

# Oncology Financial Navigators

*Integral members of the  
multidisciplinary cancer care team*

The lights were dim when I entered the room of a newly-diagnosed cancer patient. As an oncology social worker, I had walked into rooms like this hundreds of times before. Little did I know that this encounter was going to change lives—not only the patient’s, but mine as well. In fact, this one visit with “Cathy” would affect thousands of other patients diagnosed with cancer in the future.

Having been a medical social worker for well over 10 years, I had all too often observed the financial devastation that a major medical issue could bring down on an individual and/or family. In fact, just six months before my meeting with Cathy, I’d had discussions with the leadership team at Lacks Cancer Center about the need to have a skilled individual on staff who could address the financial distress that our patients were experiencing, and to address it *differently* than we had in the past.

Far too many of my patients were anxious about their ability to pay for their cancer treatments. Too many were confused about options for reducing their out-of-pocket financial responsibilities; some were turning down care altogether. Not that charity care wasn’t available. In fact, our hospital wrote off millions of dollars in charity care every year. But when I spoke with the leadership team, I communicated that our current healthcare system was complicated, and our solutions to reduce the financial distress of our cancer patients were too simplistic.

But let’s return to the patient encounter that changed everything. Cathy had been admitted to our hospital with newly-diagnosed acute myeloid leukemia (AML). I recognized immediately that she would need extensive treatments for the next six months and close follow-up for several more years. Cathy had turned 65 a few months earlier; therefore, Medicare was her

primary insurance. Although she did not have secondary insurance, Cathy did have a Medicaid spend-down (deductible) of about \$800 a month.

When I entered the room to talk to her about coverage options, I found Cathy sitting alone in a corner of the room with various papers and forms in front of her. I introduced myself and asked if I could spend some time with her to talk about her health insurance status and her options for reducing her out-of-pocket responsibility.

For the next 45 minutes we talked through Cathy’s options. One option was to enroll in a Medicare plan that would provide 100 percent coverage for radiation treatments, chemotherapy, and hospitalizations. This policy (at that time) would cost Cathy \$25 a month. Obviously this was a much-improved scenario over the \$800 a month Medicaid spend-down deductible. Cathy expressed her wish to enroll in this plan, and I walked her through the enrollment process.

Having completed the work of getting the appropriate coverage for her care, I was ready to leave for my next patient visit. As I started to leave the room, Cathy said, “*Thank you.*” I stopped and acknowledged her kindness and turned once again to leave. Again she called out, “*Thank you,*” so I turned and acknowledged her again. Finally, she said it again, “*Thank you!*” but this time with more force. I turned around and saw tears forming in her eyes, so I walked over to Cathy and gave her a hug. As I turned to leave for the fourth time, she grabbed my arm and said, “*You just don’t get it! Before you walked into my room, I was planning my funeral. I knew I couldn’t afford the care I needed, so I was writing down what I wanted my funeral to look like. Now, I will plan to live.*”

Cathy was right of course—I didn't get it. At the time I didn't fully understand the significance of the financial distress Cathy was experiencing. For this patient, the financial cost of her cancer care had implications far beyond something as basic as putting food on the table.

When I left her room that day, I had a new appreciation for the role of the financial navigator and a newfound passion that compelled me to step away from medical social work to become an expert in the field of financial navigation services.

I knew then that the status quo had to change. I thought to myself, "If we're truly going to be a cancer center of excellence, we cannot allow our patients to go through what this patient just experienced." Cathy needed help to understand *all* of her coverage options—not just the simplest and/or partial options that had been offered to her prior to my visit. Without my intervention that day, the "status quo" method of delivering financial navigation services would likely have put Cathy on a path to her premature death. Since that fateful visit, I have worked each day to make sure that all of my patients are given the best, most practical, and comprehensive options for paying for their cancer care.

**Today's cancer programs must accept that their old, band-aid approaches to discussing financial issues with patients are inadequate for solving a complex, systemic problem.**

For social workers, financial advocates, patient navigators, and others who wish to offer a similar level of service at their own cancer programs, here is why we need to step up for change.

### **Challenging the Status Quo**

Simply put, the standard of financial intervention in most cancer programs is inferior. When patients are underinsured with their Medicare plan, most cancer programs automatically try to get patients qualified for Medicaid benefits. Cathy qualified for that program—but with an \$800-a-month cost-sharing responsibility. Obviously, the rote "business as usual" option did not solve Cathy's problem. Today's cancer programs must accept that their old, band-aid approaches to discussing financial issues with patients are inadequate for solving a complex, systemic problem.

Mercy Health Saint Mary's health system has provided financial advocacy services at its hospital for many years. In fact, most

U.S. hospitals have financial advocates to assist cancer patients. But as Cathy's example illustrates—we need to ask ourselves if our current services are truly meeting the needs of our patients.

When we read the work of Zafar<sup>1</sup> and Ramsey<sup>2</sup> and reports about financial distress among cancer patients provided by the Kaiser Family Foundation,<sup>3</sup> the Oncology Roundtable,<sup>4</sup> the Community Oncology Alliance,<sup>5</sup> and the American Society of Clinical Oncology,<sup>6</sup> we must acknowledge that, as a whole, the oncology community is not alleviating the financial distress of a significant portion of the oncology population. And we must be ready to ask some difficult questions. For example, if the financial counseling services we provide are effective:

- Why do more cancer patients fear the financial obligation more than dying from the disease itself?<sup>5</sup>
- Why are oncology patients twice as likely to file for bankruptcy compared to the general public?<sup>2</sup>
- Why does 29 percent of this same population avoid or delay filling prescriptions due to the cost?<sup>1</sup>
- Why do 24 percent of oncology patients suffer relationship problems due to the financial pressures of the cost of care?<sup>1</sup>
- Finally, why are patients making treatment decisions based on cost rather than factors such as survivorship or ability to tolerate treatments?

These grim statistics clearly show that the oncology community has done an inadequate job of addressing the financial burden of this country's oncology patients.

When patients receive a cancer diagnosis, they trust that the care they will receive will be the best available. Most cancer programs promote their use of the latest available technology; I contend that financial navigation services need to match this same high level of care.

In 2009 the Advisory Board's Oncology Roundtable released a statement that succinctly captured the issue:<sup>4</sup>

*At present, few cancer programs have a systematic process in place to identify patients in need and to develop a plan to meet their cost of care. Rather, financial counseling services are typically fragmented, with responsibility for various aspects of the process divided among registration staff, social workers, business office staff and clinicians. As a result, many miss opportunities to assist patients and improve revenue capture."*

Unfortunately, this "siloes" approach to financial navigation services plays out daily in cancer programs across the country. But it's time to get serious about change. Our patients desperately need the oncology community to provide these services at a level that truly meets their needs.

### **Understanding the Problem**

Over the last few years, researchers have paid increased attention to this issue, resulting in a newly coined term—financial toxicity.



“Financial toxicity” is defined as both an objective financial burden and subjective financial distress. Recent research by Yousuf Zafar, MD, MHS, found the following:<sup>1</sup>

- 42 percent of individuals applying for co-pay assistance reported a significant or catastrophic subjective financial burden
- 68 percent cut back on leisure activities
- 46 percent reduced spending on food and clothing
- 46 percent used savings to defray out-of-pocket expenses
- 20 percent took less than the prescribed amount of medications
- 19 partially filled prescriptions
- 24 percent avoided filling prescriptions altogether.

Zafar’s conclusion: having health insurance does *not* eliminate financial distress or health disparities among cancer patients.<sup>1</sup>

A recent ASCO report found similar results among insured cancer patients, with more than 47 percent of the patients in the study reporting concerns about healthcare costs.<sup>6</sup>

At the same time, financial navigation services face a number of hurdles, including lack of resources, a lack of motivation to change, internal system failures, and/or a shortage of informed, qualified personnel. And certainly the complexity of available coverage options and the time required to fully understand how to apply these options to meet the unique needs of each patient are also important factors.

### **It’s Complicated**

Let’s face it, financial navigation is complex. Patients and providers alike get lost in a maze of health insurance policies and assistance programs, all requiring different information for successful enrollment. For example, the rules governing Medicare Part D, with the initial coverage, coverage gap, catastrophic coverage levels, co-pay assistance guidelines, and steps to qualify for extra assistance programs are overwhelming for most individuals. With up to 35 percent of new oncology products being oral medications<sup>7</sup> and 11 out of 12 of these medications costing more than \$100,000 a year,<sup>8</sup> it is essential that we help patients apply for programs that are the most appropriate and readily available to meet their specific needs.

All too often I have seen patients refuse oral treatment recommendations due to cost; only to find out that if these patients had received comprehensive financial navigation, they would have had access to these medications without significant cost-sharing responsibilities. In fact, a recent report published by the Community Oncology Alliance stated that Medicare beneficiaries abandoned their oral prescriptions almost twice as frequently as commercially insured beneficiaries; data showed that 16 percent of Medicare beneficiaries abandoned oral oncolytic treatments due to cost-sharing responsibilities.<sup>9</sup>

The complexity of Medicare coverage choices, for example, understanding the coverage differences of Medicare Advantage plans vs. Medigap vs. employer-based plans vs. Medicaid, frequently results in patients making uninformed decisions, often at the advice of well-meaning family members or friends. The fact is that Medicare beneficiaries who must choose from a list of 30 to 60 different coverage options—many of which have significant cost-sharing responsibilities—need advice from someone with more experience. More importantly, the uninformed consumer often is not aware of national open-enrollment and special-enrollment periods for Medicare plans. Patients who are unaware of the “fine print” details of their insurance plans often experience problems accessing care. At times, patients find themselves having to change doctors as a result of selecting a plan that puts their current providers out-of-network. Other patients choose plans that put them outside networks that are vital to their recovery needs.

This confusion harms not only the patient, but also the financial stability of the cancer program treating the patient.

While patients sometimes have questions about open enrollment and if, or when, they should apply, most often I see patients who are confused about the high out-of-pocket responsibilities that come with the Medicare plan they have enrolled in. The reasons for this confusion over cost-sharing responsibilities are multifaceted, but one major reason to consider is the host of Medicare options available to the general public. A recent publication from the Kaiser Family Foundation reported that the leading contributor to medical debt for the individuals surveyed was cost-sharing responsibilities incurred for in-network services.<sup>3</sup> Studies have also found that non-elderly Medicare beneficiaries experience more problems with cost-sharing responsibilities compared to elderly Medicare beneficiaries.<sup>1</sup>

In most states, access to supplemental policies for non-elderly Medicare beneficiaries is more restrictive, thus increasing the odds that these patients will enroll in a high cost-sharing Medicare plan. A well-trained financial navigator can help educate patients so that they enroll in the most advantageous plan for their specific medical needs.

The oncology community is seeing similar trends with the roll out of the health insurance exchanges under the Affordable Care Act (ACA). Again, patients are overwhelmed and confused about the enrollment process and the choices of coverage policies available to them. As an example, I recently worked with a patient who was facing medical costs exceeding \$150,000 after being diagnosed with ALL (acute lymphoblastic leukemia). He had not enrolled in a healthcare-reform-based insurance plan. Feeling overwhelmed and confused about that process, he was now

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outside the ACA's open enrollment period. Just prior to being admitted to our cancer center, the patient had been seen at two other hospital systems—neither of which provided financial navigation services. On his admission to our program, I assessed his situation and was able to assist the patient with enrollment into an ACA health exchange plan under special enrollment guidelines. As a result this patient will now avoid medical bankruptcy and the hospital will be reimbursed for services provided.

When patients are left on their own to wade through the 50+ Medicare options; the extra help program for Part D; co-pay assistance programs; premium assistance programs; ACA enrollment guidelines; the choices of bronze, silver, gold, or platinum plans; and available out-of-pocket subsidies, they will likely experience financial toxicity as they journey through cancer treatment. The key to successful financial navigation is presenting patients with all the available choices in the context of their medical condition. Each patient is unique and, in most cases, the “status quo” approaches used by many hospitals and cancer programs of enrolling patients in Medicaid, charity, or patient assistance programs are simply inadequate in today's market.

### So How Can We Help?

I am proud to work for an organization that sees its mission as serving the poor and underserved. My hospital system often provides charity to those in financial distress. But charity programs can only manage a certain amount of debt load before program sustainability starts to be impacted. A better approach to financial navigation services is to educate patients on the programs that can help reduce their out-of-pocket responsibility. This education results in savings for the hospital's charity program and reduces the number of patients who fall into collection services. Furthermore, this process helps preserve the dignity of our patients, as most would prefer to avoid applying for charity altogether.



In 2009, following my experience with Cathy, I asked to head up a six-month pilot program (on a .5 FTE basis) where I would provide financial navigation services to the hospital's oncology population. My responsibilities during the pilot period were to reduce financial barriers, improve access to care, and measure the financial benefit for patients and the cancer program. For the pilot, I targeted patients who were uninsured and underinsured and for whom Medicaid was not their best option. Specifically, I targeted patients who were:

- In health insurance plans with out-of-pocket responsibilities of more than \$5,000 a year
- Medicare Part D patients in the coverage gap due to high-cost oral oncology medications
- Medicaid patients with a spend down
- Patients with Medicare A/B only
- Patients without health insurance coverage
- COBRA recipients who could not afford the COBRA premiums
- Patients receiving off-label treatments
- Any patients expressing financial distress due to cost of care.

The pilot had two governing goals: 1) to improve access to care by reducing the financial barriers experienced by oncology patients and 2) to reduce charity and bad debt by \$70,000 within the pilot program's six-month time period. Everyone agreed that the first goal would always take precedence over the second goal. The decision to prioritize these goals in this way was not only the right one to make, but it also created an atmosphere of trust that contributed to the success of the pilot program.

To put this in perspective, medical providers see patients at quite possibly the most vulnerable time in their lives, a time when they are being asked to make long-term, deeply life-impacting decisions. When a patient is considering their future financial security, they need to trust that the providers advising them truly have their best interests in mind. If patients do not have that level of trust, they will not be open to education about better solutions for their health coverage needs.

### Our Approach

I would first interview patients to get to know them and understand their medical and financial situation. Next, I would introduce patients to coverage options that improved their out-of-pocket responsibilities.

In most cases, I sought out patients myself, but I also educated the social work, case management, and nursing departments to refer patients to the pilot program who met the specific patient types described above. I also worked closely with the billing department to identify patients with significant write-offs on their accounts. I made a concerted effort to communicate with each patient's oncologist so that I would have a more informed under-

standing of his or her medical needs. This improved understanding allowed me to better educate patients about coverage options that would complement their upcoming treatment regimen. This communication also helped me to build trust with oncologists, who then referred more patients for consultation.

The pilot program had great success. I reached the \$70,000 goal in savings to the hospital by the second month. By the end of month five, I had saved the hospital system \$265,000 and decreased out-of-pocket expenses for the patient by more than \$700,000. In all, 78 patients were navigated. Based on these results, the hospital hired one FTE for the financial navigator position. Since then, the program has achieved the following outcomes:

- **Year two of the program:** 218 patients received navigation services, reducing out-of-pocket responsibility for patients by more than \$2.6 million and saving the hospital system over \$1 million in reduced charity and bad debt.
- **Year three of the program:** 168 patients received navigation services, and The Lacks Cancer Center added a second .8 FTE. Out-of-pocket responsibility for patients was reduced by more than \$4 million and saved the hospital system \$2.5 million in reduced charity and bad debt.
- **Year four of the program:** 211 patients received navigation services, reducing out-of-pocket responsibility for patients by more than \$5 million and saving the hospital system \$3.7 million in reduced bad debt and charity.

The decrease in the number of patients receiving financial navigation over the program's four years is due to a large backlog of patients needing these services during the program's first two years. However, the program's benefits have increased significantly every year—even when fewer patients received services. This is attributable to the roll out of the federally funded Pre-Existing Condition Insurance Plan (PCIP) program during year two of our financial navigation program. PCIP utilization significantly increased savings to both our patients and our cancer program.

Today, we offer financial navigation services to the following patient types:

- Uninsured
- Underinsured (relative to the patient's income status; we allow patients to self-describe as being underinsured)
- Patients on high-dollar oral medications who need assistance with their co-pays
- COBRA recipients
- Medicaid patients with a spend-down
- Patients with Medicare A/B only
- Patients who are entering into the Medicare system
- Every patient with advanced-stage disease.

Financial navigators may self-refer patients or receive referrals from the multidisciplinary cancer care team. Financial navigators

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then interview patients to see if they want to discuss their financial obligation for the medical care they are seeking, and if they'd like to discuss options for finding coverage systems that may reduce their out-of-pocket responsibilities.

For individuals with advanced-stage disease, we educate patients on the available options (STD, LTD, SSDI, SSI, COBRA, and Medicare) and answer any other questions they may have about how their disease may affect their long-term financial health. Anecdotally, our team has found that patients and families who address their initial fears of financial obligations early on tend to be more at peace with the disease and more compliant with care.

### **Financial Toxicity & Patient Satisfaction**

A recent study by the Duke Cancer Institute found a correlation between high financial burden and patients' dissatisfaction with their healthcare services, concluding that:<sup>10</sup>

*Understanding the connection between financial burden and patient satisfaction may help identify the extent to which modification of burden can improve this important metric of quality patient-centered care and improve the downstream results of an enhanced patient experience.*

Anecdotal evidence from our cancer program suggests that successful financial navigation programs can improve patient satisfaction scores. Successful financial navigation can also reduce distress among oncology patients. It is rare that a day goes by without a patient approaching me or my colleague with heartfelt gratitude for the services we've provided to them. Some of the comments we've received:

- *Because of you, we were able to keep our house.*
- *Thank you for helping us access the medication we needed but could not afford.*
- *I would never have understood my insurance options without your guidance.*

I suspect that financial navigators from other cancer programs have heard similar sentiments from patients. At The Lacks Cancer Center, we have focused attention on the issue of financial toxicity, reducing the problem with solutions tailored to meet the needs of individual patients.



## The Right Person for the Job

The financial navigation program has now been successfully replicated at 12 different cancer programs. I've learned that successful replication requires that financial navigators have a singular focus on the task, comprehensive training, one-on-one education, and peer support as solutions and programs constantly change and evolve. Successful financial navigation programs also require support from different departments, including billing, patient access, and pharmacy.

Successful financial navigators require multiple skill sets. The ideal candidate should possess clinical, financial, and mental health skills. It's essential that financial navigators are able to build trust within the first few minutes of meeting with the patient—otherwise the ability to fully assist the patient becomes very difficult. Financial navigators must be prepared to have treatment-planning conversations with the ordering physician and understand how different coverage policies can complement the treatment regimen. Financial navigators need to have empathy and the skills to have difficult conversations with patients; this is why good mental health skills are critical to the role. Finally, the person you hire for this unique position must exhibit utmost professionalism, balanced with a clear passion for the role.

Financial navigators play a critical role on the multidisciplinary cancer care team. Unfortunately, in many cancer programs, financial navigation services are relegated to secondary status, resulting in less than optimal solutions being offered to patients. Focused, educated, and passionate financial navigators are motivated to improve their skills and continually identify better solutions for their patients.

In the end, financial navigators with a clear understanding of the patient's medical diagnosis and treatment needs and who build trust with the patient can reduce or even alleviate patient financial toxicity. In some cases, a small delay in treatment may be an option as the financial navigator waits for new or added coverage to take effect. However, a comprehensive financial navigation program should never get in the way of providing optimal care for the patient. With the onset of the Affordable Care Act and considering some of the more complex solutions mentioned above, I believe that we are entering a new chapter of financial navigation services. This new era requires new wisdom and new processes so that our patients suffer less and our cancer programs remain financially stable.

## Six Years Later . . .

I saw Cathy again this spring—six years after our first meeting. A little more frail and now in a wheelchair, her body is showing signs of aging. But one aspect of her personality has not changed—her smile. When I saw her in our cancer center, she yelled out “Hi Dan!” with a grin that defies description. Our first meeting changed the trajectory of my vocation and my life. I hope that Cathy realizes how her emphatic words of “You just don't get it!” have gone on to impact the lives of thousands of other cancer patients being treated in our health-care system.

*Dan Sherman, MA, LPC, is a clinical financial consultant for Mercy Health Saint Mary's, The Lacks Cancer Center, Grand Rapids, Mich. He is also founder and president of “The Navectis Group,” a consulting company that assists oncology providers in implementation of financial navigation programs. He can be reached for comment or questions at [dsherman@navectis.com](mailto:dsherman@navectis.com).*

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