ASSOCIATION OF COMMUNITY CANCER CENTERS

FINANCIAL ADVOCACY NETWORK

2016 Learning Labs

Practical strategies to address financial toxicity

As the cancer community gains a deeper understanding of how financial burdens impact patient care, more emphasis is being placed on effective interventions that can minimize financial toxicity. Studies have shown that financial toxicity is associated with greater pain, more symptom burden, and poorer quality of life in cancer patients undergoing active treatment.[1] While the immediate costs of treatment often cause distress during the active treatment period, a review of 25 research studies found that up to 78 percent of cancer survivors continue to experience financial hardship due to their cancer diagnosis and treatment.[2]

The ACCC Financial Advocacy Network

Cancer programs are all on different parts of an ongoing journey to provide better financial counseling, navigation, and advocacy services to patients. Since 2011, ACCC has led national efforts to provide practical education, training, tools, and resources through its Financial Advocacy Network initiative. In 2016 and 2017, ACCC continued to grow the initiative with a series of case-based regional workshops, on-site learning labs at member cancer programs, and the launch of the Financial Advocacy Boot Camp (accc-cancer.org/FANbootcamp).

Case-Based Regional Workshops

In 2016, ACCC held three case-based regional workshops for financial advocates, counselors, social workers, administrators, and clinicians. The 2016 workshops were held May 23 in Cleveland, Ohio; Aug. 17 in Dallas, Tex.; and Sept. 29 in Philadelphia, Pa. Attendees at each meeting were actively engaged in learning as they spent time discussing de-identified patient cases in small groups and listened to presentations. The patient cases illustrated real-world examples of financial interventions that could transform a patient's experience by effectively reducing the financial burden associated with various treatments. The cases included a mix of common cancers (lung and colon cancer) and less common cancers (lymphoma). The all-day sessions wrapped up with actionable takeaways on how to apply process changes and implement effective practices for financial advocacy within a community cancer program. Highlights from the meetings include:

- **Recognizing and proactively assisting patients who are underinsured.** Although most patients now have some form of health insurance, those with high out-of-pocket responsibilities and/or those with limited income may be functionally under insured. Proactive interventions can help some of these patients, if implemented in a timely fashion.
- **Understanding the complexities of Medicare and the need to educate clinicians and patients about all the different options.** This includes Medicare Advantage, Medicare Supplement (Medigap), Medicare Select, the four types of Medicare Savings Programs, Medicare Low Income Subsidy (Extra Help), and much more.
- **Improving communication across all members of the cancer care team regarding the patient's financial questions and concerns.** Since this information is often not documented in the patient's electronic health record (EHR), it may be difficult for clinicians to know how these concerns are impacting the care journey. Improving those lines of communication could lead to more proactive ways to reduce financial toxicity.
- **Establishing processes and metrics to track the financial savings achieved by the financial advocacy team.** Almost every cancer program may direct patients to pharmaceutical drug assistance programs, but some cancer programs have difficulty tracking this information and coordinating reimbursement with their billing office.

Learning Labs

In 2016, ACCC also went on site and conducted Learning Labs at four member programs in August and September. Learning Lab attendees spent several hours discussing how they currently provide financial advocacy services and identified specific and practical opportunities for improvement. The 2016 FAN Learning Lab sites were:

- Ohio Valley Medical Center in Wheeling, W. Va.
- NewYork-Presbyterian Weill Cornell Medical Center, New York, N.Y.
- St. Luke's University Health Network Cancer Program, Easton, Pa.
- Nebraska Medical Center, Omaha, Nebr.

Following the Learning Labs, each cancer program developed and implemented several process improvement plans using the Plan-Do-Study-Act (PDSA) cycle for improvement and then reported their progress to ACCC after three months. Below are strategies from these improvement plans, including practical strategies for cancer programs looking to address financial toxicity. Access the PDSA Worksheet and user instructions at: ihi.org/resources/Pages/Tools/PlanDoStudyActWorksheet.aspx.

Association of Community Cancer Centers

STRATEGY 1. Establish Processes to Proactively Address Financial Distress

As a cancer patient receives treatment, the financial burden may evolve over the course of time. Therefore, cancer programs should have a systematic process in place to screen for financial distress to proactively address concerns in a timely fashion.

Routine psychosocial distress screening processes may not consistently identify cancer patients who are at risk of experiencing significant financial distress. Cancer patients generally pay higher out-of-pocket costs compared to patients suffering from other chronic conditions.[3] Some have suggested that financial burden and financial toxicity should be assessed based on whether cancer patients accrued debt, sold assets to cover treatment costs, skipped vacations due to financial pressures, refinanced their home, borrowed money, or experienced a 20 percent or greater decline in their annual revenue as a result of treatment-related expenses.[4] Researchers have also proposed specific questionnaires designed to reliably measure financial toxicity in cancer patients.[5] While it may not be practical or feasible to use these research instruments in routine practice, cancer programs may consider modifying their current distress screening tools to better identify patients who are at-risk for experiencing significant financial distress.

Many cancer programs use screening tools, such as the NCCN Distress Thermometer, but they may not be capturing every patient who may benefit from early financial counseling interventions. Several of the cancer programs that participated in the Learning Labs agreed that they could improve how they identify cancer patients who may benefit from receiving financial advocacy and counseling services earlier in their course of treatment.

To continue improvements spurred by the Learning Lab, St. Luke's University Health Network Cancer Program identified the need for a lead financial counselor role. The financial counseling team developed a process to provide financial counseling services as early as possible. When new patients call to schedule their initial appointment, new patient schedulers now follow this process:

- **Step 1.** Gather and review health insurance information at the time of appointment scheduling.
- **Step 2.** Check and review a list of criteria to see if the patient meets the requirements for a referral to financial counseling.
- **Step 3.** Refer patients who meet criteria for financial counseling.

This practical, easily replicable process has led to more patients being seen by financial counseling before their first visit.

At St. Luke's University Health Network Cancer Program, new patients who have been referred for financial counseling have received guidance or interventions that have helped reduce or minimize their risk for experiencing financial toxicity. Some of these interventions may include a change to better health insurance coverage or awareness of different types of patient assistance programs. Since health insurance policies and coverage details change at the beginning of each calendar year, the financial advocacy team spends time educating the schedulers about these major updates. The new process has led to more communication and feedback between the schedulers and the financial advocates. Given that the schedulers are now spending more time on the phone when new patients call for appointments, the cancer program has recognized the need to hire additional schedulers.

Nebraska Medical Center made changes in its EHR to include more specific questions about financial distress. The routine distress screening tool that had been built into the EHR simply did not have enough financial-specific questions. After Nebraska Medical Center made changes to incorporate additional financial distress questions, it worked with the IT team to generate reports based on these newly added questions. Each month, the financial advocacy team reviews these reports and assesses how well they are proactively providing interventions for patients who are experiencing financial distress.

Practical Suggestions for Improvement

- Consider modifying screening forms and questionnaires to include more questions about financial distress.
- Assess whether some cancer patients may benefit by receiving financial counseling earlier in their care journey.
- Discuss whether all of the appropriate patients are receiving financial counseling. If some are getting missed, explore ways to capture those patients earlier in their treatment course.

STRATEGY 2. Develop Processes for Improving Health Literacy

Limited health literacy has been linked to worse clinical outcomes in cancer patients because they have a limited capacity to obtain, process, and understand information about the services they are receiving.[6] Healthcare bills and Explanation of Benefits (EOB) letters may cause significant anxiety, especially when patients do not understand what they are reading.[7] Researchers have stressed the importance of educating and engaging patients around the topic of financial distress.[8]

At NewYork-Presbyterian, the financial advocacy team committed to proactively communicate with patients to alleviate their anxieties about medical bills. The team recognized that some patients would form piles of unopened medical bills at home because they knew that they would not be able to pay those bills. Patients would not answer their phones when the hospital would call, fearing that those calls would be from the billing department. The financial advocates developed a process to speak with patients at every appointment to alleviate those concerns and to assure them that they would find ways to find assistance programs. The financial advocates also encouraged patients to bring those bills and EOBs with them to their clinic visits so they could help them understand what was written in those letters. The team recognized that patients appreciated learning how to interpret their bills, and they felt a sense of relief when they knew that an EOB was not a medical bill.

Practical Suggestions for Improvement

- Use visual aids and easy-to-understand materials when explaining health insurance terms to patients.
- Offer to educate patients about specific issues like the difference between an EOB and a medical bill, the difference between co-pay and coinsurance, etc.

- Provide patients with ongoing reassurance that financial advocates and counselors are there to help and support patients through their treatment journey.

STRATEGY 3. Guide Patients through the Medicare Maze

Every cancer program that participated in the Learning Labs agreed that the Medicare landscape can be very confusing for patients. There are so many options, and providers and patients often get terms confused or may not know about programs and resources that are designed to help Medicare beneficiaries. Medicare is so complex that patients often get lost in the Medicare "maze" of options that include Medicare Supplement Plans; Medicare Advantage Plans; Medicare Parts A, B, C, and D; and much more.

At the Ohio Valley Medical Center, the financial advocacy team used a two-pronged approach to provide education about Medicare coverage and options:

1. Educate clinicians and support staff so they can speak more clearly and effectively with patients about Medicare.
2. Educate patients prior to Medicare open enrollment so patients can make better coverage decisions.

To educate patients, Ohio Valley Medical Center's financial advocacy team developed a public educational seminar and promoted this to eligible patients prior to the Medicare open enrollment period. The education has helped new Medicare patients become more knowledgeable about their options. However, many existing Medicare patients still continue to struggle because they lack prescription drug coverage (Part D) or do not have supplemental coverage. Ohio Valley Medical Center saw the value of educating clinicians and support staff about some of these topics, so their compliance department now requires staff to participate in training focused around specific parts of Medicare.

Nebraska Medical Center also saw the benefit of proactively educating staff and patients about Medicare issues, so it trained financial counselors to provide individualized education about Medicare options to patients throughout the year. Financial advocates became more knowledgeable about the different types of Medicare options including the four types of Medicare Savings Programs:

1. Qualified Medicare Beneficiary Program
2. Specified Low-Income Medicare Beneficiary Program
3. Qualifying Individual Program
4. Qualified Disabled and Working Individuals Program.

The team also learned about Medicare Extra Help for Part D, also called the Low Income Subsidy.

Practical Suggestions for Improvement

- Consider providing a patient education seminar about Medicare before the open enrollment period.
- Provide staff with ongoing training about important Medicare topics and issues, including the four types of Medicare Savings Programs and Extra Help for Part D.
- Be sure that patients and staff clearly understand the differences between Medicare Supplement Plans versus Medicare Advantage Plans, as these are often confused or misunderstood.

STRATEGY 4. Improve Coordination During Care Transitions

At NewYork-Presbyterian, the financial advocacy team recognized an opportunity to improve the patient experience as cancer patients are discharged from the hospital and begin their outpatient chemotherapy. Before NewYork-Presbyterian made changes, patients who were discharged had to call several different phone numbers to schedule clinic appointments and chemotherapy treatments because the scheduling systems were not linked. Moreover, some patients might have experienced delays in outpatient treatments because the necessary prior authorizations were not completed in a timely fashion. To minimize these delays and frustrations, NewYork-Presbyterian instituted a new process when hospital inpatients were preparing to be discharged:

- The hospital social worker or financial advocate would coordinate and schedule the outpatient clinic and treatment appointments before the patient left the hospital.
- The outpatient treatment center would receive all the health insurance information and begin the process of filling out the required paperwork and prior authorizations to ensure that treatments could begin in a timely fashion.

This process has led to significant improvements in care coordination, reduced delays in treatments, and improved patient experience scores. The multidisciplinary cancer team continues to discuss how it may improve care coordination as patients transition from the inpatient to the outpatient setting. In 2017, NewYork-Presbyterian will be switching to a centralized scheduling system to streamline outpatient clinic and treatment schedules.

Practical Suggestions for Improvement

- Identify opportunities to improve care coordination as patients transition from inpatient care to outpatient treatment plans.
- Hold meetings with the inpatient and outpatient social workers and financial advocates to uncover gaps or delays that may occur during care transitions.
- Collect feedback from patients about their experience transitioning from inpatient to outpatient care to find opportunities for improvement.

STRATEGY 5. Develop Metrics and a Process to Measure Cost-Savings and the Effectiveness of Financial Advocacy Interventions

While many cancer programs use spreadsheets to manually track some of the financial savings achieved by their financial advocates, this process may not provide enough metrics on the overall effectiveness of the team. During the 2016 Learning Labs, financial advocates and administrators discussed ways to improve tracking and reporting so they can gain a deeper understanding of their effectiveness.

Following its Learning Lab, Nebraska Medical Center built a decision matrix for its financial advocates and trained staff on how they can properly enroll patients into the right patient assistance programs. The ACCC *Patient Assistance and Reimbursement Guide* served as a template as the team created an algorithmic process that every financial counselor could follow to find the right types of patient assistance

programs. After training its financial advocates, Nebraska Medical Center customized a tracking tool in its EHR by creating a new task that was linked to a report that measures how much time financial advocates spent on patient assistance. The report would also indicate how many patients were being enrolled into patient assistance programs.

Ohio Valley Medical Center developed a financial advocacy tracking sheet to measure how much money this team saves the hospital. Using information from an electronic cancer navigation file that lists every newly diagnosed patient, the financial advocacy team added columns to that file so they could track the effectiveness of their financial advocacy interventions. The new columns included:

- Original primary insurance
- Secondary insurance
- Deductible and out-of-pocket limits
- New primary insurance
- New secondary insurance
- New deductible and out-of-pocket limits
- Co-pay card assistance monetary amount
- Co-pay card assistance company
- Drug replacement monetary amount and company
- Oral drug co-pay assistance monetary amount and company
- Free oral drug monetary amount and company
- Grant assistance monetary amount and grant program.

Formulas were built into the spreadsheet to calculate and total the monetary assistance that patients received. After creating this tool, the team calculated that they had received nearly half a million dollars ($487,500) in assistance in 2016. The team also discovered that 95 percent of the patients evaluated for financial assistance received some form of assistance.

At NewYork-Presbyterian, the financial advocacy team refined its manual tracking process and collected more detailed information about co-pay and patient assistance programs. Over a period of several months in 2016, the team tracked a savings of $300,000. Moreover, they improved lines of communication with their pharmacy and billing departments to ensure that the hospital was being reimbursed from drug replacement and co-pay assistance programs. Financial advocates made sure to collect the EOB paperwork from patients so that they could submit all the required paperwork to receive reimbursement.

Practical Suggestions for Improvement

- Partner with your IT department to develop better reports that reflect the financial advocacy team's time spent on specific tasks and its overall productivity.
- As your program tracks savings from co-pay and patient assistance programs, be sure to track how your hospital is being reimbursed from these programs.

Looking Ahead

Given that financial distress directly impacts overall suffering and quality of life for patients with advanced cancer and their families, cancer programs must continuously find ways to improve how they are addressing financial distress.[9] As cancer programs adopt a mindset of continuous improvement across all the members of the care team, financial advocates and counselors have a special opportunity to play a role in significantly improving the patient experience. Small changes and structured pilot projects may lead to measurable improvements, especially when those ideas are generated from those providers interacting directly with patients.

As mentioned previously, in April 2017, ACCC launched the online Financial Advocacy Boot Camp, a resource for oncology professionals across the country. The Boot Camp is designed to educate and equip financial advocates across five major domains through a series of 14 online learning modules. ACCC remains committed to providing ongoing resources for cancer programs that are looking for ways to improve their financial advocacy services.

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