup>

The National Comprehensive Cancer Network (NCCN) Guidelines for Distress Management recommends the use of the NCCN Distress Thermometer where patients circle a number from 0 to 10 that best describes how much distress they have been experiencing in the past week. While the NCCN Distress Thermometer is not specific to financial concerns, there is a problem list under Practical Concerns, which includes elements that could affect financial hardship such as finances, housing, insurance, transportation and childcare. Patients are asked to mark all that apply for items where they have had concerns in the past week.

While validated tools to measure patients' financial distress exist, they are not uniformly adopted. Thirty seven percent of the National Cancer Institute (NCI)-designated Comprehensive Cancer Centers could not estimate the number of their patients who experienced cancer-related financial hardship, and 50% of the centers reported that patients were reluctant to ask for financial help when they needed it. Most NCI-designated Comprehensive Cancer Centers offer a range of financial services. However, 40% of the centers reported a lack of staff awareness about available financial services, and 46% reported that the pathways or workflows to connect cancer patients with existing financial services were unclear. In a study of NCCN member institutions, 76% of the responding centers screened patients routinely for financial distress, 18% screened occasionally and 6% did not screen at all. Social workers or financial counselors most often performed the financial distress screening, and 19% used a dedicated questionnaire. In those hospitals and health systems where financial distress screening was deployed, patients who screened positive for financial distress received help with drug costs, meal or gas vouchers, payment plans and charity care.<sup>11</sup>

Additionally, the American Association of Community Cancer Centers (ACCC) set up Financial Advocacy Service Guidelines that recommend screening and monitoring patients on a regular basis for risk of developing financial toxicity.<sup>12</sup> Without philanthropic support, community-based cancer centers may lack the resources to implement patient distress screening and its associated workflows.

## **Reducing or Eliminating Financial Toxicity**

To reduce patients' financial distress, some providers are using technology integrated with patients' Electronic Health Record (EHR) and collaborating with non-profit foundations. These financial assistance programs include proactive financial distress screening, patient- and provider-activated referrals, resource connection points and pharmaceutical, insurance and community/foundation resources. These programs help to reduce limitations associated with insufficient staff resources, challenges in showing patients' unmet health-related and social needs, inadequate infrastructure to track resource availability and referrals, and inadequate foundation and community funding.<sup>13</sup> Patients experiencing financial distress suggest that providers simplify the patient financial assistance process, provide individualized support and be more proactive by intervening earlier.<sup>14</sup>

## ABOUT THE AUTHOR

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With three decades of experience leading cancer services, Patricia Falconer, MBA has an unfaltering belief in what is possible. In her current consulting role as President, Health Options LLC, Patricia partners with hospitals, health systems, and medical group leaders and charitable organizations to increase access and reduce disparities in cancer care by eliminating financial barriers. As Executive Director, Cancer Care Programs, Cancer Network, and Strategic Initiatives for Stanford Health Care, Patricia transformed cancer services into an integrated network doubling the size of the service line while achieving top decile performance for patient experience and employee engagement. Patricia launched psychosocial distress screening and comprehensive cancer support services to provide holistic care. She co-authored four publications, most notably, "Distress Screening through PROMIS at an academic cancer center and network site". Prior to March 2015, Patricia provided practice management consulting services to community-based cancer centers. She has served on the National Comprehensive Cancer Network (NCCN) Board of Directors, Cancer Support Community SF Bay Area as Vice Chair, Board of Directors, Pink Ribbon Girls Bay Area Advisory Board and the American Society of Clinical Oncology (ASCO) Consultancy Board. Patricia has a BA in Physiology with Highest Honors from U.C. Berkeley and an MBA with Honors from Santa Clara University.

## ABOUT ATLAS HEALTH

Atlas Health automates philanthropic aid to improve access, affordability, outcomes and health equity for vulnerable populations. Through intelligent matching and enrollment to 20,000 philanthropic aid programs, health care organizations can improve patient outcomes and reputation, increase cash and reduce staff administrative burden. Learn more at [Atlas.Health](https://atlas.health).

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# 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?

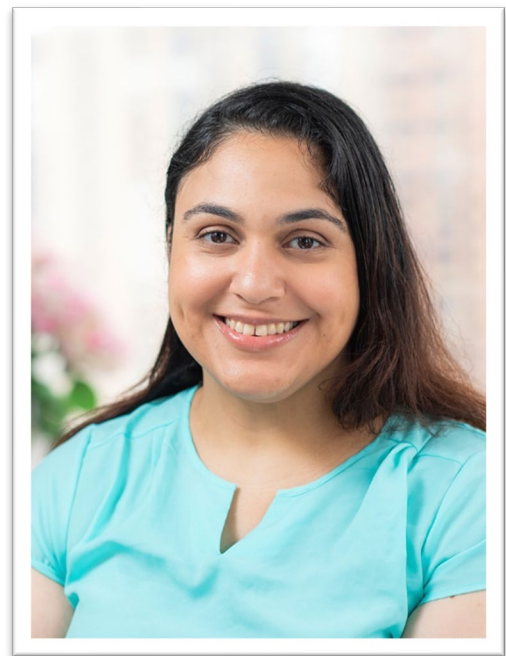
**Leeann Medina-Martinez:** Nutrition is an important part of maintaining strength and weight. It helps patients keep their bodies fueled and better manage treatment side effects. Lack of proper nutrition can impact treatment plans. For example, if a patient who is on chemotherapy loses too much weight 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.

# Oncology Pharmacists Help Cancer Patients Navigate Treatment

If you are a cancer patient receiving chemotherapy, do you know everyone on your care team? You probably know your medical oncologist well, and the nurse(s) in the infusion center. Perhaps you're on a first name basis with the reception desk personnel and the technician who draws your blood. You may have met with a social worker or patient navigator. But there is an important person on your care team whom you may not have met: your oncology pharmacist.

Oncology pharmacists are medication experts with the training and experience to help cancer patients navigate their treatment. They are an integral part of a cancer patient's care team that includes surgeons, medical oncologists/hematologists, radiation oncologists, nurses, physician assistants, and nurse practitioners.

Oncology pharmacists work in hospitals, outpatient cancer clinics, infusion centers, and specialty pharmacies. They carefully prepare cancer medications to ensure they are safe, given at the right dose, and will produce the best outcome. They help patients understand how those medicines work and know of ways to minimize medication side effects. They also work closely with patients and their care team to make sure that other medicines, vitamins, or herbal supplements won't lower the efficacy of their cancer medications, or vice versa.

"Thanks to advances in science and medicine, people with cancer are living longer than ever," said Heidi Finnes, PharmD, BCOP, FHOPA, past president of the Hematology/Oncology Pharmacy Association (HOPA), senior manager of Pharmacy Cancer Research at the Mayo Clinic Cancer Center, and assistant professor of Pharmacy at Mayo Clinic College of Medicine. "As a result, patients are often taking multiple medications to treat conditions like high blood pressure or diabetes. I encourage patients to share a list of their current medications with their oncology pharmacist and let them know before taking any new pills, even those purchased over the counter."

## **Complying with Cancer Medication Instructions**

Many patients receive cancer treatments in the hospital, a doctor's office, or an infusion center, where nurses administer chemotherapy intravenously. Others take oral chemotherapy at home.

An oncology pharmacist can teach patients the best way to store their oral chemotherapy medicines at home and how to take the medicines. Dr. Finnes suggested that patients talk with their oncology pharmacist about what they eat and drink to make sure food and beverages don't keep medicines from working.



*Heidi Finnes*

"Some medicines will work better if your stomach is empty, while others work better if you eat food when you take them," Dr. Finnes said. "And some foods should not be eaten at the same time as taking the medicine."

According to Dr. Finnes, when oncology pharmacists are closely involved in patients' at-home care, patients adhere more closely to medication protocols and can stay on oral chemotherapy longer. When side effects are identified earlier, it allows pharmacists to adjust medication doses if needed.

"Sometimes patients with side effects like diarrhea think they have to 'tough it out,' but their pharmacist can help them avoid or lessen those side effects so that the patients can stay on their medication," she said.

HOPA is currently studying various pharmacist interventions for patients taking oral cancer agents and plans to announce results soon.

### **Addressing Treatment Barriers**

Oncology drugs are expensive, and newer therapies like CAR-T and immunotherapy can be difficult to access. Oncology pharmacists can help patients access medication therapies and find ways to save patients money on the cancer medications they take.

"Many newer therapies are only available by participating in a clinical trial," Dr. Finnes explained. "Oncology pharmacists can identify available clinical trials, help patients fill out required paperwork and consent forms, educate patients on the risks involved in clinical trials, and make sure the patient adheres to trial requirements."

In instances where patients don't meet the criteria for a clinical trial, Dr. Finnes has helped patients get access to the medication through a single-patient investigational new drug (IND) process, giving the patient permission from the trial sponsor and FDA to take the medication under strict protocols.

Oncology pharmacists also can help alleviate the burden of patients' out-of-pocket costs by identifying opportunities for financial assistance through patient assistance programs (PAPs) available through drug companies or through charitable foundations such as the [HealthWell Foundation](#). Some PAPs provide grants for medications, while others provide financial assistance for transportation, lodging and food related to cancer treatment.

"HOPA is especially passionate about oral chemo parity," Dr. Finnes said. "Copays for oral cancer drugs can be very expensive because they are billed through prescription coverage, whereas IV medications are billed through medical coverage. We are lobbying to make sure that, if no IV equivalent for an oral chemo agent exists, the out-of-pocket costs will be the same."

HOPA also is working to offer more control and autonomy to oncology patients through initiatives such as telehealth visits, education on home infusion, and monitoring patients at home with wearable tech to track vital signs.

"We want to help bring oncology treatments to the patient rather than always requiring the patient to come to a treatment center or to an academic medical center for a clinical trial," Dr. Finnes concluded. "Especially for patients who have active lives, children and/or careers; it's important to be able to meet patients halfway."

## Oral Oncolytics Offer Advantages & Pose Challenges for Cancer Patients

Oral oncolytics – targeted cancer medications self-administered in pill form at home instead of intravenously in a cancer clinic or the hospital – have freed patients from the burdens associated with commutes to and from, and hours spent in infusion centers. However, while these oral medications are equally as efficacious as their IV chemotherapy counterparts, they come with a significantly higher cost-sharing burden for patients. For some patients, a monthly prescription can cost thousands of dollars, resulting in financial toxicity, treatment non-adherence and unnecessary treatment delays.

“Innovation in oral therapies, such as ibrutinib and venetoclax for patients with chronic lymphocytic leukemia (CLL), significantly changed the paradigm for patients and have become a standard of care in both the frontline setting and for refractory disease,” said Kirollos S. Hanna, PharmD, BCPS, BCOP, FACCC, director of pharmacy at [Minnesota Oncology](#), Assistant Professor of Pharmacy at Mayo Clinic College of Medicine, member of the [NCODA](#) Executive Council, and committee chair and clinical advisor to the [Association of Community Cancer Centers](#) (ACCC). “In addition to their clinical efficacy, these oral agents remove the risk of infusion reactions, hematologic side effects and tumor lysis, which are associated with monoclonal antibody infusions.”

### Complying with Medication Protocols at Home

With traditional IV chemotherapy, patients typically visit an infusion center for regularly scheduled appointments at which health care professionals deliver the therapy within tightly controlled parameters. Oral therapies taken at home place the onus for proper storage, dosing, and timing on the patient.

“Dosing instructions for most CLL oral oncolytics are relatively easy to adhere to, and drug manufacturers help with color-coded blister packs,” said Hanna. “However, cancer clinics must be diligent about educating their patients to comply with protocols.”

ACCC and NCODA echo Dr. Hanna’s advice about patient education, noting that “effective integration of these agents depends on the close collaboration of cancer care team members and patients/caregivers. Shared decision-making is essential during all phases of care, but particularly so when the treatment option relies so heavily on compliance. Medication adherence is directly linked to the patient’s comprehension of their disease and treatment.”

“We treat many patients with CLL, who tend to be a bit older and may have trouble remembering when to take their medication,” added Dr. Hanna. “They may benefit from a calendar reminder, phone alarm or scheduling the pills around a daily activity like brushing their teeth or walking the dog.”



*Kirollos S. Hanna*

## Medically Integrated Pharmacies Enhance Continuity of Care

In addition to challenges relating to patient education and medication adherence, oral oncolytics can be difficult for patients to access cost-effectively and safely. Enter the medically integrated pharmacy (MIP). MIPs give patients the option to obtain oral oncolytic prescriptions directly from their cancer clinic instead of from a third-party pharmacy (typically mail order) removed from the core patient care team.

NCODA, a grassroots not-for-profit organization dedicated to helping medically integrated oncology teams deliver top-tier care, defines MIP as “a dispensing pharmacy within an oncology center of excellence that promotes a patient-centered, multidisciplinary team approach. The MIP is an outcome-based collaborative and comprehensive model that involves oncology health care professionals and other stakeholders who focus on the continuity of coordinated quality care and therapies for cancer patients.”<sup>1</sup>

According to Michael Reff, RPh, MBA, founder & executive director of NCODA, the concept of dispensing oral oncolytics in the cancer clinic emerged in the last decade, right around the time that oral medications came onto the market. It was further enabled by the use of electronic medical records (EMRs), which allow MIPs to truly integrate the pharmacy function into the care team to enhance the continuity of care and ensure that the patient has the best experience possible.

“This model of care is right inside the clinic,” Reff said. “The onsite pharmacy team has access to the patient’s EMR, knows in real time what their labs show, when their next appointment is, and whether there have been any changes to medications or dosing. If the MIP has a question or concern, they have direct access to the patient’s doctor and care team down the hall. That kind of visibility and access doesn’t exist when oral oncolytic prescriptions are filled by off-site, third-party mail-order pharmacies.”



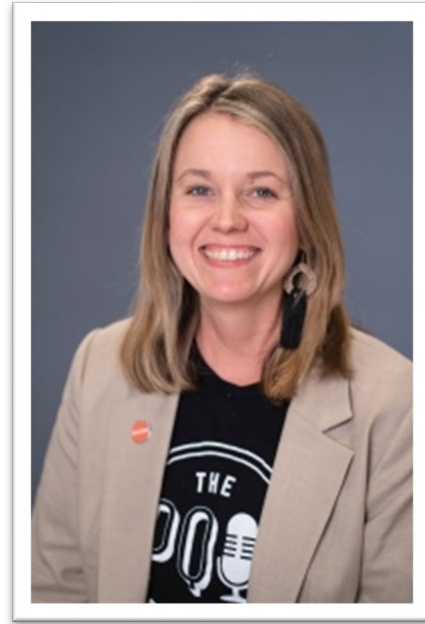
*Michael Reff*

With some insurance contracts forcing patients to fill prescriptions outside of the MIP, NCODA is on a mission to overturn these unnecessary hurdles for patients. Through innovation and the development of concise and relevant resources for all members of the oncology care teams, NCODA is showing clear evidence that the MIP model is the answer to solving these challenges.

NCODA stresses the importance of patient education in promoting adherence to medication protocols. Every time a new oral oncolytic medication or IV therapy enters the market, a committee of NCODA members and other collaborators creates an Oral Cancer Treatment Education (OCE) sheet with information on the drug, dosing instructions, potential side effects, and information to help patients manage the side effects. Written on a 6<sup>th</sup>-grade level, the OCE sheets are designed to start patients out on the right foot for their treatment.

For clinicians, NCODA creates Positive Quality Intervention (PQI) documents, which are precise and concise peer-reviewed clinical guidance resources for specific aspects of cancer care. This tool is used as an internal medically integrated team training resource and supports practices pursuing pharmacy accreditation.

“PQIs provide cancer care teams with information they need to counsel their patients about the oncolytics they prescribe, including summaries of the studies that helped bring the medication to market, the lab tests recommended to establish proper dosing, how to modify dosing throughout treatment, drug-drug interactions to be aware of, and related toxicities,” said Ginger Blackmon, PharmD, assistant director of Clinical Initiatives at NCODA. “Our members take the time to understand the nuances and attributes of each drug, which helps the other members of the care team focus on providing quality care to the patient.”



*Ginger Blackmon*

### **MIPs Do More Than Fill Scripts: Addressing Financial Toxicity**

Reff noted that MIPs also help cancer clinics manage one of the thorniest issues relating to oral oncolytics: the therapies are billed through a patient’s prescription benefits while IV therapies are billed through medical benefits. Not only does that delineation require new business process flows for the clinic, it also can increase the amount of money the patient must pay in out-of-pocket costs.

“Our members are specially trained and have the tools required to work as a bridge between the clinic and the insurance companies,” Blackmon added. “We manage prior authorizations and screen patients for financial stress. Plus, we connect them with financial assistance programs to help them afford their oral medications, so they stay on their prescribed therapy.”

Financial assistance programs include those available from oncolytic manufacturers as well as through independent non-profits such as the HealthWell Foundation, which helps patients fill their insurance gaps by assisting with copays, premiums, deductibles, and out-of-pocket expenses. As of this writing, HealthWell offers several funds in oncology for eligible patients.

<sup>1</sup>Medically integrated pharmacy. NCODA. Available from: [www.ncoda.org](http://www.ncoda.org). Accessed: August 18, 2023.