

# Advocating Amid a Crisis

## The expanding role of financial advocates in the age of COVID-19

As consumers are expected to assume an increasing percentage of their healthcare costs, and as co-pays, coinsurance, and deductibles continue to rise, demand for the services of financial advocates is outpacing supply. Given that the COVID-19 pandemic has left millions of people unemployed and without the insurance benefits they once possessed, the need for financial advocacy in healthcare is reaching new heights.

Evidence of that need is increasingly apparent. In a survey of more than 1,200 cancer patients and survivors conducted between March 25 and April 8, 2020 by the American Cancer Society Cancer Action Network (ACS CAN), 38% of respondents report that COVID-19 has had a notable impact on their financial situation that affects their ability to pay for healthcare.<sup>1</sup> Forty-six percent of respondents whose annual household income is \$30,000 or less say they are worried that the financial impact of the pandemic will make it difficult for them to afford their healthcare. Forty-three percent of respondents who reported that they or a family member living with them has recently lost a job say that person had employer-sponsored health insurance.

Although it is too early to accurately gauge the long-term impact on healthcare of the massive unemployment that has accompanied COVID-19, it is helpful to understand the state of financial advocacy before the pandemic hit. In late 2019, the Association of Community Cancer Centers (ACCC) asked its member institutions to answer survey questions about their financial advocacy services. In response, 292 people from 153 unique cancer programs shared information about their concerns, challenges, workload, training, resources, and technology regarding their financial advocacy services.


### Workload

Most of the cancer centers represented in the survey (60%) employ one to three dedicated financial advocates. Ten percent employ four to five advocates, 13% employ six or more, and 10% employ none. One-third of respondents say they provide financial advocacy services to more than 20 patients per week. Asked if they have enough FTEs to meet their demand for financial advocacy services, 36% of respondents said they do not, and 34% replied “not always.”

Rifeta Kajdic, the oncology program manager at St. Luke’s Cancer Institute in Boise, Idaho, and a member of the ACCC Financial Advocacy Network Advisory Committee, says she is unsurprised by these numbers. “The cost of treatment is only increasing,” says Kajdic. “In the past, financial navigation roles focused on high-risk patients, which were mainly those who were uninsured or underinsured. Now even patients with insurance need our help. With rising copays, coinsurance, and expensive drugs, just because you have insurance doesn’t mean you won’t be financially impacted.”

In her capacity, Kajdic supports oncology patient financial advocates across five sites operated by St. Luke’s in Idaho. She says St. Luke’s employs 18 financial advocates dedicated to oncology across those sites. “At all sites combined, we might see about 400 new patients a month,” says Kajdic. “We meet with an average of 70 patients per week. Demand for our services is only increasing as the pandemic puts so many people out of work.”

In June 2020, the U.S. unemployment rate was 11.1%.<sup>2</sup> By July 2020, nearly 50 million people had filed for first-time unemployment benefits since the start of the pandemic.<sup>3</sup> In May, the



Kaiser Family Foundation estimated that nearly 27 million people in the U.S. may have lost employer-sponsored insurance due to massive layoffs.<sup>4</sup>

### Distress Screening

An essential element of financial advocacy services is accurately identifying the patients who most need assistance. The National Comprehensive Cancer Network (NCCN) recommends that cancer programs conduct financial distress screenings for incoming patients and at regular intervals throughout treatment—particularly when there is a change in disease status—to determine their risk of being unable to afford their care. Forty-one percent of ACCC survey respondents say they always use distress screening tools, while 32% say they sometimes use such tools. Respondents cite multiple methods for assessing financial hardship, including using the NCCN’s Distress Thermometer and other standardized assessments; assessing individual patients’ insurance benefits; and interviewing patients.

Kajdic says it is important to be able to identify patients who may have a need for financial advocacy services as early as possible. “Some patients may not know they need help immediately,” she explains, “but long-term they will likely need some assistance, so we want to make contact early on. Identifying patients and letting them know the resources they have is crucial to helping them have a successful patient journey.”

Kajdic says that St. Luke’s screens each incoming patient, and those evaluations are entered into the cancer institute’s EHR (electronic health record). As soon as a patient referral is received, St. Luke’s financial advocates review the patient’s health insurance benefits and calculate deductibles, copays, and other patient responsibilities. Financial advocates then make appointments with the patients they deem at risk to explain to them their benefits and the potential availability of additional resources. “Patients look to financial advocates as an expert source to locate the resources they need,” says Kajdic, “and the number of people who need financial advocacy services is only growing.”

### Organizational Challenges

To get a better handle on the roadblocks that most hinder the ability of financial advocates to help as many patients as possible, ACCC asked survey respondents to identify their biggest

organizational challenges. Thirty-two percent cite “difficulty finding funding and/or resources for patients,” 24% cite “ineffective organizational structure and/or processes,” 16% cite “limited staff and increasing demand,” and 11% cite “patient education needs/low financial health literacy.”

Kajdic says these frustrations are common, given that the many recent clinical advances in oncology and subsequent new therapies have come with high price tags. “There are promising new treatments out there now,” says Kajdic, “but reimbursement complexities associated with these treatments can result in heavier financial burden on the patient. Our goal is to help patients get the treatments they need without putting them at financial risk.”

Because an increasing number of people are requiring assistance to afford new therapies, Kajdic says there are less resources to go around. “More people are tapping into assistance avenues to pay for treatment,” she explains. “It’s difficult finding resources now because more people need them. The resources that are available are being pulled in all directions.”

Indeed, 50% of respondents say that lack of resources is their top concern in providing financial navigation services, followed by navigating a highly complex, changing landscape (37%), and patient education needs/low financial health literacy (31%). “Not being able to devote enough time to each patient to help as much as they need is the most challenging,” said one respondent. “There is not enough of me.”

Often these problems are exacerbated by issues that may not immediately come to mind, such as a patient’s citizenship status. Another survey respondent remarked that “not having any resources for patients who do not have a social security number” is a big problem.

These challenges create roadblocks to treatment that can have a very real impact on patient outcomes. Eighty percent of survey respondents estimate that 1 to 10 patients they saw in the past month declined treatment due to financial concerns. Twenty percent of respondents say more than 11 patients a month decline treatment for this reason.

### Navigation Know-How

Knowing how to navigate the labyrinth of funding resources for patients in need is a cultivated skill that most financial advocates



learn on the job and through relationship-building. Foundations, nonprofits, charity programs, manufacturer discounts, and other funding outlets often lack a steady funding stream, and each have variable (and often changing) qualifications. Being able to identify a patient's most promising options and see applications through to completion requires staying on top of a steady stream of continually changing resources.

Survey respondents say they are most confident navigating manufacturer and advocacy patient assistance programs, although they say they need additional help sorting through the wide variety of resources available. Seventy-six percent of respondents say they need additional help navigating Medicare and/or Medicaid options, 73% say they need help identifying private insurance options, and 53% say they need more assistance navigating manufacturer and/or advocacy patient assistance programs.

"As healthcare reimbursement, insurance, and funding grows more and more complex, financial advocate roles will grow in demand," says Kajdic. "There is an increased need for the skills and understanding that financial advocates possess, and they need to be able to tap resources to help them better understand insurance navigation, medical necessity, prior authorization, and all of the complex elements of healthcare funding."

### Training and Resources

Currently, training for financial advocates is little more than a passing on of accumulated knowledge from one advocate to the next. Seventy percent of survey respondents say they have received no formal professional training in financial navigation.

"We need continuing education that allows financial advocates to be up to date in their area of expertise," says Kajdic. She points out that, as financial advocates bring more and more specialized knowledge to the multidisciplinary patient care team, they are being invited to participate in clinical care discussions. As they assume more prominent roles in patient care, says Kajdic, there is a growing need to standardize and pass on their collective knowledge.

"That's where tools like ACCC's Financial Advocacy Boot Camp and Patient Assistance Guide come in," says Kajdic. "These resources allow us to pass down crucial information that all financial advocates can benefit from. There has to be a sharing of information and tools and tricks and tips," she adds. "It's up to us to come up with these resources, or our knowledge is in danger of being lost."

Of those survey respondents who say they have received formal training in financial advocacy, 60% say it was through the ACCC Financial Advocacy Boot Camp. The Boot Camp provides new and veteran financial advocates training in conducting distress screening, maximizing insurance coverage and patient assistance, promoting cost-related health literacy, and other topics crucial to a successful financial navigation program. Thus

far, more than 1,000 individuals have graduated from the ACCC Financial Advocacy Boot Camp.

Kajdic says a best practice for sustaining any financial advocacy program is to document and pass on advocates' cumulative expertise. "That's how most of us have learned," she says, "and now it's up to us to pass down our learning to others." In this spirit, ACCC continues working with financial advocates across the multidisciplinary cancer care team to harness their collected knowledge and formalize it into training and resources for members.

### Measuring Impact

Many financial advocates will tell you that the ability to demonstrate the economic impact of their work plays a large role in their profession. "Gauging your impact allows you to take any abstract idea of what you do and turn it into valuable information," says Kajdic. "It's an important part of sustaining and growing future financial advocacy roles. Tracking the value of financial advocacy work illustrates its benefit to patients and to a cancer program's bottom line. Financial advocates really do help ensure the financial security of cancer programs."

However, only 45% of financial advocacy programs track their impact. When asked how they measure their financial success, 23% of survey respondents say they do not track their return on investment (ROI). Thirty-two percent say they are in the process of developing metrics or a tracking system to document the impact of their work. The programs that do track their impact use a variety of metrics, the most common of which include measuring overall reduction in institutional debt and calculating the number of patients who gained access to treatments through the intervention of financial advocates.

The ACCC Financial Advocacy Boot Camp and the ACCC Financial Advocacy Toolkit provide training, resources, and case studies that help financial navigation programs demonstrate the economic impact of their work on both patients and the cancer program.

### Looking Forward

Looking ahead, we can see that the effects of the COVID-19 pandemic on healthcare delivery will continue to ripple through our entire healthcare system in ways we may not yet be able to imagine. This will make the work of financial advocates more important than ever.

Millions of people who were insured before the pandemic have lost their insurance due to cutbacks, layoffs, and shuttered businesses. "We anticipate a surge of patients who need serious assistance," says Kajdic. "There will be a higher demand for financial advocates to find resources. At the same time, resources will likely be more limited due to the economic fallout from the pandemic."

Kajdic says she trusts that financial advocates will rise to the occasion, as they always do when confronted by significant odds. “We’re going to need to get creative,” affirms Kajdic. “The people who come into these roles are first of all people who just want to help. We’re going to have to pool our resources with other specialties, train people fast, find patients in the most need, and prioritize them.”

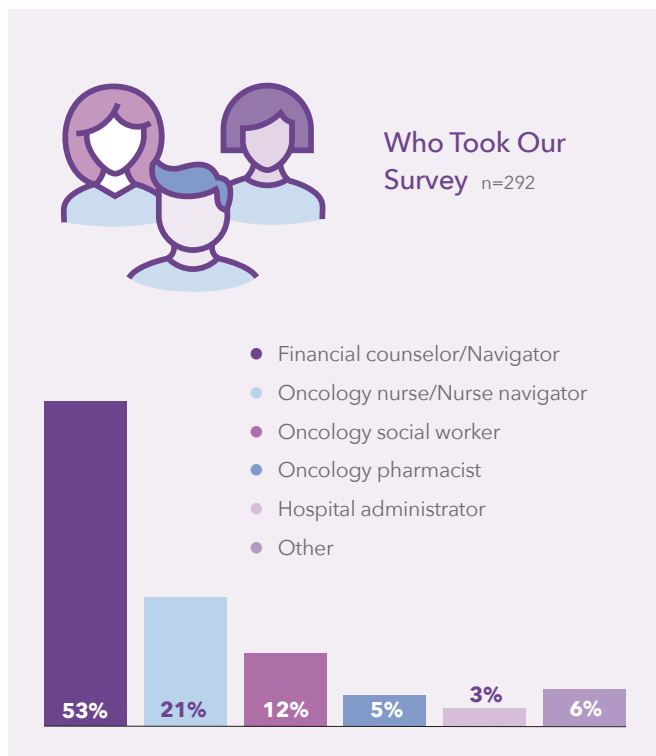
Kajdic says she believes this profession is up to the task: “Financial advocates are very savvy. They feel a need to help their patients, and they will dig and dig until they find an answer.” ●

## References

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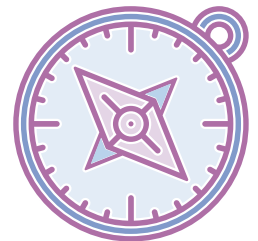
# 2019-2020 ACCC Financial Advocacy Network Census Survey

292 survey respondents from 153 unique cancer programs and practices



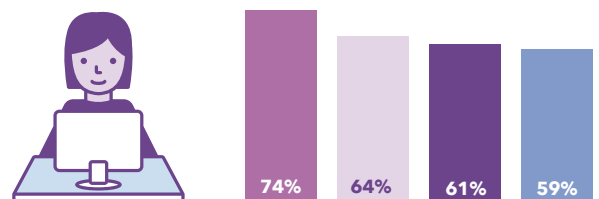
## Years of Experience Providing Financial Navigation Services n=270

- 48% Less than 5 years
- 23% 5-10 years
- 22% 11-20 years
- 7% 20+ years



## Roles and Responsibilities n=192

- Work directly with patients to address financial concerns
- Screen patients for their risk of financial toxicity and/or distress
- Identify and enroll patients in manufacturer financial assistance
- Identify and enroll patients in free-drug programs





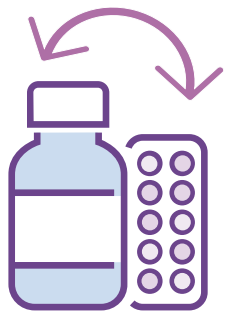
### What's a Co-Pay Accumulator?

A co-pay accumulator—or accumulator adjustment program—is a strategy used by payers and pharmacy benefit managers (PBMs) that stop manufacturer co-pay assistance coupons from counting towards the deductible and the maximum out-of-pocket spending. When the co-pay card

or coupon is exhausted, beneficiaries must pay the entire amount of their deductible before their plan benefits kick in.

A majority (**71%**) of respondents are unaware of co-pay accumulators. n=197

**89%** indicated they need better understanding and resources to feel adequately prepared to explain and assist patients in navigating these new rules. n=84

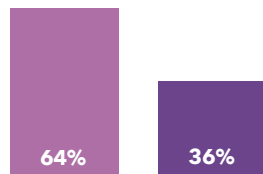


### What's Non-Medical Switching?

Non-medical switching is when a payer changes a patient's treatment regimen for reasons other than efficacy, side effects, or adherence. It is a drug formulary tactic used by payers to reduce drug costs.

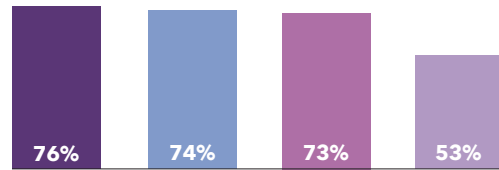
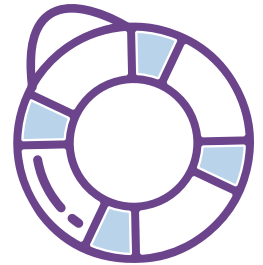
**64%** of respondents are unaware of non-medical switching.

Of the **36%** that are aware of this trend, **81%** say "it always or sometimes impacts patient care." n=190



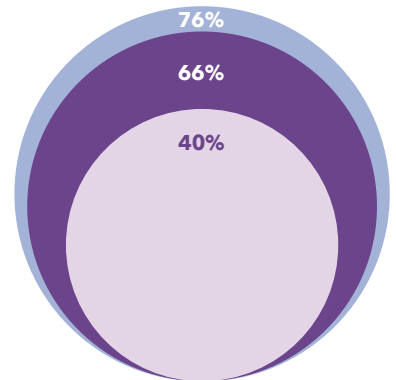
### Help Needed Stat! n=197

- Need help optimizing Medicare and/or Medicaid options
- Need training and materials on cost-related health literacy education
- Need help optimizing private insurance options
- Need help navigating manufacturer and/or advocacy patient assistance programs



### What Can ACCC Do? n=174

- Create videos and webinars on select topics
- Provide customizable tools to support program implementation
- Provide more peer-to-peer learning opportunities



The ACCC Financial Advocacy Network is supported by Pfizer, Janssen, Johnson & Johnson, and Pharmacyclics

Cornerstone Partner: Silver Partners:

The **Association of Community Cancer Centers (ACCC)** is the leading education and advocacy organization for the cancer care community. Founded in 1974, ACCC is a powerful network of 25,000 multidisciplinary practitioners from 2,100 hospitals and practices nationwide. As advances in cancer screening and diagnosis, treatment options, and care delivery models continue to evolve—so has ACCC—adapting its resources to meet the changing needs of the entire oncology care team. For more information, visit [accc-cancer.org](http://accc-cancer.org).

The **ACCC Financial Advocacy Network** is the leader in providing professional development training, tools, and resources that will empower providers to proactively integrate financial health into the cancer care continuum and help patients gain access to high-quality care for a better quality of life.

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