ONCOLOGY ISSUES

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Association of Community Cancer Centers

March | April 2020

Outcomes from a Community-Based Cancer Survivorship Program

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FROM THE EDITOR

Right to Try: Two Years In

BY JENNIE CREWS, MD, MMM, FACP

May 30, 2020, marks the two-year anniversary of the passage of the federal Right to Try law. Like the experiences in states that have passed similar legislation, there was considerable debate over the benefits versus harms that a national Right to Try law would usher in. Proponents argued that existing processes for patients seeking non-U.S. Food and Drug Administration (FDA)-approved, potentially life-saving medication were arduous, and a more direct approach was needed to improve patient outcomes. Opponents worried that this law would threaten patient safety, clinical trial enrollment, and stakeholder legal and financial liability.

Since the passage of Right to Try, reality looks quite different. The law allows patients with a life-threatening illness who have exhausted approved options or are unable to participate in a clinical trial to receive an investigational drug (that has been through Phase 1 testing) from a manufacturer by providing written informed consent to their treating physician. However, there is no obligation on the part of the physician to pursue the request, the manufacturer to provide the drug, or the insurance company to pay for treatment or treatment-related complications. The law also offers liability protections for physicians and manufacturers.

Thus, Right to Try truly is a "right to try," leaving patients with little assurance and potentially high risk. It is difficult to know for certain how many people have tried to access investigational drugs under this law because there are no mandated reporting requirements. News outlets cite two patients who have used Right to Try—one with glioblastoma and one with Lou Gehrig's disease. It is unknown whether either benefited from the treatments they accessed.

Instead of using Right to Try, many physicians and manufacturers prefer using the FDA's Expanded Access Program, which was established in 1987 and offers some advantages over Right to Try. Expanded Access has similar eligibility requirements but provides patients with broader options by allowing access to drugs in earlier phases of development. The program also provides third-party oversight and guidance to physicians on drug dosing and safety monitoring. The FDA reports that 99 percent of the applications it receives are approved, usually within a few days. About 20 percent of these requests come from oncologists, and in June 2019 the FDA launched Project Facilitate to streamline the Expanded Access Program by providing a single point of contact for oncology requests.

Thus far, it appears that Right to Try has not substantially benefited patients and is not favored by providers or manufacturers. So, who is benefiting from this law? Perhaps organizations seeking to monetize this legislation. A clinical research organization has emerged with plans to broker Right to Try access between manufacturers and medical organizations by providing patients with medication and collecting real-world data on outcomes. The Access Hope clinical research organization (CRO) was founded by an attorney with experience in biotech and Right to Try legislation. Its website cites benefits of this business model to patients, providers, and sponsors for whom "Right to Try creates heretofore unthinkable flexibility, legal immunity, and time and cost reductions while creating new data"[1] and "truly exclusive control over your data."[1] The website also states that Access Hope also will be exploring "patient pay"[1] for services and medications.

Red flag? Perhaps the concerns originally raised by opponents to Right to Try are founded after all. OI

Reference

1. Access Hope CRO. For Sponsors/CROs. Available online at ahcro.com. Last accessed February 18, 2020.

The Year of the Biosimilar

BY ALI MCBRIDE, PHARMD, MS, BCOP

With the advent of biologics decades ago, the practice of oncology was forever changed. Today, the United States has the largest market for biologics in the world, accounting for nearly 50 percent of all prescription drug expenditures. This class of drugs also represents the nation's fastest growing pharmaceutical sector. More than 80 percent of the revenue from biologic therapy is derived from oncology indications, and this percentage is expected to increase in coming years as the use of these essential drugs expands throughout clinical care. These trends are not limited to the United States, however, as the global biologics market is expected to top $100 billion by 2023.[1]

The Biologics Price Competition and Innovation Act of 2009, which created an abbreviated pathway to approval for biosimilar agents, was designed to increase competition with reference biologics to lower prices, increase patient access, and accelerate innovation. Anticipated cost savings with the introduction of biosimilars in the U.S. market was estimated to be from $40 billion to $250 billion over the following 10 years.[2] The added advantages of biosimilar implementation under alternative payment models, such as the Oncology Care Model and Merit-Based Incentive Payment System are still yet to be fully realized.

To date, more than 25 biosimilars have been approved by the U.S. Food and Drug Administration (FDA), including rheumatology therapies, oncology supportive care agents, and therapeutic oncology drugs. The first biosimilar, filgrastim-sndz, was approved in 2015, and as of early 2018 more than 60 biosimilars were enrolled in the FDA's biosimilar development program.[3] Despite this aggressive approval and development landscape, integration of biosimilars into the U.S. market has been slow. Barriers to effective biosimilar implementation vary based on the size and resources of the specific program and can include:

- State and federal legislation
- Reimbursement and coverage challenges
- Electronic health record processes and integration issues
- Insufficient or ineffective education for healthcare team members and patients
- Pharmacy and therapeutics (P&T) integration
- Pharmacovigilance processes and an understanding of biosimilar outcomes, which have been associated with a lack of knowledge of biosimilars
- Uncertainty around therapeutic outcomes.

As we move into this new decade, biosimilars represent terrific innovation and (as yet) unrealized potential for cost savings. Use of these therapies may help cancer programs improve access to care, reduce total healthcare expenditures, and meet alternative payment model goals and requirements. If we are to realize the full potential of these therapies, however, integration of biosimilars is critical and must be achieved through interdisciplinary education of the entire cancer team—from physicians and nurses to pharmacy staff to financial navigators and patients and beyond. We can all play a vital role in the education, advocacy, and safety needs inherent with this new class of anti-cancer therapies. OI

References

1. GBI Research. Global immunology market to surpass $100 billion by 2023. Available online at: gbiresearch.com/media-center/press-releases/global-immunology-market-to-surpass-100-billion-by-2023. Last accessed February 18, 2020.
2. Deloitte. Winning with biosimilars: opportunities in global markets. Available online at: www2.deloitte.com/content/dam/Deloitte/us/Documents/life-sciences-health-care/us-lshc-biosimilars-whitepaper-final.pdf. Last accessed February 18, 2020.
3. Dolan C. Opportunities and challenges in biosimilar uptake in oncology. *Am J Manag Care*. 2018;4(11):S237-S243.

Coming in Your 2020 *ONCOLOGY ISSUES*

- "Prescribing" Exercise and Nutrition in Cancer Care
- Medical Marijuana (Cannabinoid-Derived Products) for Cancer Patients
- Developing a Model of Risk Modification for Breast Cancer Using Integrative Oncology
- Helping Patients Navigate the Clinical, Psychosocial, and Financial Aspects of Cancer Care
- Telemedicine Improves Access to Supportive Group Psychotherapy for Young Adults with Cancer
- Electronic Multidisciplinary Conference (eMDC): Case Planning in the Virtual Space
- Developing and Implementing a Radiation Oncology App to Improve the Patient Experience
- Cancer Life reiMagined: The CaLM Model of Whole-Person Cancer Care
- Implementing Genetic Cancer Screening and Testing in a Medically Underserved Community
- Reducing Revenue Loss and Patient Financial Toxicity with Pharmacy Pre-Certification and Denials Management
- Food Security: A Key Component in One Practice's Financial Advocacy Program
- Researching the Use of Virtual Reality (VR) in the Oncology Infusion Clinic
- Optimizing Provider Access in the Rural Healthcare Setting by Utilizing a Physician-Advanced Practice Provider Model

more online @ accc-cancer.org

RESOURCE

Trending Now in Cancer Care

As the demand for cancer services rises in the U.S., cancer programs continue to rank three factors as top challenges to growth: payer reimbursement requirements, the move to value-based payments, and uncertainties in drug pricing reform policies. In ACCC's 2019 survey, the vast majority (88%) of respondents selected improving care coordination as a top opportunity for cost savings. Other areas identified for cost savings opportunities included: improving symptom management (85%); utilization of lower cost drugs through implementation of pathways (76%); and reducing variations in care (72%). Read key findings at accc-cancer.org/trends.

BLOG

Pursuing Quality Cancer Care for Sexual and Gender Minority Patients

These patients are often misrepresented or overlooked in healthcare. Although social acceptance has grown for sexual and gender minority communities, LGBTQ-specific health risks and recommended screenings are not consistently taught to healthcare providers and patients. One way to improve care of this patient population is to promote and collect sexual and gender minority information whenever patient demographics are collected, for example adding language that asks patients their preferred name and pronouns to create gender-neutral intake forms. Read more at accc-cancer.org/acccbuzz-SGM.

PODCAST

The Immunotherapy Patient Perspective

Journalist Mary Elizabeth Williams, one of the first patients treated with combination immunotherapy, discusses her experience as an immunotherapy patient and how to bridge communication gaps among patients, providers, and researchers. At the ACCC 36th National Oncology Conference, Williams shared that communication boils down to "making sure patients and providers are on the same page. Telling the same stories, because stories are how we make decisions. Communication is about empathy and being clear. It's not optional." Hear more at accc-cancer.org/podcast.

WEBINAR

BiomarkerLIVE Resource Library and Lexicon

The important role that biomarkers and molecular profiling play in cancer diagnosis and treatment continues to grow, but keeping pace with this rapidly evolving field can be challenging. ACCC's BiomarkerLIVE program puts a library of resources and a comprehensive glossary of terms at your fingertips, giving you the knowledge and tools to discuss biomarker testing with colleagues and patients. The BiomarkerLIVE Advisory Committee has developed a webinar on how to use these valuable tools, with expert review of the current cancer biomarker landscape and three case examples. Learn any time, anywhere! accc-cancer.org/biomarker-live-webinar.

fast

Executive Physician Wellness Leaders Needed STAT!

In a 2019 consensus paper, the National Academy of Medicine's Action Collaborative on Clinician Well-Being and Resilience recommended an executive level physician wellness leader in ALL healthcare delivery organizations. Most organizations have no such leader and many believe there is a shortage of qualified candidates to draw from.

Source. NAM. Taking Action Against Clinician Burnout: A Systems Approach to Professional Well-Being. Available online at nap.edu/catalog/25521 taking-action-against-clinician-burnout-a-systems-approach-to-professional.

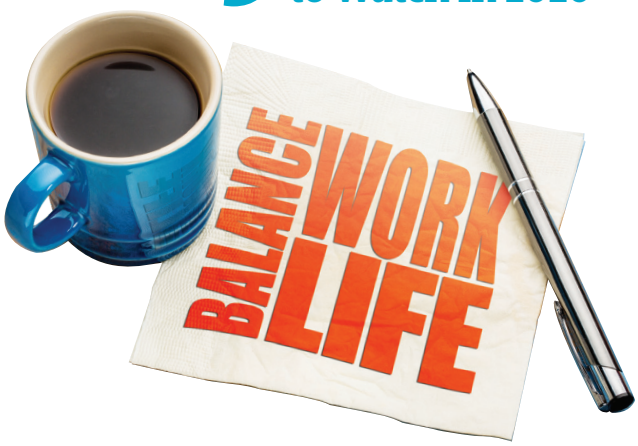
Top 4 Challenges Managers Face

- Juggling management of my team with my other responsibilities—**68%**
- Hitting team goals—**14%**
- Getting my team to collaborate with one another—**11%**
- Retaining my employees—**4%**

Source. 2019 State of One-on-Ones Report. soapboxhq.com/state-of-one-on-ones-report.

facts

5 Wellness Trends to Watch in 2020



1. Financial Wellness. With **64%** of Americans experiencing stress about money,[1] more employers are offering financial wellness programs to educate employees and help improve employee health and productivity.

2. Technology Integration. As wearables and online platforms allow users to sync data in real-time, more employers will move to mobile platforms for health interactions. Allowing employees to connect with their health info via mobile platforms make employer health programs more accessible to remote employees.

3. Wellness at Work. From company walking groups to onsite fitness facilities, more employers are seeing the benefits of small investments, like standing desks and healthier food options in breakrooms.

4. Flexible Work/Life Balance. Advanced technology and an always-on culture means that work isn't restricted to an office or from 9-5. More employers are embracing flexible working hours and remote work in response to Gen Z and Millennials pushing for greater work/life balance.

5. Health Coaching. More employers will add health coaches to their benefits. These coaches can help employees set goals, identify obstacles, and find solutions, creating healthier, more productive workplace cultures.

Source. StayWell Shares Top 5 Employer Wellness Trends in 2020. staywell.com. staywell.com/news/top-5-employer-wellness-trends-in-2020.

1 American Psychological Association. Stress in America: Paying With Our Health. apa.org/news/press/releases/stress/2014/stress-report.pdf.

Physicians Give EHRs an "F" Grade

In a recent study, the usability of current EHR systems received a grade of **"F"** by physician users. The same study found a strong relationship between EHR usability and physician burnout. Study authors recommend, "Given the association between EHR usability and physician burnout, improving EHR usability may be an important approach to help reduce healthcare professional burnout."

Source. Melnick ER, et al. The association between perceived electronic health record usability and professional burnout among U.S. physicians. *Mayo Clinic Proc.* DOI: 10.1016/j.mayocp.2019.09.024.

Generational Differences in Physician Burnout

- **48%** of Generation X physicians report burnout, compared to **39%** of Baby Boomer physicians and **38%** of Millennial physicians.
- **50%** of Baby Boomer physicians say that burnout has had a strong and/or severe impact on their lives, compared to **46%** of Generation X physicians and **38%** of Millennial physicians.
- **77%** of Millennial physicians say that burnout has impacted their relationships, compared to **73%** of Generation X physicians and **69%** of Baby Boomer physicians.

Source. Medscape National Physician Burnout & Suicide Report 2020. medscape.com/slideshow/2020-lifestyle-burnout-6012460?faf=1#1.

Policy Round Up

BY CHRISTIAN G. DOWNS, JD, MHA

In this election year, U.S. healthcare policy is center stage. To help its members keep current on recent policy issues that may affect their programs and patients, ACCC provides a brief update.

CY 2021/2022 Medicare Advantage and Part D Proposed Rule

On Feb. 5, the Centers for Medicare & Medicaid Services (CMS) released CMS-4190-P, which would:

- Require Part D plans to offer real-time drug price comparison tools to beneficiaries starting Jan. 1, 2022, to allow consumers to shop for lower-cost alternative therapies under their prescription drug benefit plan.
- Allow a second, "preferred" specialty tier in Part D with a lower cost-sharing amount.
- Require Part D plans to disclose the measures they use to evaluate pharmacy performance in their network agreements. This would allow CMS to track and report publicly how plans are measuring and applying pharmacy performance measures.
- Strengthen network adequacy rules for Medicare Advantage plans by codifying CMS's existing network adequacy methodology. The proposed rule has provisions addressing access to care in rural areas and encouraging use of telehealth in all areas. For rural areas, the agency proposes to lower the percentage of beneficiaries required to live within the maximum time and distances standards from 90 percent to 85 percent. Telehealth remains a topic of great interest to ACCC member programs. Data from the 2019 ACCC Trending Now in Cancer Care Survey found that in the next two years, 35 percent of cancer programs plan to use telehealth for delivery of genetic counseling (already difficult to access in rural areas), 28 percent for symptom consults, 28 percent for oral chemotherapy adherence and support, 28 percent for symptom monitoring (e.g., through an app), 24 percent for psychosocial counseling, and 22 percent for nutrition counseling.

Comment deadline on the proposed rule is April 6, 2020.

Together with the Medicare Advantage and Part D proposed rule, CMS released the 2021 Medicare Advantage and Part D Advance Notice Part II, in which the agency solicits comments on potentially developing measures of generic and biosimilar utilization in Medicare Part D as part of a plan's star rating. Comment deadline on Advance Notice Part I and Part II proposals was Friday, March 6, 2020.

Coverage for Diagnostic Tests Using Next-Generation Sequencing

On Jan. 27, 2020, CMS issued a National Coverage Determination that expands coverage of U.S. Food and Drug Administration (FDA)-approved laboratory diagnostic tests that use next-generation sequencing for patients with germline, or inherited, ovarian or breast cancer. CMS also gave Medicare Administrative Contractors the ability to determine coverage of next-generation sequencing laboratory tests for other inherited cancers.

Importation of Prescription Drugs

As part of the administration's push to lower prescription drug prices, the FDA released a proposed rule and draft guidance on drug importation into the United States. The proposed rule would authorize states, wholesalers, or pharmacists to submit proposals to import prescription drugs from Canada into the United States. The rule excludes importation of biologics and infused drugs.

The FDA issued draft guidance that describes pathways that drug manufacturers would use to import prescription drugs (including biologics) into the United States that are FDA approved, manufactured abroad, and originally intended for sale in a foreign country.

The proposed rule comes after the Dec. 28, 2019, administration release of a notice of proposed rulemaking on drug importation and draft guidance. These actions follow the administration's "Safe Importation Action Plan," released in July 2019, which laid out pathways for importing certain prescription drugs into the United States.

340B Under Scrutiny

In early January, the Government Accountability Office (GAO) released a report calling on the Health Resources and Services Administration (HRSA), an agency of the U.S. Department of Health and Human Services (HHS), to improve processes for assuring that

participating non-governmental hospitals meet 340B Drug Pricing Program eligibility requirements. The GAO report recommends that HRSA:

- Implement a process to verify that all non-governmental hospitals have contracts in place, including throughout hospitals' audit periods.
- Amend its contract reviews to include an assessment of whether contracts meet statutory requirements.
- Provide better guidance on contract reviews.

HHS agreed with the GAO recommendations except for the recommendation to set up a process to verify that all non-governmental hospitals have contracts in place. HHS says that HRSA does not have the resources to carry out the recommended verification process and that it would over-burden the agency.

Later in January, the GAO issued a second 340B report calling on HRSA and CMS to take action to prevent drug manufacturers from paying duplicate discounts under Medicaid and the 340 Drug Pricing Program. In response, HHS and 340 participating hospitals asserted that HRSA cannot legally follow the GAO's request to examine states' duplicate discount prevention policies and procedures and then act to enforce these if providers do not comply. CMS states that HRSA lacks the authority to determine the adequacy and appropriateness of state Medicaid policies and procedures to prevent duplicate discounts. On Jan. 8, 2020, CMS issued guidance on "Best Practices for Avoiding 340B Duplicate Discounts in Medicaid" (medicaid.gov/sites/default/files/Federal-Policy-Guidance/Downloads/cib010820.pdf).

ACCC Response to Center for Medicare and Medicaid Innovation on Oncology Care First Model

ACCC provided comments to the Center for Medicare and Medicaid Innovation's (CMMI) request for information on its concept for the Oncology Care First Model. Though applauding CMMI for making the Oncology Care First Model voluntary and envisioning a multi-payer model, ACCC urged CMMI to:

- Make significant changes to the risk tracks for purposes of performance-based payment episodes.
- Structure the prospective payment for care management and certain other services as a supplemental payment.
- Provide more detail on the methodology for the novel therapy adjustment and ensure that the final adjustment adequately accounts for the cost of innovative and often life-saving new therapies.
- Provide more details and future opportunities to comment on the Oncology Care First Model before finalizing the model.

Read the full letter at accc-cancer.org/advocacy.

Medicaid Block Grants: Impact on Cancer Patients

On Jan. 29, 2020, CMS released guidance that would permit states to receive a block grant for adults not otherwise eligible for Medicaid (i.e., adults younger than age 65). Dubbed the "Healthy Adult Opportunity," the agency is referring to the plan as a demonstration. In accepting the block grant—capping the state's federal funding for Medicaid beneficiaries—the state would have greater flexibility in determining benefits' coverage and benefit from a less cumbersome process for adding work requirements and other restrictions. Oncology stakeholders, along with patient advocacy groups, expressed concerns that transformation of Medicaid through block grants could reduce access to care and result in the rationing of services for the most vulnerable patient populations. As with Medicaid work requirements, the agency's legal authority to push this plan forward is likely to be the subject of litigation. OI

Christian G. Downs, JD, MHA is executive director, Association of Community Cancer Centers, Rockville, Md.

Preparing for E/M Changes to Outpatient Visits in 2021

BY TERI BEDARD BA, RT(R)(T), CPC

There is no argument that the Evaluation and Management (E/M) coding guidelines are in need of an update. The Centers for Medicare & Medicaid Services (CMS) has not updated E/M guidelines since 1997, with many providers and coders still following the 1995 guidelines. The use of electronic health records (EHRs) has prompted requests for updates. The ability to copy and paste documentation from another provider's visit notes and templates, which incorporate full documentation of the Review of Systems and Physical Exam, can result in documentation that is more complex than what took place during the encounter, creating issues not foreseen in 1995 or 1997.

It is not uncommon to see E/M visit notes run pages long and with no clear documentation of what is actually new and part of the patient encounter. Additionally, the ability to pull in statements from elsewhere in the EHR creates an issue with continuity, because these statements may be old or outdated and no longer pertain to the patient's current situation, resulting in contradictory documentation.

To solve this, CMS issued sweeping changes to the outpatient visit codes (**99201-99215**) in the CY 2019 Medicare Physician Fee Schedule (MPFS) Final Rule, CMS-1715-F, which go into effect Jan. 1, 2021, including collapsing visit levels from three individual reimbursed rates to one. Based on stakeholder feedback that showed that many disagreed with these reimbursement changes, the agency convened additional stakeholder meetings.

At the same time, the American Medical Association (AMA) convened a taskforce dedicated to updating the E/M CPT® codes. The AMA came up with guidelines based solely on medical decision-making (MDM) and time, as well as a dedicated prolonged services code specific to outpatient E/M visits. This meant that history and/or physical exam would no longer be used to determine the billable level. In an about-face, CMS did away with most, but not all, of the changes finalized in the CY2019 PFS rule and instead aligned with those established by the AMA. The agency's decision allows for consistency and continuity of coding and billing for all patients across all payers. Because most commercial and private payers follow AMA guidelines when using CPT codes, it made sense for CMS to do the same and not create more work and confusion for providers.

At the Resource-Based Relative Value Scale Symposium in Nov. 2019, the AMA provided updated definitions, time ranges, and MDM criteria for the outpatient E/M codes (**99202-99215**) that go into effect Jan. 1, 2021. The following is a summary of the changes for CY 2021 as we know them now, with the expectation that more updates and information may come during the CY 2021 CMS rulemaking cycle, as well as AMA coding updates for the CY 2021 CPT Manual. Beginning Jan. 1, 2021, practitioners will select either MDM or time on which to base their documentation and coding.

MDM Criteria

Providers who select MDM for documentation and coding can select from four levels, using these updated AMA parameters:

Straightforward

- Self-limited.
- Minimal or no data review and/or analyzed.
- Minimal risk from treatment (including no treatment) or testing. (Most would consider this effectively as no risk.).

Low

- Stable, uncomplicated, single problem.
- Two documents or independent historian.
- Low risk (i.e., very low risk of anything bad), minimal consent/discussion.

Moderate

- Multiple problems or significantly ill.
- Count: Three items between documents and independent historian, or interpret or confer.
- Would typically review with patient/surrogate, obtain consent and monitor, or there are complex social factors in management.

High

- Very ill.
- Same concepts as Moderate.
- Discussion includes difficult topics or decisions for the very ill patient that could happen for which physician or other qualified healthcare professional will watch or monitor.

When counting the number and/or complexity of data reviewed and analyzed, three different categories are part of the MDM:

- Tests, documents, orders, or independent historian(s)—each unique test, order, or document is counted to meet a threshold number.

- Independent interpretation of tests is not reported separately.
- Discussion of management or test interpretation with external physician/other qualified healthcare professional/appropriate source (not reported separately).

Time-Based Criteria

Providers who use the time-based parameter must understand that more is required than just the mention of the total time spent on the date of the encounter. Documentation must include and support all of the work provided to which time was attributed on that date of service by the billing practitioner and may not include ancillary staff time. The AMA stresses that the following items are to be accounted for and/or included when using the time-based option:

- Preparing to see the patient (e.g., review of tests)
- Obtaining and/or reviewing separately obtained history
- Performing a medically necessary appropriate examination and/or evaluation
- Counseling and educating the patient/family/caregiver
- Ordering medications, tests, or procedures
- Referring and communicating with other healthcare professionals (when not reported separately)
- Documenting clinical information in the electronic or other health record
- Independently interpreting results (not reported separately) and communicating results to the patient/family/caregiver
- Care coordination (not reported separately).

The AMA also notes that practitioners should make every effort to improve their ability to document electronically in the EHR to avoid penalizing the patient and payer by charging a higher level of code billed.

Tables 1 and 2, page 10, list the updated definitions and time-based ranges for these new patient visits, **99202-99205**, and established patient visits, **99211-99215**. These will replace the current definitions and time ranges used in CY 2020.

CPT 99201 will be deleted effective Jan. 1, 2021.

Prolonged Services Code

A new prolonged services code will be available Jan. 1, 2021, that is only for use with level 5 outpatient visit codes, **99205** and **99215**. Updates will be made to codes **99358** and **99359** and providers will no longer be allowed to bill them in addition to the new and established outpatient visits. This new code has not been assigned a full CPT number, but the definition for the new **99xxx** code will be prolonged office or other outpatient evaluation and management service(s) (beyond the total time of the primary procedure that has been selected using total time), requiring total time with or without direct patient contact beyond the usual service on the date of the primary service; each 15 minutes (list separately in addition to codes 99205, 99215 for office or other outpatient E/M services).

Complexity Code

In 2021 CMS is adding a complexity code as an add-on to the E/M outpatient codes. This new code is a revision of language finalized in the CY 2019 MPFS final rule. At present not much is known about this code beyond the definition, but more is expected at the time of the 2021 MPFS rulemaking cycle. Code **GPC1X** (the full Healthcare Common Procedure Coding System code will be released by CMS) is defined as visit complexity inherent to E/M associated with medical care services that serve as the continuing focal point for all needed healthcare services and/or with medical care services that are part of ongoing care related to a patient's single, serious, or complex chronic condition. (Add-on code, list separately in addition to office/outpatient evaluation and management visit, new or established.)

As CY 2021 comes closer, more education and information from both the AMA and CMS is needed to help providers adjust to these new E/M guidelines. Both organizations understand the need for the change and are developing resources to assist providers and coders in understanding these big changes so that everyone starts off with their best foot forward in this new E/M landscape. OI

Teri Bedard, BA, RT(R)(T), CPC, is director, Client Services at Coding Strategies, Inc., Powder Springs, Ga., and Revenue Cycle, Inc., Cedar Park, Tex.

Table 1. New Patient Visit Code Updates for 2021

CPT CODE	DEFINITION	TOTAL TIME IN MINUTES ON DATE OF ENCOUNTER
99201	Deleted for 2021	N/A
99202	Office or other outpatient visit for the evaluation and management of a new patient, which requires a medically appropriate history and/or examination and straightforward medical decision-making.	15-29
99203	Office or other outpatient visit for the evaluation and management of a new patient, which requires a medically appropriate history and/or examination and low level of medical decision-making.	30-44
99204	Office or other outpatient visit for the evaluation and management of a new patient, which requires a medically appropriate history and/or examination and moderate level of medical decision-making.	45-59
99205	Office or other outpatient visit for the evaluation and management of a new patient, which requires a medically appropriate history and/or examination and high level of medical decision-making.	60-74

Table 2. Established Patient Visit Code Updates for 2021

CPT CODE	DEFINITION	TOTAL TIME IN MINUTES ON DATE OF ENCOUNTER
99211	Office or other outpatient visit for the evaluation and management of an established patient, which may not require the presence of a physician or other qualified healthcare professional. Usually, the presenting problem(s) are minimal.	No time is part of this code in 2021
99212	Office or other outpatient visit for the evaluation and management of an established patient, which requires a medically appropriate history and/or examination and straightforward medical decision-making.	10-19
99213	Office or other outpatient visit for the evaluation and management of an established patient, which requires a medically appropriate history and/or examination and low level of medical decision-making.	20-29
99214	Office or other outpatient visit for the evaluation and management of an established patient, which requires a medically appropriate history and/or examination and moderate level of medical decision-making.	30-39
99215	Office or other outpatient visit for the evaluation and management of an established patient, which requires a medically appropriate history and/or examination and high level of medical decision-making.	40-54

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tools

Approved Drugs

- On Jan. 9, 2020, the U.S. Food and Drug and Administration (FDA) approved **Ayvakit™ (avapritinib)** (Blueprint Medicines, blueprintmedicines.com) for the treatment of adults with unresectable or metastatic gastrointestinal stromal tumor harboring a platelet-derived growth factor receptor alpha exon 18 mutation, including PDGFRA D842V mutations.
- On Dec. 20, 2019, the FDA granted accelerated approval to **Enhertu® (fam-trastuzumab deruxtecan-nxki)** (Daiichi Sankyo, daiichisankyo.com) for patients with unresectable or metastatic human epidermal growth factor receptor 2 (HER2)-positive breast cancer who have received two or more prior anti-HER2-based regimens in the metastatic setting.
- On Jan. 8, 2020, the FDA approved **Keytruda® (pembrolizumab)** (Merck, merk.com) as a monotherapy for the treatment of patients with bacillus Calmette-Guérin unresponsive, high-risk, non-muscle-invasive bladder cancer with carcinoma *in situ* with or without papillary tumors, who are ineligible for or have elected not to undergo cystectomy.
- On Dec. 27, 2019, the FDA approved **Lynparza® (olaparib)** (AstraZeneca and Merck, astrazeneca.com, merck.com) for the maintenance treatment of adult patients with deleterious or suspected deleterious germline BRCA-mutated metastatic pancreatic adenocarcinoma whose disease has not progressed on at least 16 weeks of a first-line platinum-based chemotherapy regimen.
- On Dec. 18, 2019, the FDA granted accelerated approval to **Padcev™ (enfortumab vedotin-ejfv)** (Astellas Pharma Inc. and Seattle Genetics, Inc., astellas.com, seattlegenetics.com) for the treatment of adult patients with locally advanced or metastatic urothelial cancer who have previously received a PD-1/L1 inhibitor and a platinum-containing chemotherapy before or after surgery or in a locally advanced or metastatic setting.
- On Jan. 23, 2020, the FDA granted accelerated approval to **Tazverik™ (tazemetostat)** (Epizyme, Inc., epizyme.com) for the treatment of adults and pediatric patients aged 16 years and older with metastatic or locally advanced epithelioid sarcoma not eligible for complete resection.
- On Dec. 16, 2019, the FDA approved **Xtandi® (enzalutamide)** (Astellas Pharma Inc., astellas.com) for patients with metastatic castration-sensitive prostate cancer.

Drugs in the News

- The FDA has approved an investigational new drug application for a phase 1 trial of **ACE1702** (Acepodia, acepodia.com), a targeted cancer therapy created by a proprietary chemical process that directly links anti-tumor antibodies to the surface of natural killer cells. It will soon enter in-human clinical trials in HER2-positive solid tumors.
- Amgen (amgen.com) and Allergan plc. (allergan.com) announced the submission of a biologics license application (BLA) to the FDA for **ABP 798**, a biosimilar candidate to Rituxan® (rituximab).
- GlaxoSmithKline (gsk.com/en-gb) announced that the FDA has granted priority review for the company's BLA seeking approval of **belantamab mafodotin (GSK2857916)** for the treatment of patients with relapsed or refractory multiple myeloma whose prior therapy included an immunomodulatory agent, a proteasome inhibitor, and an anti-CD38 antibody.
- AstraZeneca (astrazeneca.com) announced that the FDA has granted orphan drug designations to PD-L1 **Imfinzi® (durvalumab)** and anti-CTLA4 antibody **tremelimumab** for liver cancer.
- Kite (kitepharma.com) announced that it has submitted a BLA to the FDA for the investigational chimeric antigen receptor (CAR) T-cell therapy, **KTE-X19**, for the treatment of adult patients with relapsed or refractory mantle cell lymphoma.
- CytoDyn (cytodyn.com) filed for breakthrough therapy designation for its targeted therapy, **leronlimab (PRO 140)**, as an adjuvant therapy for the treatment of metastatic triple-negative breast cancer.
- Bristol-Myers Squibb (bms.com) submitted a BLA to the FDA for **Lisocabtagene Maraleucel (liso-cel)**, its autologous anti-CD19 CAR T-cell immunotherapy including individually formulated CD8+ and CD4+ CAR T-cells for the treatment of adult patients with relapsed or refractory large B-cell lymphoma after at least two prior therapies.
- AstraZeneca (astrazeneca.com) and Merck (merck.com) announced that a supplemental new drug application for **Lynparza® (olaparib)** in combination with **bevacizumab** has been accepted and granted priority review by the FDA for the maintenance treatment of patients with advanced ovarian cancer who are in

complete or partial response to first-line platinum-based chemotherapy with bevacizumab. The FDA has accepted and granted priority review to a second supplemental new drug application for **Lynparza® (olaparib)** for patients with metastatic castration-resistant prostate cancer and deleterious or suspected deleterious germline or somatic homologous recombination repair gene mutations who have progressed following prior treatment with a new hormonal agent.

- MacroGenics, Inc. (macrogenics.com) announced that it has submitted a BLA for **margetuximab**, an investigational, Fc-engineered, monoclonal antibody that targets HER2, for the treatment of patients with metastatic HER2-positive breast cancer in combination with chemotherapy.
- OBI Pharma, Inc. (obipharma.com) announced that the FDA has granted orphan drug designation to **OBI-999** for the treatment of gastric cancer.
- Bristol-Myers Squibb (bms.com) announced that the FDA has accepted and granted priority review to its supplemental BLA for **Opdivo® (nivolumab)** in combination with **Yervoy® (ipilimumab)** for the first-line treatment of patients with metastatic or recurrent non-small cell lung cancer with no epidermal growth factor receptor or anaplastic lymphoma kinase genomic tumor aberrations.
- Precigen, Inc. (precigen.com) announced that the FDA has granted orphan drug designation to **PRGN-3006**, an investigational therapy using Precigen's non-viral UltraCAR-T™ therapeutic platform for patients with relapsed or refractory acute myeloid leukemia.
- Eli Lilly (lilly.com) announced that the FDA granted priority review for an NDA for **selpercatinib (LOXO-292)** for the treatment of patients with advanced RET fusion-positive non-small cell lung cancer, RET-mutant medullary thyroid cancer, and RET fusion-positive thyroid cancer.
- Roche (roche.com) announced the submission of a supplemental BLA to the FDA for **Tecentriq® (atezolizumab)** in combination with **Avastin® (bevacizumab)** (Genentech, gene.com) for the treatment of patients with unresectable hepatocellular carcinoma who have not received prior systemic therapy.
- Kura Oncology, Inc. (kuraoncology.com) announced that the FDA has granted fast track designation to **tipifarnib** for the treatment of patients with HRAS-mutant head and neck squamous cell carcinomas after progression on platinum therapy.
- Seattle Genetics, Inc. (seattlegenetics.com) announced that it has submitted an NDA to the FDA for **tucatinib** in combination with **trastuzumab** and **capecitabine** for treatment of patients with locally advanced unresectable or metastatic HER2-positive breast cancer, including patients with brain metastases, who have received at least three prior HER2-directed agents separately or in combination in the neoadjuvant, adjuvant, or metastatic setting.
- Karyopharm Therapeutics Inc. (karyopharm.com) announced that it has submitted an NDA to the FDA seeking accelerated approval for **Xpovio® (selinexor)** as a new treatment for patients with relapsed or refractory diffuse large B-cell lymphoma after at least two prior multi-agent therapies and who are ineligible for stem cell transplantation, including CAR T-cell therapy.

Approved Genetic Tests and Assays

- Myriad Genetics, Inc. (myriad.com) announced that the FDA has approved **BRACAnalysis CDx®** for use as a companion diagnostic test by healthcare professionals to identify patients with metastatic pancreatic cancer who have a germline BRCA mutation and are candidates for treatment with PARP inhibitor Lynparza® (olaparib).
- IceCure Medical Ltd. (icecure-medical.com) announced that it received FDA clearance for expanded indications of **Cryoablation Technology**, a non-surgical liquid nitrogen cryoablation technology that destroys benign and cancerous tumors by freezing. The new FDA clearance will enable the company to market its solution for the treatment of cancerous and benign tumors of the kidney; liver; and ear, nose, and throat; and further neurology indications.
- Myriad Genetics, Inc. (myriad.com) announced submission of a supplementary premarket approval application to the FDA for its **myChoice® CDx test** to help predict outcomes of women with first-line platinum-responsive advanced ovarian cancer treated with PARP inhibitor Zejula® (niraparib). OI

spotlight

Portneuf Cancer Center
Pocatello, Idaho

Portneuf Cancer Center calls Pocatello, Idaho, home. It overlooks the sprawling valley of the Portneuf River that leads to a beautiful reservoir. Surrounding mountains create panoramic views in every direction. The cancer center, which opened in 2004, is located in its own single-story building on the campus of Portneuf Medical Center and operates as a hospital outpatient department. The cancer center treats patients from southeastern Idaho and cares for a diverse rural population.

Under One Roof

Patients at Portneuf Cancer Center do not have to travel to separate locations for care—medical oncology, radiation oncology, dietitians, and a social worker all provide care under the same roof. "The beautiful thing about this is that when patients walk into the cancer center, our staff knows their name and the patients become part of the fabric of our center," explains Mary Keating, director of marketing.

Housed within the cancer center is an infusion suite, clinic, and radiation suite all on one floor with patient flow in mind. The infusion suite, located at the north end of the cancer center, includes 10 infusion chairs that look out onto the Portneuf Valley through floor-to-ceiling windows and 2 private infusion rooms with a hospital bed and private bedroom. The infusion suite is staffed by 6 nurses—4 full-time, 1 part-time, and 1 as needed (PRN). Three of the nursing staff hold oncology-certified nursing credentials and two others have Vascular Access Board certification. The outpatient clinic is the "hub" of the cancer center and is adjacent to the radiation oncology suite. It features 10 exam rooms and a laboratory draw station.

Radiation oncology services are located opposite to the outpatient clinic and infusion suite. The cancer center boasts an Elekta Infinity™ linear accelerator, cone beam computed tomography scanner, and large bore computed tomography scanner. Patients can receive a range of treatments, including 3D conformal, intensity-modulated radiation therapy, volumetric-modulated arc therapy, image-guided radiation therapy, stereotactic body radiation therapy, and stereotactic radiosurgery. The radiation oncology suite is staffed by three radiation therapists, one medical dosimetrist, and one medical physicist.

In addition to the infusion suite nurses and radiation suite, the Portneuf Cancer Center is staffed by two medical oncologists, two radiation oncologists, three certified physician assistants, one oncology nurse navigator, one licensed social worker, three financial counselors, one registered dietitian, and two certified tumor registrars. All of the center's medical oncology providers and staff are hospital employed; radiation oncologists are contracted.

Most patients are referred to the cancer center by Portneuf Medical Center's surgeons or primary care physicians, which streamlines the referral process. The cancer center also sees patients referred from outside of the Pocatello area.

The leading cancer sites treated at Portneuf Cancer Center include breast, lung, colorectal, and prostate. Patients with breast cancer may be seen at the cancer center's multidisciplinary breast clinic, which allows patients to meet with their medical oncologist, radiation oncologist, and surgeon all in one visit. The nurse navigator is key to this coordinated planning and responsible for ensuring that any extra testing is scheduled and completed before the clinic visit. Individuals with colon or rectal cancer follow a similar patient flow, and the aim with all other patients is to meet the cancer center's goal of scheduling a consultation within three to five days of the initial referral.

The cancer center takes pride in its multidisciplinary approach to cancer care and the variety of supportive services it provides patients. (Patients can take advantage of these services at any point during their treatment journey.) All patients meet with the program's social worker and full-time dietitian at the start of their treatment. The dietitian establishes a good nutritional base for patients, who may schedule follow-up visits, if necessary. Patients can also self-refer to meet with the social worker and financial counselors. Portneuf Cancer Center has received the American Society of Clinical Oncology's Quality Oncology Practice Initiative certification.

Outreach Clinics

Like other healthcare providers serving a large rural area, Portneuf Cancer Center's delivery of patient-centered care can be affected by its patients' geographic location, ability to travel, and weather conditions. In response to the needs of patients living in rural settings and to reduce the travel burden for these patients and their families, Portneuf Cancer Center has opened four satellite

cancer clinics. Farthest from main clinic in Pocatello is the clinic at Steele Memorial Hospital in Salmon, Idaho (about 210 miles away); the closest satellite clinic is located at Caribou Memorial Hospital in Soda Springs, Idaho (about 56 miles away). These clinics are staffed daily with licensed practice nurses, a certified medial assistant, and a physician assistant. A medical oncologist from Portneuf Cancer Center visits the clinics once a month, spending two days each in Soda Springs and Salmon and a full or half-day at the remaining two satellite sites. Depending on the clinic location, oncologists will see between 6 to 20 patients face-to-face. Chemotherapy, which is overseen by a medical oncologist, is available at each clinic.

Should a patient need to be seen by the oncologist other than during a scheduled visit, the physician assistant or certified medical assistant at the clinic uses telehealth so that patients can be seen by their oncology provider. The Portneuf Cancer Center oncologists see about 15 to 20 patients a month via telehealth appointments. The cancer center has seen tremendous growth in its patient population with the implementation of these outreach clinics because they enable patients to stay in their hometowns with their families. If patients need radiation or combination therapy, they are treated at the cancer center in Pocatello. Patients who must travel to the main facility can take advantage of the resources available at the Portneuf Medical Center to help them with the financial burden of treatment and travel.

Transportation and Lodging Support

Portneuf Medical Center has a guest house and RV park on its campus to accommodate visiting patients, their families, and visitors who travel long distances or who may experience weather disruptions that could impact treatment schedules. The RV park has six paved, full hookup sites available at no cost, situated by picnic tables and majestic mountain views. Cancer center patients are given priority and can reserve a spot through their nurse navigator or social worker. The guest house is located just two miles away from the main hospital, can house two families, and is also free of charge. The hospital runs a free shuttle for travel to the cancer center from either the guest house or RV park; valet service is available for those who drive.

Access to Cutting-Edge Treatment and Clinical Trials

For patients who need treatment beyond Portneuf Cancer Center's capacity or access to clinical trials, the cancer center facilitates referrals to the Huntsman Cancer Institute in Salt Lake City, Utah. Portneuf Cancer Center has established a streamlined referral process with the institute and coordination is prioritized by both programs. This referral pathway creates greater opportunities for Portneuf Cancer Center's rural patient population, especially those with more complex or rare diseases, to access specialist care and clinical trials.

Patient-Centered Care

Portneuf Cancer Center sees a variety of patients and prioritizes their care in many ways. Because it is located next the Fort Hall Reservation, its staff works closely with the Shoshone-Bannock Tribes. A social worker/navigator helps Fort Hall Reservation patients navigate and coordinate care with Portneuf Cancer Center. About 10 to 20 percent of the cancer center's patient population travels from Fort Hall.

There are cultural considerations in treating this specific patient population, and the center's staff takes pride in its ability to effectively coordinate and care for these patients. To further accommodate its diverse patients, staff members—a medical oncologist and social worker—speak fluent Spanish or can help translate for its Spanish-speaking patients, helping to eliminate cultural and language barriers to care.

To further its patient-centered focus, Portneuf Cancer Center holds three tumor boards—a general tumor board, a breast-specific tumor board, and a thoracic tumor board—each scheduled once a month. The tumor board brings together Portneuf Medical Center's urologists, surgeons, radiologists, interventional radiologist, pathologists, nursing staff, navigators, medical oncology, radiation oncology, and support staff. Its three breast surgeons attend the breast tumor board, while the thoracic tumor board is attended by cardiologists, pulmonologists, and cardiothoracic surgeons.

Because the Portneuf Medical Center and the cancer center's staff are a close, tight-knit group, they are in conversation with one another frequently to discuss patients' treatment. "They do not hesitate to pick up the phone to call whichever discipline they need to talk to regarding the patient," explains Jenni Adams, RN, BSN, OCN, cancer center director. Therefore, tumor boards are not the only place in which multidisciplinary cancer care is prioritized, because collaboration among clinicians and staff takes place every day.

Portneuf Cancer Center is proud to have its clinicians and staff working side by side every day. In fact, this close, collaborative environment may be an advantage of caring for patients in its rural setting—the cancer center has not experienced high turnover rates among its nurses, therapists, and/or providers. "This is a big advantage to patient-centered care," explains Robb Dye, MSW, licensed clinical social worker. "It is all behind the scenes." This approach has helped establish crucial relationships among its staff and clinicians that patients experience and benefit from firsthand. These care providers know their patients' names and stories, and patients are greeted by the same smiling face at every cancer center visit. OI

Select supportive care services include:

- Nutrition services
- Financial counseling services
- Psychosocial services
- Support groups

Approximate number of new analytic cases seen in 2019: 400

Impact of a Community-Based Cancer Survivorship Program on Quality of Life

BY RACHEL FUNK-LAWLER, PHD; HEIDI HAMANN, PHD; LAURA HOWE-MARTIN, PHD; BIJAL BALASUBRAMANIAN, PHD; MICHAEL S. BUSINELLE, PHD; JEFFREY KENDALL, PSYD; JOANNE M. SANDERS, MS; SARAH N. PRICE, MA; AND KEITH ARGENBRIGHT, MD

Despite the demonstrated need to implement evidence-based interventions that address the psychosocial and behavioral concerns of cancer survivors, few studies have evaluated the effectiveness of community-based survivorship programs. To address this need, the Fort Worth Program for Community Survivorship—a community-based cancer survivorship program at the University of Texas Southwestern Medical Center Moncrief Cancer Institute in Fort Worth, Tex.—conducted a study involving more than 200 post-treatment cancer survivors to evaluate the effectiveness of the program's services.

The Fort Worth Program for Community Survivorship aims to address the unmet psychosocial needs of cancer survivors with one-on-one attention, assessment, and referral. This study examined the extent to which the program was able to reduce psychological distress and improve quality of life (QoL) among cancer survivors and the degree to which individual program participation predicted enhanced psychosocial functioning.

The 203 post-treatment cancer survivors who participated in the study program received psychosocial and behavioral services, including exercise, dietary consult, and psychological counseling. Program participants were evaluated upon enrollment and at three subsequent intervals. Outcomes demonstrated an association between program participation and significant improvements in both QoL and distress relief, with the largest improvements occurring during the first three months of program participation, when participant attendance was highest.

Some psychological issues are not apparent until many years after treatment; long-term cancer survivors face fear of recurrence, financial concerns, difficulties with sexual health, poor emotional functioning, and adverse late-term effects of treatment.

A Need for Data

The number of cancer survivors in the United States is projected to grow to nearly 18 million by 2022, increasing more than 30 percent in just 10 years.[1] The growing body of literature on the pervasive negative effects of cancer and its treatment frequently cites emotional health and well-being among the areas of highest need among post-treatment cancer survivors.[2,3] Nearly one-third of cancer survivors report deterioration of physical and/or mental functioning up to four years post-diagnosis, and approximately 37 percent note increased psychological impairment and/or specific unmet needs years following treatment.[4,5]

Some psychological issues are not apparent until many years after treatment; long-term cancer survivors face fear of recurrence, financial concerns, difficulties with sexual health, poor emotional functioning, and adverse late-term effects of treatment.[6,7] In response, specialized, multidisciplinary programming has emerged to address cancer survivors' needs. However, most survivorship programs are restricted to large, academic-based settings, even though approximately 55 percent of cancer patients receive their medical care in community oncology settings.[8,9]

Most of the existing literature on survivorship programming focuses on building (rather than evaluating) programs.[10-12] Few studies have examined patient-reported psychosocial outcome data from cancer survivorship programs, and even fewer have focused on outcomes within real-world, community-based programs. There is a need to understand how evidence-based interventions are used by cancer survivors and how well they work.

Our evaluation of the Fort Worth Program for Community Survivorship reflects a "pragmatic" method, defined as the flexible delivery of interventions and conditions relevant to real-world clinical practice.[13] The Fort Worth Program uses a patient-centered approach to intervention; after the initial assessment, participants choose the types and intensity of the interventions they want based on their needs and preferences. To gauge the effectiveness of the interventions, we measured longitudinal QoL and psychosocial distress outcomes.

Program Overview

Study participants included 203 post-treatment cancer survivors who had enrolled in the Fort Worth Program for Community Survivorship for psychosocial and behavioral survivorship services. These adults, aged 18 and older, completed their primary cancer treatment in the community setting. For the purposes of this study, we made special efforts to include underserved and uninsured individuals in the program.[14] Participants were either self-referred to the program or they were referred by local hospitals, clinics, and agencies.

Once study participants were referred to the Fort Worth Program for Community Survivorship, program staff contacted them by phone to set up an initial appointment and gather basic demographics. At that first in-person visit, all participants received a survivorship portfolio, which contained general and targeted information about their diagnosis, treatment side effects, and post-treatment care. Participants also met with a registered nurse who oriented them to the program, conducted a basic history and physical, and discussed their current psychosocial needs based on their medical history and responses to questionnaires they completed prior to the initial visit.

Based on identified needs and individual preferences, the nurse then assisted with referrals to evidence-based services, including appointments with psychologists, social workers, dietitians, oncology exercise specialists, genetic counselors, a financial advocate, a pain physician specialist, a lymphedema specialist, and a fatigue specialist.

All survivorship services were available to participants at no charge or for a reduced fee except for pain-, lymphedema-, and fatigue-specific services, which were provided through referrals to off-site providers. Study consent and enrollment occurred at the first visit, and enrolled participants agreed to complete self-reported assessments at baseline and at 3-, 6-, and 12-month intervals post-enrollment. This analysis focuses on psychological distress and QoL data from each of these study time points.

Participants

A total of 291 program participants were approached about completing longitudinal measures, and 205 (70.4 percent) consented to participate. There were no significant differences in age, gender, race/ethnicity, marital status, education level, or language preferences among those who consented and those who declined to complete the measures. One participant withdrew before completing baseline questionnaires, and another did not complete psychosocial measures at any time point.

Thus, a total of 203 participants were included in the final analyzed sample. Table 1, below, displays participant sample size and retention rates at each time point for both outcome measures. The largest drop-off in response occurred between baseline and the 3-month follow-up, with lower attrition in the later follow-up time points (6 and 12 months). As detailed in Table 2 (right), the sample was predominantly female, with approximately one-third identifying as racial or ethnic minorities.

(continued on page 20)

Table 1. Sample Size at Each Time Point

Measures	Baseline (*N*)	3 Months *N* (% of Previous Time Point)	6 Months *N* (% of Previous Time Point)	12 Months *N* (% of Previous Time Point)
BSI-18	203	144 (71%)	125 (87%)	113 (90%)
FACT-G	203	141 (69%)	125 (89%)	113 (90%)

Table 2. Descriptive Demographic and Illness Data (*n* = 203)

Source	Mean (SD) or *n* (%)	Source	Mean (SD) or *n* (%)
Demographics		**Illness characteristic**	
Age (years), mean (SD)	56.7 (9.7)	Time since diagnisis (years)	3.6 (4.9)
Gender		**Primary cancer location**	
Female	177 (87.2)	Breast	147 (72.4)
Race/Ethnicity		Prostate	10 (4.9)
Non-Hispanic white	138 (68.0)	Head and Neck	7 (3.4)
Non-Hispanic black	31 (15.3)	Colorectal	8 (3.9)
Hispanic	28 (13.8)	Lung	4 (2.0)
Asian	1 (0.5)	Gynecological	7 (3.4)
Multiracial	2 (1.0)	Lymphoma	4 (2.0)
Other	2 (1.0)	Other	16 (7.9)
Unknown	1 (0.5)	**Cancer stage**	
Marital Status		0	12 (5.9)
Married	109 (53.7)	I	57 (28.1)
Divorced	41 (20.2)	II	64 (31.5)
Widowed	11 (5.4)	III	34 (16.7)
Separated	2 (1.0)	IV	7 (3.4)
Never married	36 (17.7)	Unknown	29 (14.3)
Unmarried couple	4 (2.0)	No history of recurrence/second cancer	179 (88.2)
Education level		**Treatment type**[1]	
Grades 9-11	4 (2.0)	Chemotherapy	133 (65.5)
Grade 12 or GED	38 (18.7)	Radiation	102 (50.2)
Some college/tech shoool	77 (37.9)	Surgery	162 (79.8)
College graduate or higher	82 (40.4)	**Comorbid symptom burden**[2]	
Unknown	2 (1.0)	Low	46 (22.7)
Preferred language		Medium	81 (39.9)
English	191 (94.1)	High	76 (37.4)
Spanish	12 (5.9)	Karnofsky performance status (median)[4]	100
DIstance from clinic in miles, mean (SD)[3]	12.2 (13.9)		

[1] *n* = 203; patients could receive more than one treatment modality.
[2] Based on the number of self-reported concerns on a confidential health questionnaire.
[3] *n* = 199, because distance was not able to be calculated for four participants.
[4] *n* = 197; a Karnofsky performance status score was not assigned to six participants.

(continued from page 18)

Explanation of Measures

The dependent variables used in this study included the Brief Symptom Inventory (BSI-18)—a well-validated, 18-item self-report assessment of psychological distress that has been recommended for use in oncology populations.[15,16] This inventory—a Likert-type scale, ranging from 0 (*not at all*) to 4 (*extremely*)—measures how much a respondent has been bothered by distress-related behaviors and symptoms during the past week. The measure provides a total score—termed the Global Severity Index—as well as scores on three subscales—Somatization, Depression, and Anxiety—with higher scores indicating greater distress.

To measure QoL, we used the Functional Assessment of Cancer Therapy-General (Version 4; FACT-G), which—like the Brief Symptom Inventory—uses 27 items rated on a 5-point Likert-type scale ranging from 0 (*not at all*) to 4 (*very much*).[17] This measure contains four subscales representing physical, functional, social/family, and emotional well-being in addition to an overall score. Higher scores indicate better QoL.

Sociodemographic information was self-reported by the participants and included age, sex, language preference, education level, marital status, race/ethnicity, and ZIP code. We also collected information on illness characteristics—including primary cancer diagnosis, history of recurrence or multiple cancers, cancer stage, time since diagnosis, Karnofsky performance status,[18] and treatment history—through a combination of self-reporting and medical chart review.

We computed the level of comorbid symptom burden (low, medium, or high) from information provided in the "Review of Symptoms" section of a confidential health questionnaire that participants completed prior to enrollment. We recorded information about service utilization—defined as participant attendance at program services and the type of service provided—for each participant during the 12 months after enrollment.

Table 3. Service Utilization Summary

Service Type	Total Number of Visits	*n*	Mean	SD
Exercise	1,994	178	11	9.8
Nutrition	237	118	2	1.7
Nursing	203	203	1	0.0
Social work	117	112	1	0.2
Psychology	252	43	6	4.5
Pain management	1	1	1	0.0
Genetic counseling	6	6	1	0.0
Financial advocacy	5	5	1	0.0
All service types	2,815	203	13	10.6

Service Utilization

Table 3, below, displays the total number of service visits attended by program participants broken down by service type. Participants attended 2,815 multidisciplinary service appointments, which included encounters with psychology, genetic counseling, social work, nutrition, individual exercise, nursing, pain management, and financial advocacy professionals. As mentioned previously, all participants received an initial nurse assessment (included in the total count of appointments reported above) as part of the orientation to the program; this assessment was completed during at least one in-person visit.

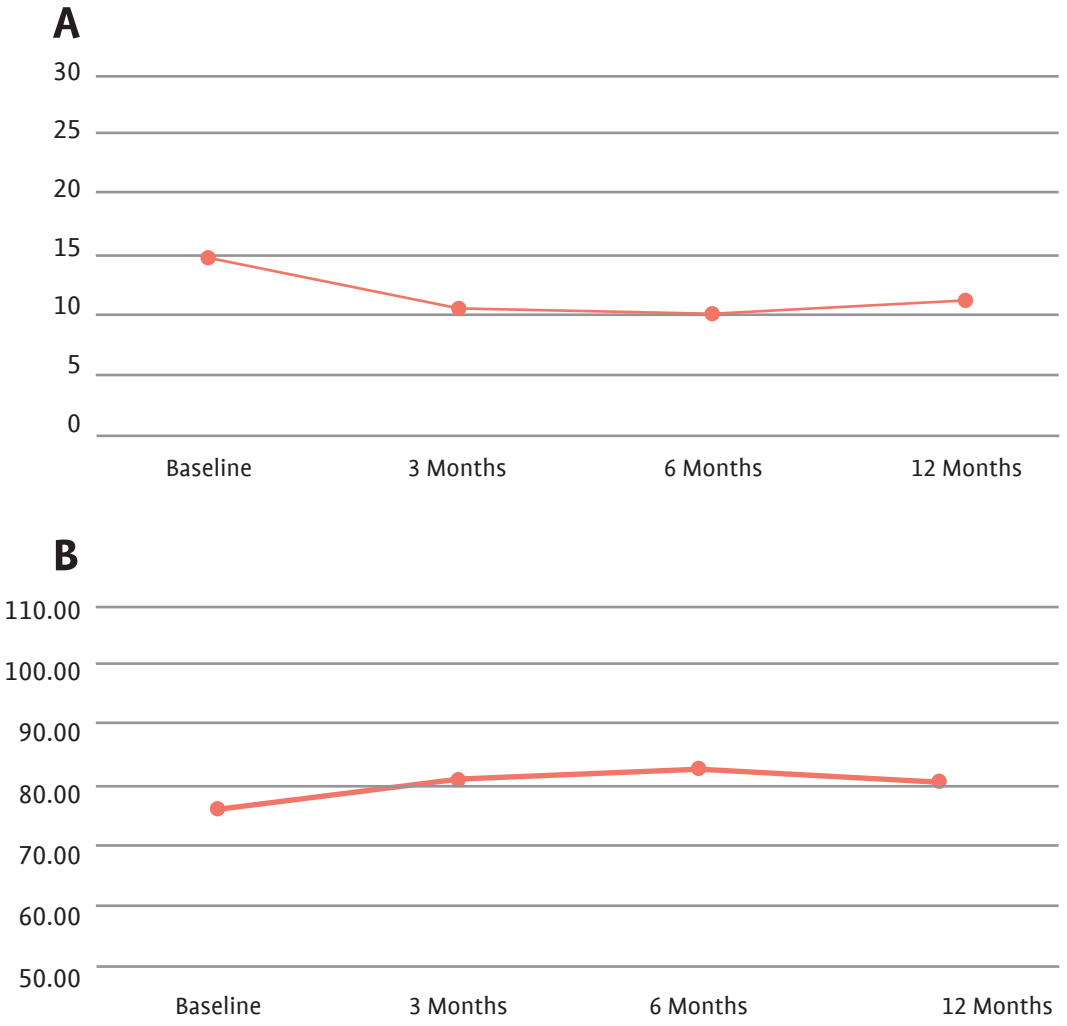
One hundred ninety-five participants (96.1 percent) completed at least one additional service appointment beyond the initial nurse assessment, with participants completing a median of 13 encounters across the various disciplines. Exercise was the most frequently attended service, with 87.7 percent of all study participants attending at least one individual exercise session. The majority of service utilization (76.6 percent) occurred within the first 3 months of participant enrollment, 12.5 percent of appointments occurred between 3 and 6 months of enrollment, and 10.8 percent occurred between 6 and 12 months after enrollment.

Results: Change in Psychosocial Functioning over Time

Physical and emotional well-being displayed a significant change over time, with respective improvements for each month of program enrollment. Figure 1, right, displays unadjusted raw scores and standard deviations for the BSI-18 Global Severity Index and the FACT-G Total Score at each time point. Significant improvements in both transformed QoL and distress scores were observed over time, with scores decreasing for each month of enrollment. These findings suggest significant improvements in both QoL and psychological distress among participants across the 12-month intervention period. Our analysis of reported data also revealed:

- The number of participants with below-average QoL decreased from nearly half (49 percent) to approximately one-third (37 percent), showing that participants' QoL significantly improved during the 12-month period following enrollment in the community-based survivorship program, with most notable gains during the first 3 months of study participation. This pattern of improvement mirrors participants' involvement with the program, because nearly three-fourths of all services were received during the first 3 months of enrollment.

Figure 1. Unadjusted Raw Scores and Standard Deviations for (A) Distress (BSI-18 Global Symptom Index) and (B) Quality of Life (FACT-G Total Score) for the Overall Sample (n = 203) at Each Study Time Point. Decreases in Distress Scores and Increases in Quality of Life Scores Reflect Improvements in These Domains, Respectively



- As with QoL scores, findings suggest that distress improved the most during the first 3 months of study participation and remained significantly lower than baseline scores throughout the study. Though 73 percent of the study sample were highly distressed at baseline, this proportion dropped to 61 percent, 56 percent, and 55 percent at 3, 6, and 12 months, respectively.
- Reported anxiety scores decreased each month. Program participation may better target anxiety-related distress symptoms than other aspects of distress and may promote emotional, physical, and perhaps functional QoL.
- Changes in functional well-being scores, though not significant, indicate a trend toward improvement over time.
- Social/family well-being scores remained relatively stable with no significant change over time.

Total service utilization did not significantly impact the rate of change in psychosocial outcomes over time. Regardless of the number of appointments attended, participants' QoL and distress improved at the same rate. All participants in the study received a considerable amount of both generalized and targeted information about cancer survivorship at enrollment. Combined with the individualized attention of supportive care staff familiar with the needs of cancer survivors, this information may have been sufficient to foster sustained improvement over time.

These results suggest that relatively brief survivorship care may help improve psychosocial functioning by normalizing and validating patients' experiences while also providing useful information on navigating the survivorship phase of cancer care.

Further research is needed to better understand the nature and mechanisms of psychosocial change experienced by program participants and its consequences on longer-term survivorship outcomes, including behavioral change, cancer surveillance, and recurrence.

Study Limitations

One of this study's strengths was its pragmatic design, which allowed for program evaluation in routine practice conditions. This design is common in dissemination and implementation studies, in which goals focus on real-world clinical settings.[19] However, because the study design did not include a comparison group, it is difficult to determine whether overall improvements better reflect increasing time since diagnosis or intervention effects. In fact, results from non-interventional studies show natural declines in distress and recovery of QoL over the first year of cancer survivorship.[20,21]

However, the current study sample included greater heterogeneity in the time since diagnosis, as most individuals (70 percent) enrolled beyond their first year post-treatment, when change is less common.[7] Although participants may have improved over time regardless of receiving an intervention, the current findings suggest that participation in survivorship programming may enhance psychosocial improvement, especially for individuals beyond one year post-treatment.

Although recruitment efforts for the survivorship program focused on enrolling underserved participants, the majority of the study sample was female, non-Hispanic white, college educated, and included survivors of breast cancer, limiting study generalizability. Data from the U.S. Census Bureau suggest that the population living in Tarrant County (location of the Fort Worth metropolitan area) is mostly non-Hispanic white (76 percent) and educated (85 percent with at least a high school education).[22] Our sample may be representative of the area, despite the higher proportion of female participants. Additionally, the composition of the study sample may represent the types of individuals who are interested in and able to attend survivorship services, especially given the evolving and deliberate recruitment strategies of the program.

Conclusions

This analysis is among the first to examine patient-reported outcomes among a group of cancer survivors enrolled in a community-based cancer survivorship program. By characterizing the trajectory of both QoL and psychological distress during participation, this study sheds light on the ability of cancer survivorship programs to improve psychosocial functioning. Chiefly relevant to clinical application, results suggest that a little intervention goes a long way, as evidenced by clinically significant improvements in psychosocial functioning early in program participation.

This recommendation may be particularly helpful for survivorship programs with limited resources and capital, as well as for cancer survivors with time constraints. Further research is needed to better understand the nature and mechanisms of psychosocial change experienced by program participants and its consequences on longer-term survivorship outcomes, including behavioral change, cancer surveillance, and recurrence. OI

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Disclosure of Interest

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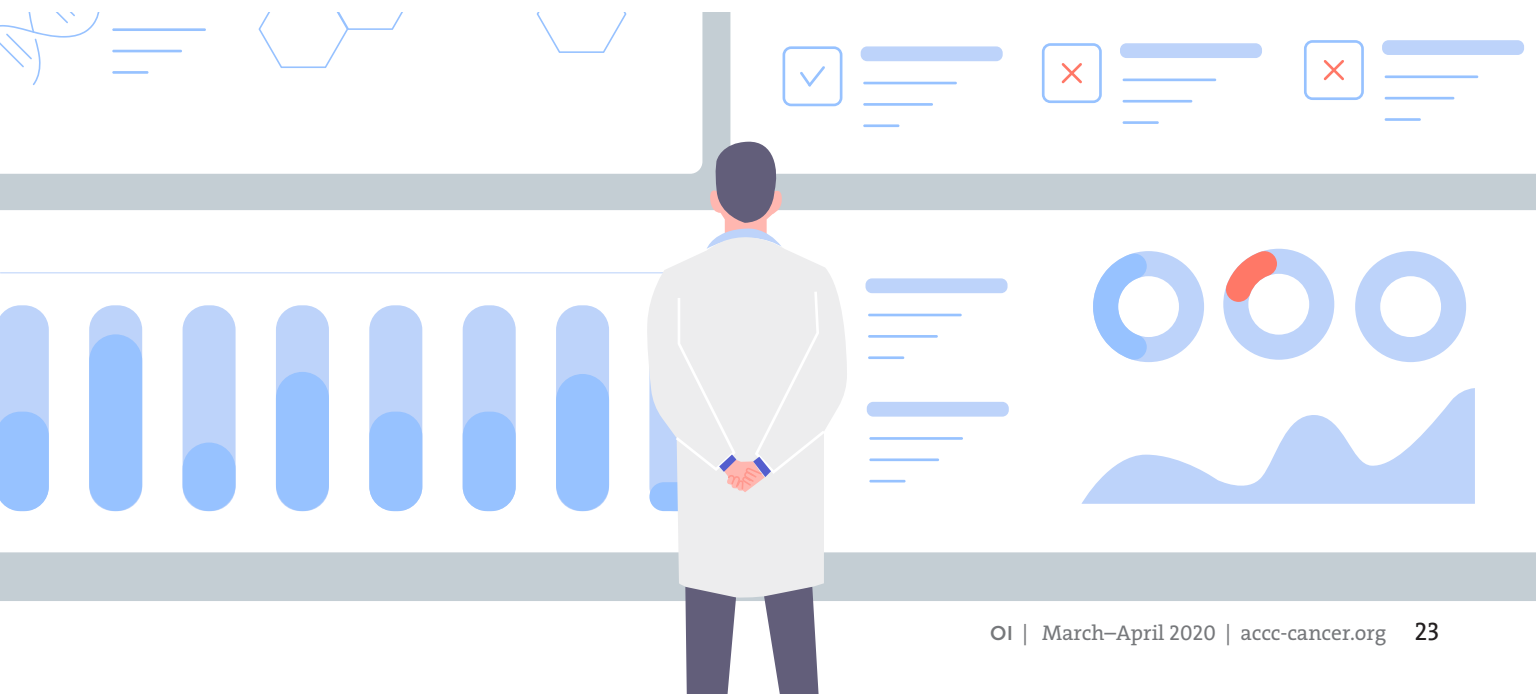

Supporting Cancer Survivors in Making Healthful Lifestyle Changes

BY WENDY DEMARK-WAHNEFRIED, PHD, RD; JENNIFER R. BAIL, PHD, RN; TERI HOENEMEYER, PHD; DOROTHY W. PEKMEZI, PHD; MARIA PISU, PHD; KARINA I. HALILOVA, MD, MPH; MICHELLE Y. MARTIN, PHD; AND LAURA Q. ROGERS, MD, MPH

I believe that people who actively participate in their own health do much better. After all, exercise is so connected to mental health, and paying attention to what you feed your body makes a big difference in overall health—it just makes sense.

Susan Rossman, breast cancer survivor, Birmingham, Ala.

Harvest for Health is testing the effects of vegetable gardening in more than 300 cancer survivors aged 60 and older—an age group that is particularly vulnerable to declines in physical functioning.

Since 1981 Alabama Master Gardeners have been important volunteers with the Alabama Cooperative Extension System, hosting displays and information booths at county fairs, offering educational programs, assisting at botanical gardens, working with historic properties, implementing civic beautification projects, partnering with local schools, donating fresh produce to charity, supporting scholarships in secondary education, and much more. Learn more at mg.aces.edu.

In 2010, when Susan Rossman was offered the opportunity to participate in a University of Alabama at Birmingham (UAB) pilot study of a vegetable gardening intervention that paired her with a local master gardener mentor from the Alabama Cooperative Extension Service and provided her with the necessary gardening supplies, she jumped at the chance. As Rossman predicted, the intervention produced significant improvements in several aspects of physical health among participants, which included four breast, four prostate, and four childhood cancer survivors (and their parents). Specifically, results indicated:

- Better hand grip strength (+4.5 [3.0 to 6.7] kg).
- Improved agility as assessed by the 8 foot Up and Go (-1.5 [-2.1 to -0.2] seconds).
- Improved leg strength as assessed by the 30-second chair stand (+1.5 [-1.0 to 5.0] stands).
- Improved endurance as assessed by the 6-minute walk (+38 [20 to 120] feet).

Half of the cancer survivors also increased their vegetable and fruit intake by at least one serving per day and two-thirds increased their physical activity by at least 30 minutes per week.[1] Results from this pilot study led to two larger feasibility studies that assessed the effects of the vegetable gardening intervention among a total of 128 additional cancer survivors. Findings from these two trials reinforced the positive changes observed in the first study[2,3] and led to a large, National Cancer Institute (NCI)-funded (NCT02985411) randomized controlled trial. The trial, called Harvest for Health, will accrue a variety of cancer survivors across

(Top) Cancer survivor and Harvest for Health participant, Susan Rossman, in her vegetable garden. (Bottom) Cancer survivor and Harvest for Health participant, Sarah Harkless, enjoying the fruits of her labor.

Alabama and will complete enrollment in April 2020 in the northern part of the state (Harvest4Health@uab.edu).

Harvest for Health

The trial is a community-based partnership between UAB and Auburn University that began in 2010, when Wendy Demark-Wahnefried, PhD, RD, a cancer survivorship researcher, was recruited to UAB and reached out to Tony Glover, an Alabama Cooperative Extension System coordinator. Dr. Demark-Wahnefried had previous experience with the Master Gardener program when she was on faculty at Duke University and wondered whether the Alabama Cooperative Extension would be interested in collaborating on a pilot study that would be supported through some of her startup funds. The small pilot study eventually led to the large randomized controlled trial currently in the field. Harvest for Health is testing the effects of vegetable gardening in more than 300 cancer survivors aged 60 and older—an age group that is particularly vulnerable to declines in physical functioning. The study aims to improve vegetable intake, physical activity and function, health-related quality of life (QoL), and select biomarkers of healthy aging (e.g., interleukin-6 and telomerase). Harvest for Health participants are randomly assigned to either the one-year mentored, home-based vegetable gardening intervention immediately or another group that will receive the intervention after a one-year waiting period. Participants are paired with master gardeners, who provide guidance in planning, planting, and maintaining a spring, summer, and fall garden. Vegetables grown in these gardens include: lettuce, peppers, squash, and tomatoes, as well as any other vegetable the survivor wants.

Every six months, participants complete surveys on their diet, physical activity, and QoL either by mail or online. In-person assessments are conducted at baseline, one year, and two years at the participants' home or community center and consist of measuring weight and height and waist circumference, testing physical performance, and collecting biospecimens (i.e., saliva and toenail clippings to measure cortisol [stress hormone], fecal samples to assess potential changes in the microbiome, and blood to quantify changes in interleukin-6 and telomerase).

Though the study is still ongoing, participant feedback is positive. Sarah Harkless, a former schoolteacher and current research participant, has enjoyed playing an active role in her health by gardening and receiving all of the necessary tools and support needed to grow a successful garden. She feels that Harvest for Health has given her a "jump start" on healthier living. "I am eating new things and I am now back in the kitchen cooking. Gardening makes me want to do better. I am eating better and have even lost 10 pounds. It has given me something to look forward to every day. I love it; my family loves it!"

Patricia Saffles, Harkless's master gardener mentor, who recently lost her husband to cancer, signed up to volunteer for Harvest for Health to "give back and make a difference in someone's life." Saffles has always had a passion for growing flowers and was so inspired by Harkless and her veggies that she has started a vegetable garden of her own. Her new passion for

growing vegetables has led her to make heathier eating choices. Saffles believes that Harvest for Health is mutually beneficial for cancer survivors and master gardeners: "We have had a great time, a lot of laughs, and are learning from each other. Sarah even inspires me to try new things in my garden."

Harvest for Health offers a holistic means to improve both diet and exercise behaviors to improve the overall health of cancer survivors. However, not all cancer survivors are interested in sowing seeds in order to "shovel-up" better health.[4] Thus, the research team, which was originally based just at UAB, has expanded to the University of Tennessee Health Science Center (with the subsequent moves of some members) and is exploring other ways to improve dietary and physical activity behaviors, as well as promote safe weight loss among cancer survivors who struggle with making changes in their diet, exercising, and managing their weight, particularly if they carried a few extra pounds before their diagnosis and gained even more weight with treatment—as many cancer survivors do.

Web-Based Clinical Trials

The UAB/University of Tennessee Health Science Center team is now recruiting cancer survivors across the southeastern United States (Alabama, Mississippi, North Carolina, and Tennessee) for two new web-based healthy lifestyle trials. See Table 1, page 28, for eligibility criteria, contact information, and other study details.

The Aim, Plan, and Act on Lifestyles (AMPLIFY) Survivor Health (NCT04000880) is NCI funded and builds on two previous NCI-funded research clinical trials that tested diet and exercise interventions that were found to be effective.

The Better Exercise Adherence after Treatment for Cancer (BEAT Cancer) research clinical trial (NCT00929617) tested an in-person exercise intervention that gradually tapered to a home-based program among 222 breast cancer survivors. The BEAT Cancer intervention significantly improved levels of physical activity, as well as fitness and quality of life—effects that were maintained at a six-month follow-up.[5]

Likewise, the Reach-out to Enhance Wellness (RENEW) in Older Cancer Survivors research clinical trial (NCT00303875) tested the efficacy of a one-year program of tailored mailed print materials plus telephone counseling among 641 older, overweight and obese survivors of breast, prostate, and colorectal cancer who resided in 21 U.S. states, as well as Canada and the United Kingdom. The RENEW intervention significantly improved diet quality, physical activity, and body weight status—effects that were durable at a two-year follow-up.[6,7] Most important, the intervention reduced the rate of physical function decline among these cancer survivors.

In the words of participant, Paul Finegan, "RENEW was, and is, so very good for me! The in-home program provided helpful information and was very convenient. I lost 15 pounds and kept it off. Ten years later, I still watch my portions and eat very little red meat. As a former teacher, I give the program an A+." Like other RENEW participants, Finegan's physical function improved on the program. Now, at age 87, Finegan says, "I have no trouble walking a mile or climbing 10 flights of stairs. In fact, I am busy building houses for Habitat for Humanity several days a week."

Harvest for Health participant, Sarah Harkless, and her master gardener mentor, Patricia Saffles, posing by Sarah's garden.

Over the past year, the AMPLIFY study team has worked to adapt both BEAT Cancer and RENEW to a web-based platform that can be delivered via computers, tablets, and smartphones to enhance dissemination potential. In addition, AMPLIFY provides diet and exercise guidance according to the most recent recommendations issued by the American Institute of Cancer Research and the National Comprehensive Cancer Network.[8,9] The goals of AMPLIFY are to test the impact of the diet and exercise interventions on change in health behaviors, physical performance, body weight, muscle mass, overall health, and QoL. Plus, AMPLIFY will determine whether the diet and exercise components are more effective if delivered one at a time (first diet then exercise or vice versa) or combined over a 12-month period. The enrollment target is 652 cancer survivors across the states of Alabama, Mississippi, North Carolina, and Tennessee and kicked off in January 2020 to coincide with the new year—a perfect time to begin healthful resolutions.

The Daughters, Dudes, Mothers, and Others Together (DUET) research clinical trial is funded by the American Institute of Cancer Research and is similar to the AMPLIFY clinical research trial. The primary difference between the two is that the DUET research clinical trial will intervene upon the lifestyle behaviors of cancer

Table 1. Study Descriptions for AMPLIFY and DUET

	AMPLIFY	DUET
Purpose and specific aims	To improve diet and exercise health behaviors of cancer survivors with suboptimal diet and physical activity and overweight/obesity by (1) adapting efficacious interventions through technology; (2) optimizing acceptability and use of interventions among older, rural, minority survivors; (3) testing the efficacy of the adapted interventions delivered alone, in sequence, or combined; and (4) determining factors that improve the dissemination and implementation of distance-delivered health behavior change interventions.	To test the acceptability and efficacy of an online diet and exercise intervention for partnered cancer survivors with overweight/obesity by (1) determining whether the intervention significantly improves weight status; (2) assessing the impact of the intervention on self-reported, objective, and select biomarkers associated with cancer risk and progression; for example, TNF-α, insulin, and IGF-1; and (3) identifying predictor variables associated with program efficacy.
Measures, assessors, and time points	Outcomes assessed via telephone and online surveys for patient-reported dietary intake, physical activity, health conditions and health care utilization, and quality of life. Visiting staff will perform anthropometric measures and physical function and blood pressure testing and collect blood and urine samples for assessment of inflammatory markers, immune status, and muscle mass. These assessments will be performed in community or home-based settings at baseline, 6, 12, 18, and 24 months.	Outcomes assessed via online surveys for patient-reported dietary intake, physical activity, health conditions, and quality of life. Visiting staff will perform anthropometric measures, conduct physical function and blood pressure testing, and collect blood samples for assessment of inflammatory and metabolic markers at baseline and six months. These assessments will be performed in community or home-based settings at baseline and six months.
Size, reach, and randomization	Six hundred fifty-two cancer survivors from Alabama, Tennessee, Mississippi, and North Carolina; 326 participants will be randomized to sequenced diet and exercise intervention group and 326 participants to the combined diet and exercise intervention group.	Fifty-six dyads consisting of cancer survivors and partners of their choice. Each dyad will be randomized evenly to receive the intervention either immediately or after a six-month delay.
Duration	Up to 24 months.	Six months.
Incentives, materials, and supplies	Participants will receive up to a total of $100 and ~$125 worth of supplies (digital scale, portion plate, exercise bands, pedometer).	Participants will receive up to a total of $30 and ~$125 worth of supplies (digital scale, portion plate, Fitbit).

survivors and their chosen partners. Fifty-six cancer survivors will enroll in this six-month diet and exercise weight management program with a partner of their choosing; for example, a friend, neighbor, spouse, or other relative. This trial banks on a previous research clinical trial, Daughters and Mothers (DAMES) Against Breast Cancer (NCT00630591), which was limited to mothers with breast cancer and their biological daughters. Significant weight loss and changes in diet and exercise were noted with this trial of 68 mother-daughter dyads.[10] In fact, success in one DAMES family was particularly remarkable. Over the course of the one-year study, the breast cancer survivor lost 23 pounds and her daughter lost 10, but pound for pound, the biggest loser was the family dog ("Rocky"), who lost 11 pounds as he served as the walking companion for the two DAMES participants. By expanding the number of eligible cancer types for survivors and the relationships between survivors and their chosen partners in the

Table 1. Study Descriptions for AMPLIFY and DUET (continued)

	AMPLIFY	DUET
Eligibility criteria	• Adult male or female aged 50+ • Residents of Alabama, Mississippi, North Carolina, or Tennessee • Completed primary treatment for the following cancers: multiple myeloma; localized (stage I) kidney, ovary; localized through regional (stage I-III) breast, colorectum, endometrium, or prostate cancer • No evidence of progressive cancer (metastasis) or recurrence (except for multiple myeloma and prostate [if just biochemically detected]) or other cancers (except for cancers listed above and non-melanoma skin cancer) • BMI 25 to <50 kg/m2 • <2.5 cups of vegetables and fruits/day • <150 minutes of moderate-to-vigorous exercise/week • High risk for functional decline • English speaking and writing; have completed at least eighth grade • No medical conditions that require dietary or physical activity limitations • Not residing in a skilled nursing or assisted living center • Have wireless coverage and an active email address or willing to have us create one • Not participating in another diet and/or exercise program.	• Adult male or female aged 18+ • Residents of Alabama, Mississippi, North Carolina, or Tennessee • Live within a 15-minute drive of qualified partner • At least one team member has been diagnosed with localized renal or loco-regional ovarian, colorectal, endometrial, prostate, or breast cancer AND completed treatment • No evidence of progressive cancer (metastasis) or recurrence (except for multiple myeloma and prostate [if just biochemically detected]) or other cancers (except for cancers listed above and non-melanoma skin cancer) • BMI >25 kg/m2 • <2.5 cups of vegetables and fruits/day • <150 minutes of moderate-to-vigorous exercise/week • English speaking and writing; have completed at least eighth grade • No medical conditions that require dietary or physical activity limitations • Not residing in a skilled nursing or assisted living center • Use the Internet and have a computer, iPad, or smart phone • Not participating in another diet and/or exercise program.
Contact information	Telephone: 1-833-535-7934 Email: amplify@uabmc.edu	Telephone: 1-866-435-7938 Email: duet@uabmc.edu

TNF-α = tumor necrosis factor-alpha; IGF-1 = insulin-like growth factor-1; BMI = body mass index.

current study, Demark-Wahnefried and her research team hope to improve the generalizability and the reach of this partner-based intervention.

The UAB/University of Tennessee Health Science Center team is eager to take cancer survivorship research to the next level by extending the reach of evidence-based interventions and programs designed to promote the health and well-being of cancer survivors. Research interventions like Harvest for Health, AMPLIFY, and DUET offer potential cost-effective, viable solutions for community cancer programs to help their patients achieve optimal health outcomes. These research programs—at no cost to community cancer programs—provide a much-needed resource for survivors and address patient goals to live a full and healthy life. Research programs are value-added to patient care. Cancer centers who are interested in learning more about the programs are encouraged to refer cancer survivors to either the AMPLIFY or DUET programs (see Table 1).

In closing and in the words of Harvest for Health participant Susan Rossman: "Cancer can be the worst thing that can happen to you, or it can be a life changing event that you do something with. If every cancer survivor could do something like this, it could change the way they look at everything."

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The In-Betweeners:
A Focus on Young Adults with Cancer

BY KRISTIN S. DONAHUE, MSN, RN, OCN,
AND ANNE MARIE FRALEY RAINEY, MSN, RN, CHC

At the 2016 Association of Community Cancer Centers (ACCC) National Oncology Conference, staff from Clearview Cancer Institute attended Suleika Jaouad's keynote session "Life, Interrupted," where the young journalist shared her experience and journey with lymphoma. After this empowering talk, our team of young adult administrators quietly agreed that we were not doing all that we could for our young adult cancer patients. This session was our call to action. When we returned to our program, our team pledged do more for this often forgotten about patient population—the In-Betweeners.

Our Program At-a-Glance

Since 1985 Clearview Cancer Institute has served adult hematology and oncology patients in north Alabama. We are a private, physician-owned, community practice with six full-service locations, two of which are in Huntsville, with others in surrounding areas, including Decatur, Florence, Cullman, and Jasper. We also have three satellite clinics in Athens, Madison, and Scottsboro that are available to serve patients for office visits on select days of the week. Our practice is home to 17 physicians and 18 advanced practice providers. Our mission statement is "Clearview is committed to providing cutting-edge, quality, compassionate, comprehensive care." These words align perfectly with Suleika Jaouad's charge that cancer programs need services tailored specifically for their adolescent and young adult (AYA) patients. Education was the first step in our journey.

Identifying Our AYA Patient Population

In 2017 we conducted an analysis of our patient population to determine how many patients could benefit from a formal AYA program. Because Clearview Cancer Institute only treats patients aged 18 and older, we adopted the criteria of patients aged 18 to 39, which is consistent with national guidelines for adolescents and young adults with cancer.[1] In terms of diagnoses, we used the criteria of either an active cancer diagnosis or a history of a cancer diagnosis for patients who were seen at any of our clinics during 2016. After reviewing data from our practice management system and electronic health record, we identified approximately 250 patients across our facilities who may benefit from a formal AYA program.

> There is very little published information regarding the needs of AYAs in relation to their understanding of medical care, side effect management, emotional challenges, and maintaining a sense of normalcy following a cancer diagnosis.

Understanding the Needs of AYA Cancer Patients

Next we conducted literature reviews to determine the needs of this special patient population.

Globally, 350,000 patients between the ages of 15 and 29 and 650,000 patients between the ages of 30 to 39 are newly diagnosed with cancer each year.[1] Approximately 70,000 AYAs (individuals aged 15 to 39) are diagnosed with cancer in the United States each year.[2] Cancer kills more 20- to 30-year-olds than any other disease except depression.[3] Several factors play into cancer being

so deadly for this age group. For example, many healthcare professionals may not consider the possibility of cancer when discussing a symptom profile or working up this age group, sometimes impeding or delaying a diagnosis and impacting outcomes.[3] In addition to this barrier, many in this age group lack access to healthcare services or may not have insurance coverage at all.[3] Often AYAs ignore signs of health issues because they do not consider the possibility of a life-threatening illness at this stage in their lives. Infrequent routine medical care—for example, a lack of annual wellness visits—may further delay diagnosis.

The age at diagnosis can significantly affect how individuals cope with cancer. In 2011 Zebrack categorized five areas of disruptions that may occur across all life stages:[4]

- Altered interpersonal relationships
- Issues of dependence and independence
- Achievement of life goals
- Concerns of body and sexual image and integrity
- Existential issues.

AYAs are already going through a transformational period from dependence as a child to independence as a young adult. These individuals are also facing body image and sexuality changes. Add a new cancer diagnosis into the mix and it is evident how coping can be extremely challenging for these patients.

There is very little published information regarding the needs of AYAs in relation to their understanding of medical care, side effect management, emotional challenges, and maintaining a sense of normalcy following a cancer diagnosis.[5] The limited studies published to date have shown that AYAs with a current or previous cancer diagnosis are more likely to suffer from quality of life issues and poor mental health and social functioning, reporting 2.5 times more fatigue than their peers who have not been diagnosed with cancer.[6]

A 2006 survey conducted by Zebrack and colleagues highlighted the many needs of AYAs. Of those surveyed, over 50 percent stated that their needs were unmet in the following areas:[7]

- Sexuality and intimacy
- Family counseling
- Camps and retreats
- Infertility treatments
- Adoption services
- Childcare
- Transportation assistance
- Alcohol and drug abuse counseling.

The Adolescent and Young Adult Oncology Progress Review Group was started in 2005 to evaluate the unique needs of AYAs and prompt further research into their unmet needs.[2] Composed of prominent members of the scientific, medical, and advocacy communities, the group is a public-private partnership between the National Cancer Institute and the LIVESTRONG Young Adult Alliance. Its purpose: to develop a national agenda for AYA oncology. *Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults with Cancer* is a recommendation report that reflects the opinions of the approximately 100 individuals who participated in the AYA Oncology Progress Review Group.[8] In 2012 the National Cancer Institute established working groups to help identify and solve issues related to AYAs. One group, the Health-Related Quality of Life and Symptoms Group, was tasked with evaluating AYA needs related to physical, psychological, social, and spiritual well-being.[2] While recognizing that spiritual well-being is a core component of patient-centered care, our team at Clearview Cancer Institute has focused on the physical, psychological, and social needs of our AYA cancer patient population.

The CAYAC group participates in a "Share Your Story" event with the local Oncology Nursing Society chapter.

Physical Considerations for AYAs with Cancer

The physical changes following a cancer diagnosis may be difficult for AYAs to deal with for various reasons. A 2013 study conducted by Kumar and Schapira revealed that both men and women struggled with the physical changes that accompanied a cancer diagnosis.[9] The loss of hair, weight gain or weight loss, and the loss of body parts can all have a negative impact on an AYA with cancer. AYAs aged 20 to 29 were significantly more likely to report that they had unmet needs around infertility, diet and nutrition, and general cancer information.[5] In a 2012 study, AYA cancer survivors were much more likely to be obese and were more likely not to engage in physical activity than individuals in the same age group with no cancer diagnosis.[10]

AYAs not only have the burden of working through physical symptoms related to their disease during and immediately following cancer treatment but may also experience long- and late-term side effects related to their diagnosis. AYA cancer survivors have a greater incidence of health issues than those who have never had cancer, including:[10]

- Cardiovascular disease (14 percent vs. 7 percent)
- Asthma (15 percent vs. 8 percent)
- Diabetes (12 percent vs. 9 percent)
- Hypertension (35 percent vs. 29 percent)
- Disability (36 percent vs. 18 percent).

AYAs are also at greater risk of recurrence and/or secondary cancers, which may bring increased burden or worries to this patient population and result in greater unmet needs related to long-term side effects and/or inadequate follow-up cancer care.[11]

AYAs who have completed cancer treatment have different needs than both the general AYA population and the pediatric and geriatric cancer patient populations. For example, fertility can be a major area of concern for AYA cancer survivors who have not yet started to consider options related to family planning. Many AYAs have limited knowledge about their reproductive health and the impact that their cancer treatment may have on future family planning. In fact, fertility information is cited as one of the biggest unmet needs for AYAs.[6] It is interesting to note that one study found that individuals in their 20s and 30s who had been treated in an adult oncology clinic were less likely to report the use of fertility information than teens who were treated in a pediatric oncology setting.[5] In addition, sexuality can be impacted during and following cancer treatment. Physical changes such as hair loss, weight changes, and loss of body parts may negatively impact sexuality.[9] One study that followed patients with breast cancer found that 52 percent of breast cancer survivors reported having a small problem in two or more areas of sexual functioning.[6]

It is important to note that physical symptoms may contribute to higher levels of distress in AYAs.[5] A 2013 study conducted by Zebrack and colleagues suggested that as treatment-related symptoms increased, AYAs reported more unmet needs for mental health services.[5] In another 2013 study, between 25 and 50 percent of respondents identified unmet needs related to physical activity and diet, meeting other AYAs, financial support, and fertility concerns, among other issues.[12]

Psychological Considerations for AYAs with Cancer

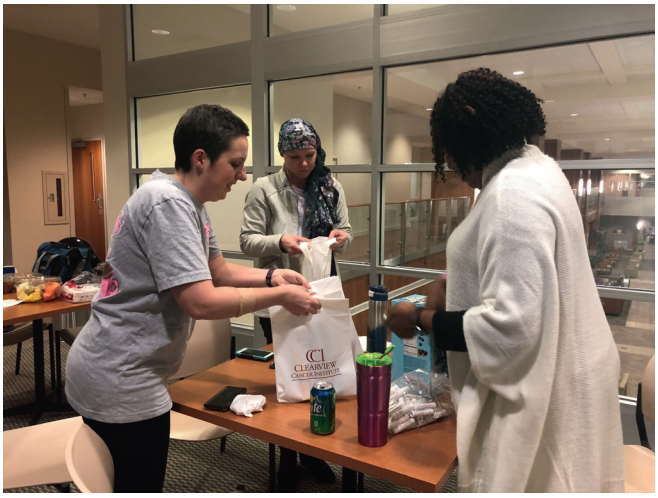
Though the psychological effects related to a cancer diagnosis can have the most impact on AYAs, they are often the most difficult to identify. Unlike physical changes that are often visible for all to see and recognize, psychological changes can be masked. These changes may be hidden and only revealed after a long period of time or may never be revealed at all but still have a significant impact on the overall well-being of an AYA. In one study, about one-third of AYA respondents indicated a need for referral to a mental health professional.[12]

A 2006 study demonstrated that AYAs place a higher value on meeting other survivors than healthcare professionals perceived; this same study also showed that AYAs placed a greater value on meeting other peer survivors over social support from family and friends.

The financial impact of a cancer diagnosis can be devastating. One study notes that AYA patients with cancer and survivors are more likely to report overall non-adherence to medications and are more likely to report cost-related barriers to care, forgo preventive or follow-up care, and engage in unhealthy behaviors.[13] One study found that because healthcare costs became so expensive with a cancer diagnosis, many of the study participants would forego psychological care entirely.[14] In the 2013 study conducted by Zebrack and colleagues, almost half of AYAs surveyed reported a need for mental health counseling, with individuals treated in an adult oncology setting reporting more unmet mental health needs than those treated in a pediatric setting.[5] For many cancer programs, limited resources and lack of knowledge regarding the care of AYAs may play a role in psychological needs remaining underaddressed or entirely unmet.

AYAs are at a stage in their lives when they are more susceptible to stress,[6] which can contribute to the increased difficulty they often experience coping with their new diagnosis.[15] A cancer diagnosis may be the first dramatic life change or experience for some AYAs, and many have not fully developed the coping skills needed to face such a challenging life event.[15]

Findings from several studies imply that AYAs have higher levels of fear of recurrence than older adults.[6] AYAs also experience more depression compared to survivors in other age groups. For example, one study showed that 16 percent of AYA cancer survivors met the clinical requirements for a depression diagnosis.[6] Increased risk of suicide, anxiety, and post-traumatic stress disorder were also found to be more frequent in this population, with



Group members make welcome bags for new AYA patients that receive treatment at Clearview Cancer Institute.

suicide rates 2.6 times higher than those of their peers without a cancer diagnosis, and the risk of post-traumatic stress disorder was four to five times higher when compared with siblings.[6]

Social Considerations for AYAs with Cancer

Adolescence and young adulthood usher in many life changes. Evidence suggests that when AYAs are diagnosed with cancer they are more likely to deal with physical and emotional challenges that are associated with the transition from childhood to adulthood.[9] Identity formation occurs during adolescence and young adulthood.[4] During this time, it is important for AYAs to form relationships with their peers. These relationships help to shape identity. Unfortunately, many AYA cancer survivors report feelings of isolation and alienation from their peers.[16] They are unsure when to tell their peers about their diagnosis or how they will be perceived by their peers. Some AYAs choose not to disclose their cancer diagnosis at all.[4]

Because peer relationships shape identity, AYAs place high importance on friendships and social life.[17] AYAs also place great importance on sense of control, because it reinforces feelings of normalcy and maintenance of relationships.[16] When a life event, such as a cancer diagnosis, disrupts or pulls AYAs from their social lives, it can cause a great deal of distress. It is important for young adults to maintain their relationships after diagnosis, throughout treatment, and once treatment has been completed. Similarly, minimal disruptions to school and work schedules may also assist in maximizing normalcy.[17] AYAs who believe that they have support from their family and peers tend to have higher levels of empowerment and are better able to cope with their diagnosis than their peers with a cancer diagnosis who do not have a social support network.[15]

It is important for AYAs to be knowledgeable of their workplace rights; they should not be fearful of losing their job as a result of disclosing their cancer diagnosis. One HOPE study reports that one in three AYAs believed that their cancer diagnosis negatively affected their employment plans.[2] As such, it is important that AYAs reintegrate into society during or following their cancer diagnosis. AYAs with the ability to return to work or school following a cancer diagnosis report an overall improvement in their quality of life.[18] Individuals who are not able to return to work or school are more likely to have increased feelings of distress and isolation. These individuals also may experience long-term consequences in relation to career opportunities and earning potential.[18] Finally, AYA cancer survivors returning to work may face "stigma and misperceptions" related to job tasks and abilities.[19] As they return to the workforce, it is important for AYAs to be educated about the accommodations and community resources available to them.[19]

Making the Case for Support Groups

Support groups can play a critical role in meeting the unique needs of AYAs. A 2006 study demonstrated that AYAs place a higher value on meeting other survivors than healthcare professionals perceived; this same study also showed that AYAs placed a greater value on meeting other peer survivors over social support from family and friends.[7] In this study, 50 percent of AYAs undergoing treatment ranked support from friends and family as a top five need and 100 percent of AYAs ranked interaction with peer survivors as a top five need. Even after completion of treatment, AYAs rank peer survivor interactions higher than support from family and friends.[7] Another study demonstrated that the further into the cancer journey the AYA was, the more likely the individual valued meeting other AYAs with cancer.[16]

Yet in a 2009 survey, three out of four AYAs stated that they had yet to be able to participate in a peer support group.[14] And, according to a 2013 study, 25 percent of teens and 40 to 45

percent of adults in their 20s and 30s reported unmet needs in regards to retreats and camps for young adults, demonstrating a need for connection with other young adults in similar life situations or scenarios.[5]

Peer support groups allow AYAs to share their unique experiences with each other and provide an opportunity to commiserate with others on their disease journey. AYAs can share their experiences and concerns without the fear of being judged. These peer support groups are different from other social networks in that they can provide information, affiliation, coping skills, and hope.[20]

Support groups can be supplemented by online communities, which have been shown to improve knowledge, problem-solving skills, and efficacy while also reducing feelings of isolation.[15] In one survey, as many as 30 percent of AYA respondents stated that there was an unmet need for age-appropriate sites on the Internet.[17]

ACCC recognizes this knowledge gap and is working to address this issue with provider resources on fertility preservation discussions for male AYA patients with cancer, developing an oncofertility program, implementing a medical oncology home for AYAs, and more at accc-cancer.org/AYA-resources.

Networking with Key Stakeholders

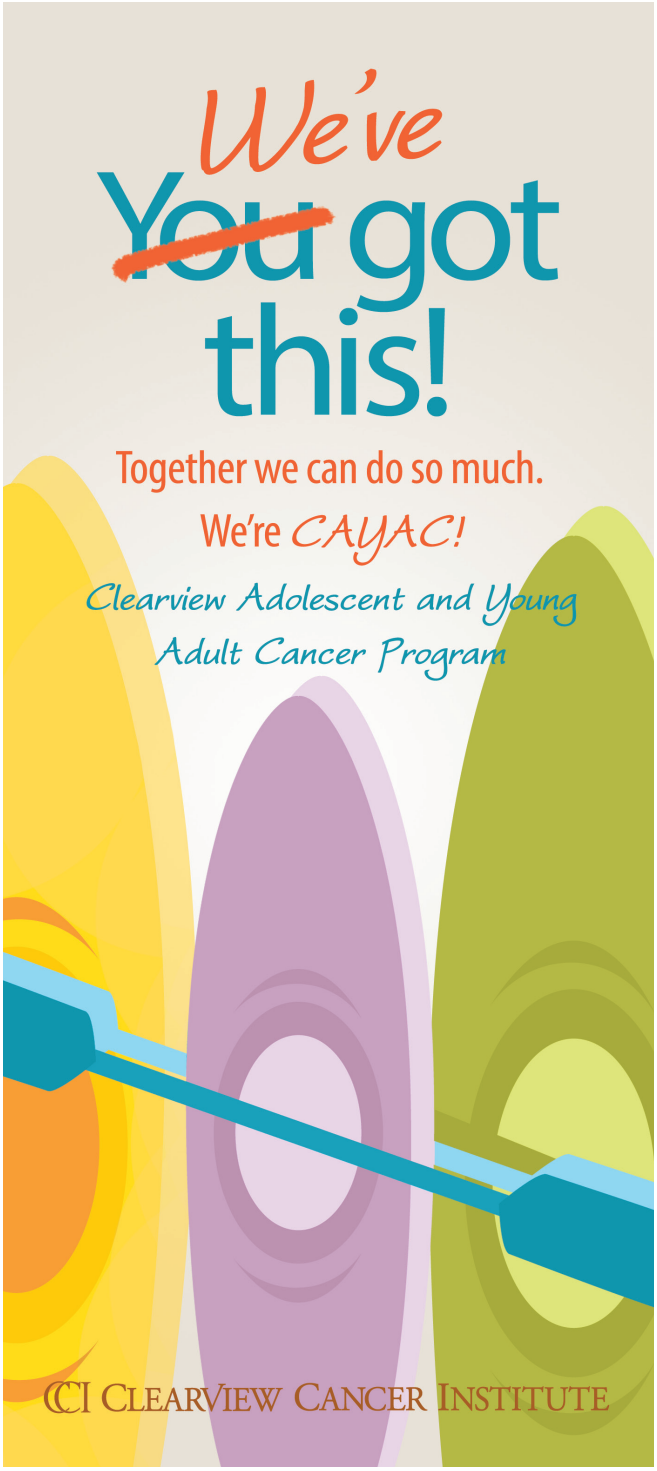
Armed with a better understanding of the unique needs of AYAs with cancer, our next step was to reach out to cancer programs that provide services to this patient population. We researched AYA programs and spoke to stakeholders from other cancer centers with similar programming in place. For example, we contacted program leaders at ACCC Member Program, the Robert H. Lurie Comprehensive Cancer Center at Northwestern Medicine, to gain more insight about its AYA program and services.

In addition to conducting research about external AYA programs and resources, we worked internally with our social work department and public relations specialist who oversees support groups to help identify other potential needs and to foster partnerships for moving forward.

Developing Program Goals

Prior to securing funding for our new Clearview Adolescent and Young Adult Cancer (CAYAC) program, we first had to identify overarching and supporting (programmatic) goals. CAYAC's overarching goal was twofold: (1) to create a support group for AYA patients and (2) to develop and integrate programming at Clearview Cancer Institute so that our clinical staff could learn more about AYAs to better identify appropriate treatment plans and improve care. To do so, we identified the following programmatic goals to help us identify and address emergent needs of this patient population:

- Foster connections between AYAs living with cancer
- Provide support during difficult situations
- Discuss effects related to cancer treatment and side effects
- Assist with complex needs of the young adult with cancer, including finances, dating and relationships, sexuality, returning to school or work, and survivorship.



CAYAC logo used for informational pamphlets, advertising, and and other promotional materials.

Through an event at HudsonAlpha Institute for Biotechnology, CAYAC members learn about genetics and genomics and research initiatives.

Securing Funding

In 2017 we developed an initial implementation budget of $4,500 and applied to a local 501(c)(3), the Russel Hill Cancer Foundation, which accepts grant applications each year in the March to April time frame. The Foundation's focus is on distributing grants related to research, education, and patient assistance for programs benefiting cancer patients or survivors. For the 2017-2018 grant year, we received $4,500 in funding to implement the CAYAC program. For subsequent years, we have secured an average of $3,000 annually to continue the CAYAC program, with the ability to request additional funds if needed for special projects.

CAYAC Programming

Once funding was in place, CAYAC's support group held its first meeting in August 2017 and continues to meet monthly. To educate our community about this new support group, Clearview Cancer Institute sent a mass mailing to eligible patients. An active Facebook page provides ongoing information about monthly programming. This information is also available on Clearview Cancer Institute's website on the Support Group page. Finally, we regularly distribute program brochures across our facilities for clinical staff to share with appropriate patients.

The CAYAC support group typically meets on Tuesday nights after 5:00 pm, which allows participants to attend after work or school. Occasionally, the CAYAC support group meets on a weekend for a special event. All meetings include a meal during our time together. These meetings have included traditional support group discussions, educational programs, service projects, and social outings. The more traditional CAYAC support group meetings are open discussion forums. Other CAYAC support group meetings:

- Host representatives from the local YMCA to discuss its Fit to Fight Program.
- Partner with our social work department to present information about local and national resources for AYAs with cancer.
- Visit a local biotechnology company to learn more about genetic and genomic testing and its cancer research initiatives.
- Host a "Share Your Story" night with our local Oncology Nursing Society chapter. At this event CAYAC support group members give a presentation about young adult cancer and breakout groups share their cancer story with infusion nurses and nurse navigators.

Participants support the CAYAC Program at the Survivors' Day Celebration.

- Conduct service projects, such as the creation of a brochure for newly diagnosed AYAs, which highlights questions to ask their provider and outlines resources for their journey; welcome bags for new AYA cancer patients; and "Brews to Benefit" events in which the CAYAC support group partners with a local brewery and a portion of sales for the night is donated to the Russel Hill Cancer Foundation.
- Participate in social outings, like bowling, golfing, an arcade night, annual holiday parties, a formal benefit dinner supporting cancer research, Survivors' Day luncheons, and attending Battle of the Buffalo, a local hot wings festival. These social outings have been the most well-attended events of all of the activities hosted over the last two years. Feedback from AYA patients indicates that they enjoy spending time with people who know what they have been through with cancer—where they can talk about the disease and its effects candidly and comfortably.

To remain true to the original goal of the CAYAC program, in 2019 we focused more on wellness, resources, and clinical education. CAYAC support group programs included:

- A Survivors' Day luncheon
- Zumba classes
- An educational program about camps and trips for AYAs with cancer
- A 5K run to support breast cancer research
- A cookie decorating class
- An annual holiday party.

Many of these activities were special requests directly from CAYAC program participants, whose feedback regularly directs our program activities and planning.

In addition to the CAYAC patient support group, we are working to improve internal clinical programming to increase awareness of this patient population. This year, we will be hosting a grand rounds-type program with our advanced practice providers to educate them about AYAs with cancer and National Comprehensive Cancer Network guidelines for this population, including a review of case studies.

Our team is also working with a local reproductive endocrinologist to provide information and resources to new AYA patients at their first clinic visit. We are in the process of adding supportive

Russel Hill Cancer Foundation provides funding for patient research, education, and assistance programs across North Alabama. Here, group leaders advertise for Russel Hill and CAYAC at a fundraising event, Battle of the Buffalo.

AYAs want to be part of the solution to improving their cancer journey. They put in the time and effort to help those on the cancer care team improve processes. They are willing to tell us what has worked for them and what has not, as well as what processes help and support them and what areas need improvement.

care regimens to our electronic health record to help address referral gaps in this area as well. At its nursing conference this year and its advanced practice symposium next year, Clearview Cancer Institute will host a reproductive endocrinologist to discuss implications of treatment, treatment considerations, and family planning options for young adults with cancer.

The Patient and Provider Experience

Since implementing the CAYAC program, Clearview Cancer Institute has distributed more than 1,000 informational brochures. Our CAYAC support group held 24 individual meetings in which we served more than 15 individual AYA patients with cancer and survivors. In addition, some program offerings were extended to the patient's support person, and those individuals were served as well. CAYAC support group participation is consistently in line with—or higher than—the average participation at other Clearview Cancer Institute support groups, demonstrating a continued need for this program. In addition, many CAYAC program participants have become close friends outside of our monthly activities. For staff, it is encouraging to see connections and relationship building growing an additional support system.

The CAYAC program has been an important forum to educate our clinical staff and employees and to raise awareness of the unique needs of the AYA patient population and the necessity of additional outreach to help AYA patients feel supported through their cancer journey. Moreover, the CAYAC program has increased community awareness of the Clearview Cancer Institute and its services within our community.

The Russel Hill Cancer Foundation has also benefited from the CAYAC program because it offers a consistent avenue for the foundation to give back to the community and further impact patient research, education, and assistance programs.

Lessons Learned

For cancer programs looking to develop a similar AYA program, our staff offers these lessons learned:

- The literature and our real-life experience clearly demonstrate that there are many unmet needs in this patient population.
- A support group-type program is an effective way to begin to address some of these needs.
- An AYA support group requires thinking outside the box and going beyond traditional support group type functions. Our experience is that AYAs with cancer do not enjoy structured educational programming or direct sharing of feelings and emotions (the more traditional formats of other support groups). Rather, we have found that social events help this group feel accepted and supported in such a way that they then become willing to share emotions, feelings, and the story of their cancer journey more openly.
- AYAs want to be part of the solution to improving their cancer journey. They put in the time and effort to help those on the cancer care team improve processes. They are willing to tell us what has worked for them and what has not, as well as

what processes help and support them and what areas need improvement. Our AYAs have big hearts and are dedicated to improving cancer care for future generations of AYAs.

To positively impact the future of cancer care for AYAs, the cancer community has several responsibilities moving forward. We must continue conducting research and investigating ways to address the needs of this patient population. In addition, we must make a commitment to continue education of our clinical staff regarding standards of care and support of these patients. Lastly, we must advocate for the implementation of programming, like CAYAC, to educate and support our communities. OI

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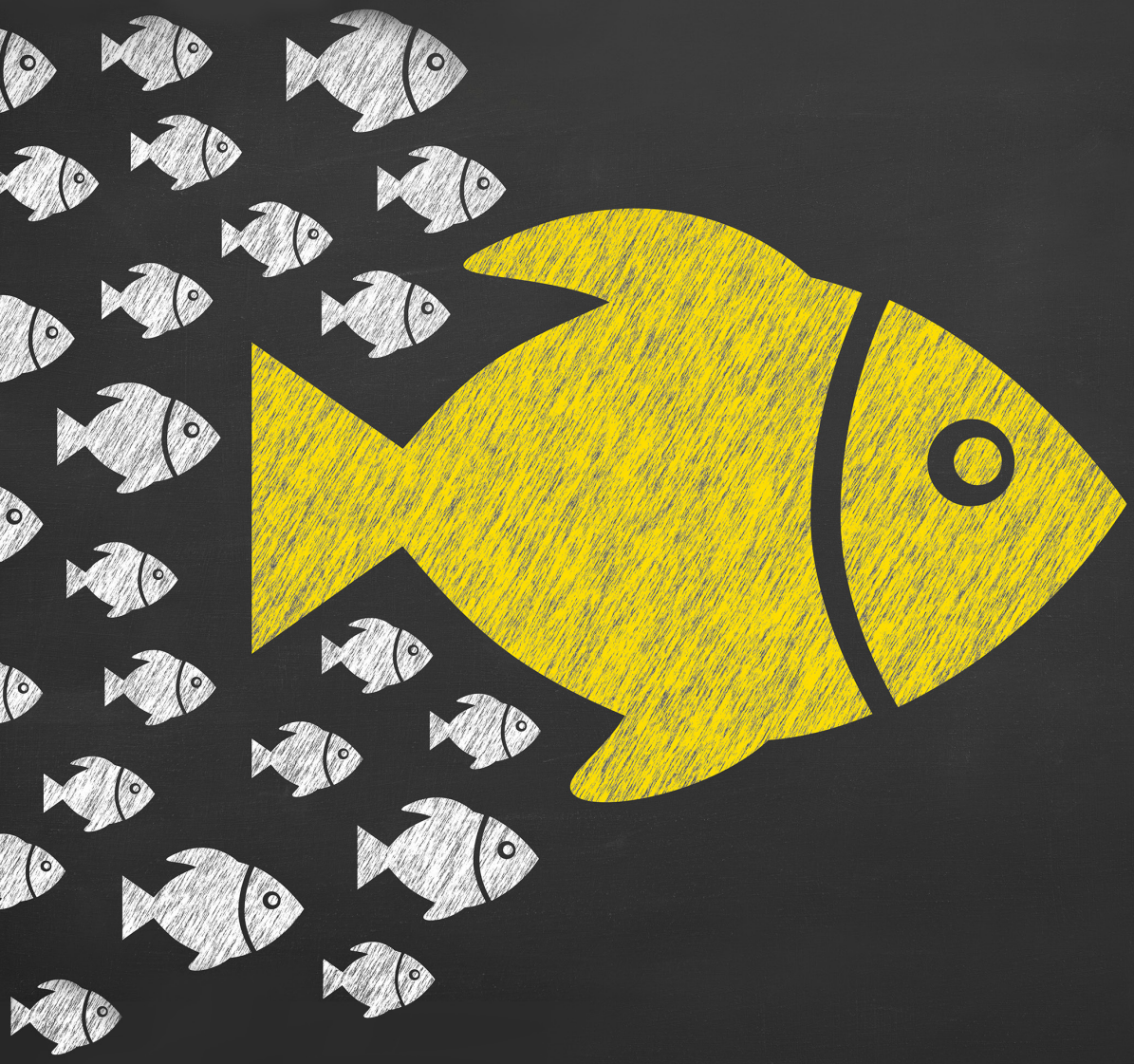
Guided Patient Support



BY JESSICA SIMA, MSN, RN, ACM; LORA ANDERSON, RD, CSO, LDN;
MARIANNA WOLFMEYER, LCPC, DCC, CT;
AND JILL BENEDECK, MS, APRN, AGCNS-BC, AOCNS

Helping patients navigate the clinical, psychosocial, and financial aspects of cancer care

At Northwestern Medicine McHenry Hospital Cancer Center, McHenry, Ill., the Guided Patient Support (GPS) Program is helping patients navigate life and care after their cancer diagnosis. This innovative program provides coordinated whole-person care, ensuring that patients receive the support they need through psychosocial counseling, social support, rehabilitation services, financial counseling, nurse navigation, nutritional intervention, transportation assistance, physical therapy, tertiary care referrals, and medication assistance. The GPS approach helps the cancer care team proactively identify patient needs and prepare patients for treatment. Patients who have participated in the program say that they feel more connected to their cancer team and experience better quality of life throughout the cancer care continuum.

Making the Case for Coordinated Care

In the 1990s, Northwestern Medicine McHenry Cancer Center (formerly Centegra Sage Cancer Center) expanded its cancer service line and began providing adjunct services to patients receiving medical, radiation, and surgical oncology care. The hospital subsequently added staff through the years, building a team of experienced professionals, including:

The GPS Program begins with a single appointment in which patients and their caregivers meet with all members of the team and learn about the specialized services they offer throughout the cancer care continuum.

- Oncology dietitian
- Licensed clinical social support counselor and chaplain
- Social worker
- Financial counselor
- Physical, speech, and occupational therapists
- Genetic counselor
- Oncology nurse navigator
- Support services administrative coordinator.

At first, referrals to these support services were largely based on recommendations from physicians and other clinicians who were part of the patient care team. So, for example, if patients told their medical oncologists that their appetites had decreased during their treatments, physicians would refer them to the oncology dietitian. Patients who seemed to struggle with the emotional burden of cancer care were referred to social support/counseling. Although patients could receive multiple referrals, these referrals were not coordinated, meaning that patients were not always aware of the full range of services available to them. As a result, at times different members of the supportive care staff found themselves making multiple calls to the same patient on the same day. Further, support team members were spread out in different locations throughout the cancer center, making care coordination challenging.

Developing the GPS Program

To streamline care, in 2018 Northwestern Medicine McHenry Hospital Cancer Center consolidated its support services into a dedicated office suite called the Cancer Resource Center. This resource center was made possible through a generous grant from the Northwestern Medicine Foundation. The resource center is designed to give patients a centralized location for cancer support services, increasing staff efficiency and more effectively connecting patients with the supportive care providers they need.

That same year the Cancer Resource Center team developed the GPS Program for newly diagnosed patients and their families. Using the GPS Program, the team created a roadmap for the support resources available throughout the cancer center. The GPS Program begins with a single appointment in which patients and their caregivers meet with all members of the team and learn about the specialized services they offer throughout the cancer care continuum. Ideally, patients attend this initial GPS session shortly after their diagnosis, as their plan of care is being developed. (To allow patients and their families time to process information received at their initial medical consultation, this first GPS appointment is scheduled on a different day.) Referring patients to the GPS Program—rather than to individual services—has resulted in a more coordinated, comprehensive approach to supportive care. Patients may be referred to the GPS program in several ways, depending on the type of oncology services they require:

- **Physician referral.** A medical oncologist or surgeon may refer patients to the GPS Program to ensure that their care is comprehensive and coordinated.
- **Breast center referral.** The breast health navigator often refers patients to the GPS Program after diagnosis or after initial surgery so that patients can immediately receive education about the wide range of support services available.
- **Radiation Oncology.** Patients who present for a radiation therapy consult receive a visit from a support staff team member, who invites them to the GPS Program and schedules visits.

Patients may also be referred by independent physicians, clinicians, and community members who know about the GPS Program.

Currently, Northwestern Medicine patients who are diagnosed at our breast center, all patients receiving radiation consults, and all new patients to our infusion center are contacted by our support services administrative coordinator, who introduces the GPS program and schedules the appointments. Appointments are made at that time for a future GPS session. Patients who are not ready to decide are encouraged to reach out to the coordinator when they are ready for support. Patients do not have to go through GPS to access supportive care services; they may be referred directly to any members of the support team individually before, during, or after treatment.

The Initial GPS Session

The supportive care team designates three hours every Wednesday morning for initial (first-time) GPS patient sessions. During these sessions, patients meet with each member of the multidisciplinary care team for 20 minutes. Our nurse navigator, dietitian, rehabilitation specialist, financial counselor, and social support/counseling specialist each conduct a screening or assessment of each patient's needs and describe the services they provide. Follow-up appointments are scheduled as appropriate, and patients are assured that even if services are not currently needed, they are available at any time in the future. Patients are also educated about additional services, including support groups and programming, genetic counseling, American Cancer Society programs, transportation options, and tobacco cessation support (see Table 1, right). These initial GPS sessions have been successful because each member of the supportive care team contributes to the care of the whole patient.

The Oncology Nurse Navigator:

- Teaches patients about how she participates in their care at different points in the continuum.
- Educates patients about their diagnoses and treatment options.
- Reviews comorbidities and hospitalizations.
- Begins to assess the patients and family's need for support (see Figure 1, page 46).
- Uses an evidence-based tool (modeled after the Billings Clinic's patient navigation acuity scale) to determine a patient's navigation acuity score. Based on the results, she is able to prioritize patient care and can make community referrals regarding transportation needs, psychosocial support, insurance options, and second opinions (see Figure 2, page 47).
- Prioritizes the level of follow-up needed as well as the timing of a follow-up call or appointment, as patients with advanced disease, such as head and neck cancer, require more coordination and support as they adjust to their cancer diagnoses.
- Sets a timeline for future discussion about the patient's survivorship care plan.

The Oncology Dietitian:

- Reviews the patient's plan of care and conducts a malnutrition screening (Figure 3, page 48), which helps determine whether nutrition intervention is necessary.
- Reviews the patient's appetite, hydration, weight changes, and potential side effects of treatment.
- Teaches about diet modification, substitutions, and supplements.
- Schedules follow-up appointments with patients to help them gain a deeper understanding of how to eat nutrient-dense meals that are essential during treatment and recovery.
- Educates patients about enteral feeding, if indicated.

The Rehabilitation Specialist (depending on the patient's treatment plan):

- Helps patients get the most out of daily living by maximizing their cognitive, physical, and social functioning.
- Assesses the need for patients to receive speech and swallow therapy and lymphedema management.
- Helps patients understand how cancer and its treatments affect activities of daily living.
- Identifies immediate needs and educate patients about potential treatment side effects that could signal a need for additional therapy support.

The Physical Assessment Screening Tool can be found on page 49 (Figure 4).

The Financial Counselor:

- Helps patients understand their financial responsibilities.
- Reviews a patient's insurance coverage, explains out-of-pocket expenses, and identifies the potential for financial distress or financial toxicity.
- Educates patients about resources that may be available to help them, offering information about programs for which the patient may be eligible to relieve the financial burden of care.

The Social Support Counselor:

- Discusses with patients and their families how cancer and its treatment affect not only the physical body but also the emotional, mental, spiritual, and social aspects of life.
- Asks patients to complete an evidence-based distress self-assessment adapted from the American Cancer Society (see Figure 5, page 50) that addresses issues including:
  - Symptoms of anxiety and depression
  - Changes in sleeping habits, focus, and appetite
  - Cancer's interference with daily family, social, and sex life
  - Pain, discomfort, and physical limitations
  - Physical, emotional, spiritual, and/or financial hardship caused by cancer
  - Body image concerns
  - Coping
  - Overall quality of life.

Table 1. Additional Supportive Care Services and Resources

- Support groups
- Home care and nursing home resources
- Educational programs
- Pharmaceutical program assistance
- Transportation assistance
- Grief counseling and "Living with Grief" program
- Palliative care and hospice referrals
- Massage therapy
- WellBridge
- Tobacco cessation program
- American Cancer Society program referrals
- Wig Boutique
- Survivorship programming.

If the self-assessment indicates a moderate to high level of distress, the counselor encourages patients to participate in individual counseling, support groups, and other programming opportunities. The counselor also educates patients about emotional distress that may develop over time. Patients and family members are often surprised to learn that distress can increase after treatment ends, when they have time to reflect on the ways in which their lives have been altered by cancer.

Information from GPS Program visits is integrated into the medical record through scheduling, charting, and scanning. Each visit is scheduled and captured in the patient's medical record as well as charted in progress notes. Any written screening tools used are scanned into the patient's medical record. This information is available to the clinical team.

Ongoing Support

The Cancer Resource Center offers supportive care services long after treatment has ended. The support team helps develop each patient's survivorship care plan, which includes information about overall health maintenance and future cancer prevention measures, the importance of adhering to follow-up appointments and testing an established timetable, and instruction about exercise, nutrition, and ongoing emotional and medical management.

We teach patients and their families how to identify future issues that could benefit from the help of our supportive care team post-treatment. Patients are encouraged to contact support team members any time after their treatment has concluded. Support services are free of charge and considered part of a patient's care at the Northwestern Medicine McHenry Cancer Center.

(continued on page 51)

Figure 1. Patient Navigation Intake Form

Name: _____ **Age:** _____ **DOB:** _____

Contact number: _____

Emergency contact person/number: _____

Okay to leave messages: _____

Primary insurance: _____

Secondary insurance: _____

Policy #: _____ **Phone #:** _____

1. How was the patient referred to the navigation program? _____
2. What has your doctor told you so far? _____
3. Biopsy date/result: _____
4. Primary doctor: _____
5. Med Onc: _____
6. Rad Onc: _____
7. Surgeon: _____
8. Specialist (dental and urologist): _____
9. Family history: _____
10. Surgery: _____
11. Chemo: _____

Navigation Acuity Score

Health decision making
1. Difficulty with decision making
2. Wants second opinion
3. Language or disability barrier

Home Life
1. Childcare issues
2. Housing issues
3. Transportation needs
4. Food needs

Physical
1. Activities of daily living
2. Falls
3. Fertility issues

Emotional
1. Distress tool
2. Support

Lifestyle
1. Smoking
2. Alcohol
3. Drug

Financial/Health Insurance
1. Prescription coverage
2. Difficulty paying bills
3. Financial assistance

Referral/order form completed: Yes / No

Education materials given: Yes / No

Contact numbers provided: Yes / No

Situation: _____

_____

Background: _____

_____

Assessment: _____

_____

Recommendation: Plan of care and follow-up (MD appointments, port placement, scans, dental forms or peg tubes, referrals for coverage): _____

_____

_____

Figure 2. Oncology Nurse Navigation Acuity Tool

The acuity scale will be applied at initial contact. Initial contact could include at consult, chart review prior to start of care, initial start of treatment, initial navigation contact, or at the first doctor day. This number can be adjusted per the clinician's discretion throughout treatment. This number is assigned during active treatment.

Acuity Level 0

(Guidelines and Considerations)

- In survivorship and stable
- Active treatment has ended
- Cancer *in situ*
- Distress scale 0-2

(**Care Coordination Focus)**

- Meet with patient initially and assure distress screen is completed
- Navigation intake documentation completed and plan reviewed with the patient
- Provide initial education/clinical coordination/referrals and support
- Follow-up only if requested by patient or provider

Acuity Level 1

(Guidelines and Considerations)

- Stage 1
- Single-agent chemo or radiation only
- Starting surveillance/observation
- Performance Eastern Cooperative Oncology Group (ECOG) = 0-1
- Distress scale less than 3

(**Care Coordination Focus)**

- Meet with the patient initially and ensure that distress screen is completed
- Navigation intake documentation completed and plan reviewed with the patient
- Provide initial and ongoing education/clinical coordination/referrals and support
- Monitor every month for any new needs and document a follow up note during treatment

Acuity Level 2

(Guidelines and Considerations)

- New cancer diagnosis
- Stage 2
- Multi-agent chemotherapy and/or radiation therapy
- Oral chemotherapy
- Performance ECOG = 1-2
- Distress scale 4-5

(**Care Coordination Focus)**

- Meet with the patient initially and ensure that distress screen is completed
- Navigation intake documentation completed and plan reviewed with the patient
- Provide initial and ongoing education/clinical coordination/referrals and support
- Monitor closely every three weeks or as needed for any new needs and document follow-up note

Acuity Level 3

(Guidelines and Considerations)

- Hospitalized in the past 60 days
- Receiving multiple treatment modalities (chemo/rad/surgery)
- Serious comorbidities
- Head/neck/gastrointestinal cancer diagnosis
- Colostomy/ileostomy
- Non-compliant with treatment
- Performance ECOG = 2-3
- Distress scale 6-7
- Stage 3 disease
- Little or no family support

(**Care Coordination Focus)**

- Meet with patient initially
- Navigation intake documentation completed and plan reviewed with the patient
- Provide initial and ongoing education/clinical coordination/referrals and support
- Monitor closely every two weeks or as needed for any new needs and document a follow-up note
- Maintain phone contact with the patient as needed in between visits and document under notes
- Assist with care coordination during transitions of care (hospital, home health, etc.)

Acuity Level 4

(Guidelines and Considerations)

- Stage 4 disease
- Feeding tube
- Tracheostomy
- Frequent hospitalizations
- Unstable and/or end-stage disease
- Performance ECOG = 3-4
- Distress scale of 8-10

(**Care Coordination Focus)**

- Meet with patient initially
- Navigation intake documentation completed and plan reviewed with the patient
- Provide initial and ongoing education/clinical coordination/referrals and support
- Monitor closely every week or as needed for any new needs and document a follow-up note
- Maintain phone contact with the patient as needed in between visits and document in notes
- Assist with care coordination during transitions of care (hospital, home health, etc.)
- Provide end-of-life support to patient/family/caregivers as needed

Resources

American Cancer Society. Tools to help measure distress. Available online at: https://www.cancer.org/treatment/treatments-and-side-effects/emotional-side-effects/distress/tools-to-measure-distress.html. Last accessed June 8, 2015.

Baldwin D, Jones M. Developing an acuity tool to optimize nurse navigation caseloads. *Oncol Issues.* 2018;33(2):17-25.

Blaseg K, Daugherty P, Gamblin K, eds. *Oncology Nurse Navigation: Delivering Patient-Centered Care Across the Continuum*. Pittsburgh, PA: Oncology Nursing Society; 2014.

Figure 3. Nutrition Screening Tool

Patient Name: _____

DOB: _____

Phone Number: _____

Date: _____

Check if form filled out by patient listed above: _____

Nutrition Screening Score: _____

Weight Changes

Weight:_____ pounds
Height:_____ inches
Weight 6 months ago: _____pounds
Weight 1 month ago:_____ pounds
During the past 2 weeks, my weight has:
- Decreased (1) _____
- Not changed (0) _____
- Increased (0) _____

Food Intake

During the past 2 weeks, I have eaten:
- My usual amount—no problem eating (0) _____
- More than usual (0) _____
- Less than usual (1)_____

If less, I am now taking:
- Normal food but less than normal amount (1) _____
- Little solid food (2) _____
- Only liquids (3) _____
- Only nutritional supplement drinks (3) _____
- Very little of anything (4) _____

I have (or will have) a feeding tube (4) _____
- I receive IV feedings (4) _____

Activity Level

Over the past month, I would rate my activity level as:
- Normal, with no limitations (0) _____
- Not my normal self, but able to be up and about most of the time with fairly normal activities (1) _____
- Not feeling up to most things but in bed or chair less than half the day (2) _____
- Able to do little activity and spend most of the day in bed or a chair (3) _____
- Pretty much bedridden, rarely out of bed (3) _____

Symptoms

I currently have the following symptoms:
- No problems eating (0) _____
- No appetite, do not feel like eating (3) _____
- Nausea (1) _____
- Vomiting (3) _____
- Feel full quickly (1) _____
- Problems with chewing or swallowing (2) _____
- Depression (1) _____
- Dry mouth (1) _____
- Mouth sores (2) _____
- Smells bother me (1) _____
- Constipation (1) _____
- Diarrhea (3) _____
- Things taste funny or have no taste (1) _____
- Pain (3) _____

Figure 4. Physical Assessment Screening Tool: Oncology Rehab and Support Services

Completing this form will help us partner together in your care. You may be asked to complete this assessment tool more than once during your cancer experience.

Patient Name:_____DOB:_____

Phone Number: _____Date: _____

		No	Yes, and I would like to address this	Yes, but this has already been addressed. I don't need to discuss it
1	**Are you having any joint or muscle pain? *If yes, where?***			
2	**Do your hands and/or feet feel numb or tingle? *If yes, where?***			
3	**Does any part of your body feel swollen? *If yes, where?***			
4	**Are you feeling weak or having trouble moving around?**			
5	**Are you experiencing excessive tiredness/fatigue?**			
6	**Are you having trouble concentrating or remembering things?**			
7	**Are you having trouble with your balance?**			
8	**Are you having trouble swallowing?**			
9	**Are you having trouble taking care of yourself (bathing, dressing or grooming)?**			
10	**Are you having trouble with daily tasks like chores or shopping?**			
11	**Are you having trouble driving?**			
12	**Are you having trouble completing your tasks at work?**			

Please choose only one response for each question.

A	**Do you exercise? Please circle: Yes or No** **If you answered yes, how many days a week?**
B	**If yes, please specify what your exercise program consist of (i.e., strength training, cardio, etc.):**
C	**If no, are you interested in more information about the programs that can help you get started with an exercise regimen?** **Please circle: Yes or No**

Please list what you are concerned about the most and that you would like to address immediately:

This box is for internal use only.

This form was reviewed by (please print): _____

Date:_____

Figure 5. Evidence-Based Distress Self-Assessment*

Name: _____

Date: _____

Support Recommended to Address Distress—Patient Self-Assessment

I have felt anxious or worried about cancer and the treatment I am receiving.

Not at all 1 2 3 4 5 All the time

I have felt depressed or discouraged.

Not at all 1 2 3 4 5 All the time

I have been irritable or unusually angry and I have not controlled it well.

Not at all 1 2 3 4 5 All the time

My sleeping habits have changed.

Not at all 1 2 3 4 5 All the time

I have noticed a change in my appetite.

Not at all 1 2 3 4 5 All the time

I have had trouble focusing at work or at home or on routine things such as reading the newspaper or watching television.

Not at all 1 2 3 4 5 All the time

Cancer and its treatment have interfered with my daily activities.

Not at all 1 2 3 4 5 All the time

Cancer and its treatment have interfered with my family or social life.

Not at all 1 2 3 4 5 All the time

Cancer and its treatment have interfered with my sex life.

Not at all 1 2 3 4 5 All the time

Pain and discomfort have caused me to limit my activities.

Not at all 1 2 3 4 5 All the time

Cancer has caused physical, emotional, spiritual, and/or financial hardship for me.

Not at all 1 2 3 4 5 All the time

Cancer and its treatment have caused changes in how I look, and this concerns me.

Not at all 1 2 3 4 5 All the time

I have had trouble coping with the distress I have been having.

Not at all 1 2 3 4 5 All the time

My quality of life during the past 2 weeks has been:

Excellent 1 2 3 4 5 Very poor

If many of your answers are 4s or 5s, you may be having significant distress and it is recommended that you consider talking with a counselor or other mental health professional.

*Adapted from the American Cancer Society. Tools to help measure distress. Available online at: https://www.cancer.org/treatment/treatments-and-side-effects/emotional-side-effects/distress/tools-to-measure-distress.html. Last accessed June 8, 2015.

(continued from page 45)

Our Results

During implementation of the GPS Program, our supportive care team met weekly to address real-time issues as they arose. Today, the team meets biweekly to review the program and make adjustments as needed. Fourteen months after the program's launch, our team continues to make improvements to enhance efficiency and improve the patient experience. Our evaluation indicates:

- ***Number of patients offered GPS*:** 458 patients were offered information on the GPS Program from October 2018 through December 2019.
- ***Patient acceptance rate*:** 54 percent of patients accepted the offer to attend the program.

Though all patients said that the GPS Program was beneficial, one message was particularly consistent: patients felt more closely connected to members of our team and were more likely to use our services after they participated in the GPS Program.

Patient acceptance rates of the GPS Program—measured by whether patients attend the initial session—are not where the team hoped they would be. Some of the reasons patients have given for refusing a GPS appointment include concern about having multiple appointments, uncertainty about their plan of care, the belief that they already have enough support, concern about lack of time, and the belief that they "don't need it." The team has found that patients are often so focused on their medical treatment plans that they are unable to absorb much more information early on. Many times, it is someone close to the patient who recognizes the need for supportive care, whether it is for the patient or for him- or herself as a caregiver.

While not every patient accepts the referral to the GPS Program, many who do attend say that they did not know they needed the team's services until they met the specialists who provide supportive care. Based on the low acceptance rate, we have changed the scripting of how the GPS Program is presented to patients. It is now described as an integral part of care rather than optional. In the next year we have a robust list of additional areas we are addressing. We increased our time from three hours a day to six hours on Wednesdays, noting a need for afternoon options and time to see more patients. We will add reminder calls prior to scheduled appointments to increase attendance rate. Our reach will now include Northwestern Medicine medical oncology offices opening in 2020, adding a social worker to our support team, and including new screening tools. We are looking to conduct a participant survey to identify barriers to care or gaps in resources provided, and gather feedback to help analyze our program and identify areas for improvement. Upcoming enhancements to the electronic medical record will allow for standardized templates, decreasing the team's time spent charting and scanning.

Initial Outcomes

From the launch of the GPS Program, it has been important to the team to monitor how and whether the program is impacting patients' use of supportive care and services in ways that improve the quality of patients' overall cancer experience. Early outcomes for the program indicate that patients' needs are being more efficiently and effectively served as care and services are being offered to and used by more patients and families affected by cancer. Supportive care services are also being offered to people earlier in their cancer treatment. These earlier, proactive interventions are reducing the severity and length of challenges that patients face in cancer management. For example, patients who are less worried about finances, appointments, and transportation have more time and energy to devote toward their physical and emotional health and wellness. Patients have even verbally expressed decreased anxiety with just knowing who—and when—to contact if, and when, a need arises. Below are some of the findings and outcomes data we have seen after implementation of our GPS Program:

- Nutrition screening scores during GPS showed 84 percent low risk, 14 percent moderate risk, and 1 percent high risk for malnutrition. Typically patients receive nutrition counseling after initial cancer treatment. Therefore, nutrition screening during GPS provides the opportunity for early nutrition intervention and discussion of side effect management or initiation of enteral nutrition support.
- GPS has allowed us to identify patients who need transportation prior to the start of treatment, ensuring availability of the bus service and avoiding a delay in the start of treatment.
- Thirty patients and/or family members received supportive counseling as a direct result of connecting with the counselor through the GPS Program.
- Fewer individual referrals resulted in fewer phone calls to patients, improving continuity of care.
- The financial counselor assisted 40 patients in applying for various programs, including 11 patients who applied for financial assistance, 7 patients who signed up for Medicaid, 9 patients who applied to foundations grants/co-pay programs, 4 patients who were found eligible to receive supplements from Medicare, 4 patients who were enrolled in medication replacement programs, and 13 patients who received help with co-pays, deductibles, and/or out-of-pocket costs. (Note: Some patients were eligible and signed up for more than one program.)
- Twenty-four percent of patients seen by the nurse navigator were assigned with an acuity level 4, which is the highest level of acuity. The GPS Program allowed for early face-to-face contact with high-acuity patients and their families. The meeting time has allowed for reinforcement (and continued

By referring patients to the GPS Program—rather than to individual services and staff—patients have benefited from a more coordinated, comprehensive approach to their care. Patients have also gained an increased knowledge and more comprehensive understanding of the suite of services offered by the cancer center team.

education) of the treatment plan and time to discuss pertinent follow-up that is needed, improving care coordination and identification of gaps in care.

Patient Feedback

Follow-up interviews between the cancer center's manager of patient care and GPS patients reflected the need for the wide range of services the team offers. Though all patients said that the GPS Program was beneficial, one message was particularly consistent: patients felt more closely connected to members of our team and were more likely to use our services after they participated in the GPS Program. During the interviews, patients shared:

- "*Having cancer is scary—this comprehensive team made it amazing. I am cared for.*"
- "*I did very well all throughout treatment, but it was good to know that if I did need anything there was a team to help me.*"
- "*I felt like meeting with the whole team at once was really beneficial and made me much calmer. I knew what to expect.*"
- "*I didn't feel like I needed it, but if I had then I see how it would have been helpful.*"
- "*This made me more comfortable. I thought the experience was very helpful in letting me know what I needed.*"

Early in the program, it became evident that our initial follow-up method—gathering feedback through telephone calls from the team's manager—was not working due to time constraints. We are now using a post-GPS survey card (Figure 6, right) in the hope that it will gather more feedback for the team about the value of the program.

Patient Case Study 1

A young patient and spouse attended an initial GPS session. The patient—who presented with neoplasm of the tonsil—and spouse seemed anxious about the cancer diagnosis, yet ready to handle upcoming treatments and procedures.

The dietitian counseling session led to an assessment that the patient was at mild risk for nutritional issues due to reported pain, dysphagia, and taste changes. The patient had already lost weight prior to the start of treatment, and the dietitian provided counseling about the reasons a feeding tube was indicated. She explained how the tube would be inserted and described feeding schedules to proactively educate the patient.

The nurse navigator's discussion ensured that the couple was prepared for the upcoming treatments, and they seemed organized and informed about the care that was planned. The navigator reviewed upcoming clinical appointments with the couple, which included the percutaneous endoscopic gastrostomy port, dental clearance, medical imaging, fertility visits, a swallow study, and medical oncology visits. At the time, there were no home life, physical, or lifestyle issues identified.

The physical therapy evaluation included education about post-treatment lymphedema therapy, and the therapist provided the patient a referral to a swallow evaluation.

During their meeting with the social support counselor, the patient and spouse each acknowledged a history of anxiety and depression and described the ways in which they had dealt with and continued to address their individual mental health concerns. The couple agreed that future counseling specifically related to the challenges of living with and beyond cancer and treatment could be helpful, but they did not immediately schedule services because they had so many other clinical appointments scheduled already.

During the financial counseling session, our counselor explained that the patient had an outstanding balance in excess of $1,200 and the patient paid the balance in full.

As this patient's treatment progressed, the true benefit of the GPS Program was revealed. The patient began to experience increased distress in response to the growing emotional and physical demands and side effects of treatment. The couple experienced more conflict as the patient's mood became increasingly variable, with depressive symptoms growing more significant and exacerbated by the use of alcohol.

Because of the initial GPS session, the patient's spouse was already familiar with the cancer center's staff and knew who to reach out to for assistance. The couple began regular counseling to address the distress they were experiencing and received multiple interventions, including adjustments in medication to regulate and stabilize mood, adjustments in tube feeding practice, and a rehabilitation program.

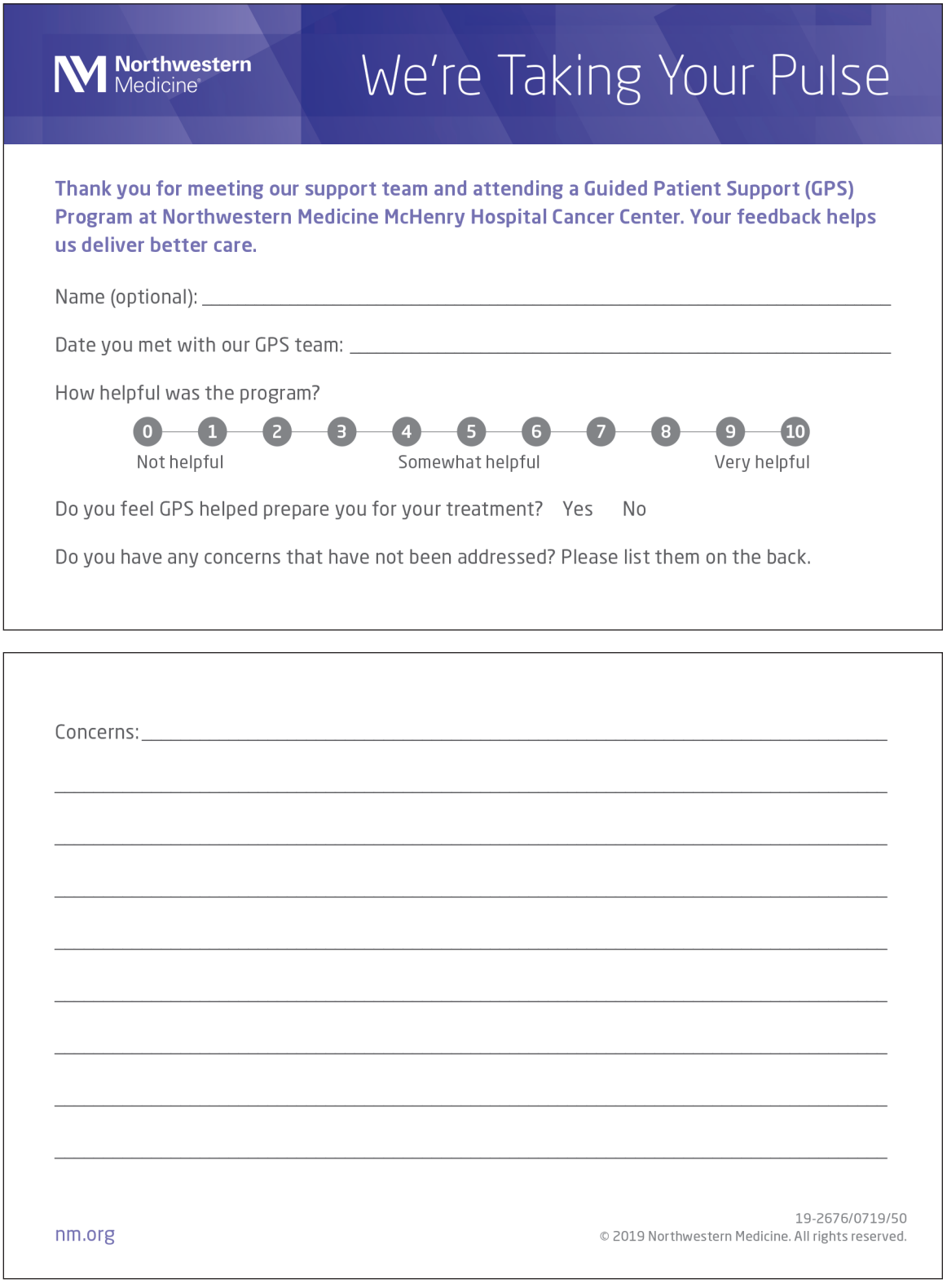
The coordinated team effort resulted in the patient and spouse being connected to the services and support they needed to successfully complete treatment and achieve their goals of care and treatment.

Patient Case Study 2

A patient with breast cancer was enthusiastic about her introduction to the GPS Program, which was scheduled shortly after her oncology surgery. During her initial GPS session, the patient demonstrated low distress levels and seemed capable of navigating

(continued on page 54)

Figure 6. GPS Program Feedback Card



Northwestern Medicine

We're Taking Your Pulse

Thank you for meeting our support team and attending a Guided Patient Support (GPS) Program at Northwestern Medicine McHenry Hospital Cancer Center. Your feedback helps us deliver better care.

Name (optional): _____

Date you met with our GPS team: _____

How helpful was the program?

0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10

Not helpful — Somewhat helpful — Very helpful

Do you feel GPS helped prepare you for your treatment? Yes No

Do you have any concerns that have not been addressed? Please list them on the back.

Concerns: _____

_____

_____

_____

_____

_____

_____

_____

_____

nm.org

19-2676/0719/50

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her care. The patient had previously met with a physical therapist, and her related needs were already being addressed.

Although some of the patient's risk levels were determined to be low, team members identified the patient's need for additional education regarding her diet and finances. The patient was at low risk for cancer-related dietary issues, but she demonstrated a lack of knowledge about how nutrition could affect her diabetes. Because of her own concerns about diabetes and her husband's high cholesterol and blood pressure, our dietitian identified an opportunity to provide more information about nutrition to improve their overall health.

During the financial counseling session, the patient shared her concerns about the financial burden of her cancer care. The counselor described ways in which she could help the patient obtain co-pay benefits and work with her insurance providers. Together, they created a follow-up plan.

In the following months, the patient received dietary counseling and financial counseling and contacted the team for psychosocial support for needs that arose after the initial GPS session. Each of the patient's needs was addressed during the radiation therapy treatment period. Without the GPS Program, it is possible the patient may not have discussed her concerns about her diabetes and financial questions; she had not understood how those concerns related to her radiation therapy.

After treatment, the patient met with the social support counselor to address her distress related to managing her life and fear beyond treatment. Through this contact, the patient has become more involved in supportive care through groups and programming, which are improving her emotional health and overall quality of life.

Future Direction

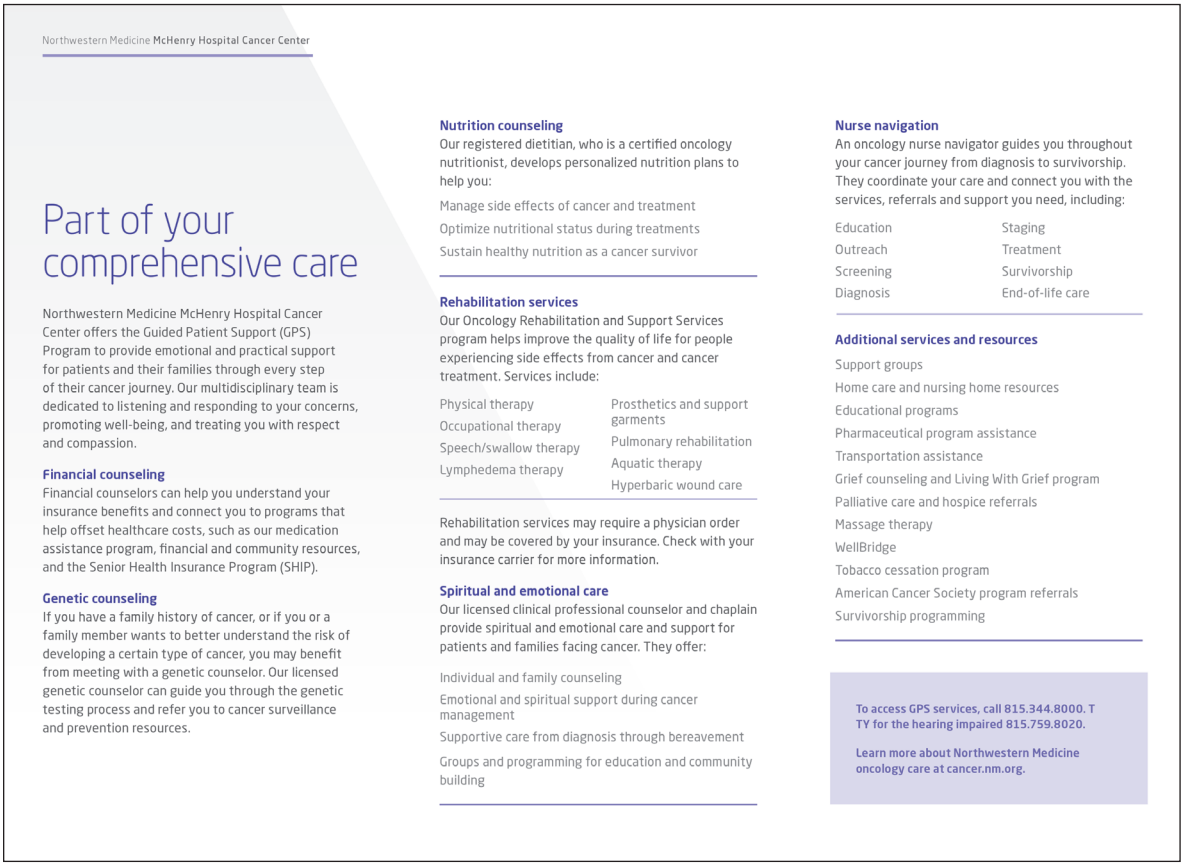
Going forward, we hope to make a number of improvements and enhancements to our GPS Program, including:

- Enhancing the scheduling process, which currently takes more time than is desired.
- Creating new ways to track and report: (1) when patients are coming to the Cancer Resource Center; (2) referrals to the GPS Program; (3) follow-up calls, scheduling, reminders, and rescheduling; and (4) services scheduled, completed, and referred at GPS visits.
- Evaluating new opportunities to generate revenue for appointments that are scheduled through the GPS Program. The cancer program currently offers support services as a community benefit, and psychosocial and nutrition counseling are potentially billable services. Although the nurse navigator position is currently filled by a master's degree-level nurse, an advance practice nurse could fill the position and charge for follow-up survivorship care plan appointments.
- Educating patients who have lung and colon cancers about the GPS Program earlier in their cancer journeys. The team is expanding partnerships with thoracic surgeons and gastrointestinal specialists to promote earlier referrals to the program.
- Updating scripting to communicate to patients that GPS is part of a patient's care plan rather than an optional appointment.

By referring patients to the GPS Program—rather than to individual services and staff—patients have benefited from a more coordinated, comprehensive approach to their care. Patients have also gained an increased knowledge and more comprehensive understanding of the suite of services offered by the cancer center team (see Figure 7, right). Bringing the support team together to one centralized location has also enabled increased collaboration and more effective, timely communication among staff members. Members of the once-fragmented team have noted that their new configuration has made them a more cohesive unit, allowing them to better collaborate and provide timely services to patients. This strong team environment acts as a support mechanism for staff members, who help one another improve their performance and enhance their professional development. Building these professional bonds and being able to rely on one another is extremely important when serving patients with cancer. OI

Jessica Sima, MSN, RN, ACM, is oncology nurse navigator; Lora Anderson, RD, CSO, LDN, is an oncology dietitian; Marianna Wolfmeyer, LCPC, DCC, CT, is an oncology counselor and chaplain; and Jill Benedeck, MS, APRN, AGCNS-BC, AOCNS, is the oncology manager at Northwestern Medicine McHenry Hospital Cancer Center, McHenry, Ill.

Figure 7. GPS Program Brochure



Improving Care Coordination

A Model for Lung Cancer

Executive Summary

In 2016, the Association of Community Cancer Centers (ACCC) received a three-year grant from the Bristol-Myers Squibb Foundation (BMSF) to develop a model that would help healthcare entities improve care coordination for lung cancer patients covered by Medicaid.

Leading the project Advisory Committee were co-principal investigators Christopher S. Lathan, MD, MS, MPH, Medical Director, Dana-Farber at St. Elizabeth's Medical Center, and Randall A. Oyer, MD, Medical Director, Oncology Program, Penn Medicine Lancaster General Health.

The process for model development encompassed three phases: research and beta model development, testing the model, and data analysis and outcomes.

Research and beta model development began with an environmental scan to better understand the current state of care access and coordination for patients covered by Medicaid, identify barriers and challenges, and review existing studies suggesting potential strategies to improve care coordination for this patient population. The scan incorporated a literature review as well as insights from members of the project's interdisciplinary Advisory Committee, a lung cancer survivor and patient advocate, and multidisciplinary health professionals from two ACCC-member cancer programs. In June 2016, ACCC published the full environmental scan, "Optimal Care Coordination Model for Lung Cancer Patients on Medicaid," on the ACCC website, along with a brief that highlighted the following key findings:

1. The financial and social barriers that Medicaid beneficiaries face in pursuing lung cancer treatment are significant, detrimental to outcomes, and largely unaddressed. These include:
    - Accessing reliable transportation
    - Taking time off from work/lost incomes
    - Procuring childcare or other family support
    - Covering out-of-pocket expenses for services and drugs
2. Medicaid beneficiaries have unequal access to high-quality care. Disparities in care access can be attributed to multiple causes, including how patients typically access the healthcare system.
3. Increasing patient engagement is critical to improving outcomes but will require a tailored approach given the unique challenges Medicaid beneficiaries face.
4. Integration of patient navigators into the care team can promote Medicaid beneficiaries' access to timely, high-quality care. Both clinical and non-clinical navigators may play a key role in ensuring access to care, coordination of services across providers, education, and follow-up to promote adherence to treatment recommendations.
5. Multidisciplinary teams are key to improving care coordination. Opportunities may exist to strengthen and build on the team approach to caring for patients with lung cancer.
6. Improvement is needed to promote timely access to supportive services for this patient population, including attention to biopsychosocial needs, palliative care needs, survivorship issues, hospice, and end-of-life care.

Results from the environmental scan were used by the Advisory Committee and ACCC staff to develop an application and criteria for the selection of Development Sites, and to create an interview guide to compile information in a standardized format across programs.

The following ACCC Cancer Program Members participated as Development Sites:

- Florida Hospital Memorial Medical Center
- Genesis HealthCare System, Genesis Cancer Care Center
- MaineGeneral Health
- Mary Bird Perkins – Our Lady of the Lake Cancer Center
- Sidney Kimmel Cancer Center at Thomas Jefferson University

The ACCC project team traveled to the five Development Sites to conduct comprehensive interviews with cancer program staff, including both clinical and administrative personnel; patients insured through Medicaid; palliative care and hospice providers; the interdisciplinary care team involved in the diagnosis and treatment of patients with lung cancer; and healthcare staff from referring practices and healthcare facilities. Through this process, ACCC project staff were able to map some of the existing care pathways for Medicaid patients with lung cancer.

Comprehensive reports based on the information gleaned during these site visits provide snapshots of successes and challenges in delivering care for patients with lung cancer, with a focus on individuals insured by Medicaid or without healthcare coverage. The Development Site reports, outlining the findings from each site visit, were published online on the ACCC website.

Informed by the environmental scan and the Development Site reports, the project's expert Advisory Committee convened an in-person meeting in November 2016 to discuss key findings in the context of model development. Ultimately, consensus developed around the concept of a beta "Optimal Care Coordination Model for Patients with Lung Cancer on Medicaid" built directly upon the Multidisciplinary Care (MDC) Assessment Tool created by the National Cancer Institute (NCI) Community Cancer Centers Program (NCCCP), a project funded by NCI from 2007-2014.

The NCCCP pilot, which eventually engaged 30 participating hospitals and health systems across the country, sought to build a community-based research platform to support a wide range of basic, clinical, and population-based research on cancer prevention, screening, diagnosis, treatment, survivorship, and palliative care at community hospitals—contributing to enhanced quality of care for patients and advancing cancer research. (See *The NCCCP—Enhancing Access, Improving Quality of Care, and Expanding Research in the Community Setting*, available at accc-cancer.org/publications.) In drafting the model, project stakeholders aimed for a framework that could benefit cancer programs of all resource levels interested in improving care for patients with lung cancer.

To enrich Model development, ACCC formed a Technical Expert Panel (TEP) chaired by Thomas M. Asfeldt, MBA, RN, BAN, Director, Outpatient Cancer Services and Radiation Oncology, *Sanford USD Medical Center.* All members of the TEP were former NCCCP pilot participants. The TEP collaborated with the Advisory Committee and the ACCC project team to create a beta version of the **Optimal Care Coordination Model (the Model)**. The beta Model consisted of 13 assessment areas with high impact on optimal care for patients with lung cancer covered by Medicaid. The Model was designed to provide a framework that could be used to evaluate care coordination for lung cancer patients from the time of initial patient referral to cancer services through survivorship and end of life. Each assessment area had five levels, with level 1 representing the most basic provision of care and level 5 representing optimal best practice.

Testing the Model

Through an application process that required submission of quality improvement (QI) projects within the beta Model's assessment areas, ACCC Cancer Program Members* were invited to apply to serve as Testing Sites for the Model. As part of the Testing Site application process, programs used the beta Model for program self-assessment, and then submitted quality improvement project(s) that would utilize one or more of the Model's 13 assessment areas. The following seven ACCC Cancer Program Members were selected as Testing Sites:

- Advocate Lutheran General Hospital Cancer Care Program
- Ascension Wheaton Memorial Medical Center
  (Formerly, Ascension Wheaton Franciscan Cancer Care)
- Cowell Family Cancer Center, Munson Healthcare
- Florida Hospital Memorial Medical Center
- Genesis HealthCare System, Genesis Cancer Care Center
- Northwest Medical Specialties, PLLC
- Southern Ohio Medical Center, Southern Ohio Medical Center Cancer Care

Over a 12-month period, from October 2017 through September 2018, the Testing Sites deployed the beta Model, participated in data collection, and reported challenges and progress to the ACCC project team while executing one or more QI projects.

In November 2018, the Advisory Committee met with leaders from the Testing Sites, the ACCC project team, and members of the Technical Expert Panel to review the experiences of the seven programs in implementing the Model for quality improvement. During this meeting, the Testing Sites also offered input on potential approaches for Model dissemination. (Four Testing Sites describe the impact of using the Model for quality improvement on pages 60–67.)

In early 2019, the ACCC project team reconvened the Technical Expert Panel for a live working session to review and incorporate the findings from the Testing Sites and the output from the fall 2018 Advisory Committee meeting to finalize the Model. For more information on the Model development process, visit accc-cancer.org.

**Under the terms of the grant, programs in the following states were excluded from participation in this project: AL, GA, KY, MS, NC, TN, SC, and WV.*

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Snapshots of the Testing Site Experience

ACCC would like to thank the seven member programs that served as Testing Sites for the beta Model. *Oncology Issues* interviewed four of the participating cancer programs for a deeper dive into lessons learned and how the experience impacted care coordination for lung cancer patients, with a focus on patients covered by Medicaid.

13 Assessment Areas of the Beta Care Coordination Model

This version of the Model was implemented by the Testing Sites to conduct 12-month QI projects.

1. Patient Access to Care
2. Prospective Multidisciplinary Case Planning
3. Financial, Transportation, and Housing
4. Management of Comorbid Conditions
5. Care Coordination
6. Treatment Team Integration
7. Electronic Health Records (EHRs) and Patient Access to Information
8. Survivorship Care
9. Supportive Care
10. Tobacco Cessation
11. Clinical Trials
12. Physician Engagement
13. Quality Measurement and Improvement

Ascension Wheaton Memorial Medical Center

Leveraging Technology for Prospective Case Planning

In 2016, Wheaton Franciscan Healthcare joined Ascension to create Ascension Wisconsin—a healthcare system encompassing 23 hospitals and more than 19,000 associates, including 1,000 physicians and 110 clinics. Ascension SE Wisconsin Hospital in Milwaukee is part of that system.

Ascension's cancer center offers diagnostic techniques, innovative cancer treatments, comprehensive supportive services, clinical trials, and integrative therapies. Its survivorship program focuses on wellness and the management of long- and late-term treatment side effects. Its cancer rehab program proactively addresses the rehabilitation needs of Ascension's post-treatment patients. Ascension chose to develop quality improvement (QI) projects for two of the Model's 13 assessment areas: patient access to care and prospective multidisciplinary case planning.

When staff from Ascension began evaluating their program to identify the areas they wanted to target for improvement, they took a holistic look at their entire continuum of cancer care services. Sherri Costa, MS, RN, AOCNS, Manager of Cancer Support Services & Quality Improvement Coordinator, explains, "We looked at how our lung cancer patient services should ideally fit into a whole lung program, from diagnosis through the end of treatment."

"The care coordination tool [the Model] really helped us formally evaluate our program," adds Costa. "We knew that patients diagnosed with lung cancer were getting lost in our system. We had a lot of late-stage lung cancer patients, and we needed to improve our case planning so we could identify those patients sooner." Costa and her colleagues decided that they could best address this shortcoming by strengthening the multidisciplinary case planning they relied on to create optimal care plans for patients.

Assessment Area: Prospective Multidisciplinary Case Planning

The Ascension oncology team wanted their strategy to focus on increasing the number of lung cancer patients reviewed by the multidisciplinary care team. But this strategy would require busy providers to squeeze yet more time out of their already full schedules, cutting into time that could be spent on direct patient care. Costa says she and her colleagues saw a solution in technology, and they set out to create a virtual tumor board that physicians could easily access when their schedules allowed.

At the start of Ascension's Improving Care Coordination project, lung cancer patients who entered the cancer

"The care coordination tool [the Model] really helped us formally evaluate our program. We knew that patients diagnosed with lung cancer were getting lost in our system. We had a lot of late-stage lung cancer patients, and we needed to improve our case planning so we could identify those patients sooner."

– Sherri Costa, MS, RN, AOCNS, Manager of Cancer Support Services & Quality Improvement Coordinator

program were often evaluated by a single provider or specialist, with multidisciplinary discussions taking place after the start of treatment. The program's tumor board reviewed a limited number of cases, many of which were retrospective. A lack of data meant that the program did not know whether the work of the tumor board was influencing patient care.

To enhance its multidisciplinary patient case planning capabilities and not overtax its providers with the additional time required for more in-person tumor boards, Costa says the Improving Care Coordination team committed to developing, implementing, and piloting a virtual tumor board (VTB). Costa says the VTB is capable of overcoming a number of obstacles: "Because the system is asynchronous, providers can access it on their own schedules, overcoming the challenges posed by bringing providers from multiple locations and specialties physically together."

Tumor board participants can access the VTB from a variety of technology, including desktop computers, laptops, and phones. The interactive platform allows users to edit information, attach images, and leave audio notes. The VTB has caught on quickly with Ascension's clinical staff, and the number of cases they review has increased, enhancing patient care management and coordination. During the one-year testing period (October 1, 2017 – September 31, 2018), 100 percent (75/75) of patients with newly diagnosed lung cancer were presented to the VTB—four times as many as were previously presented to Ascension's traditional tumor board. Sixty-seven percent of those patients were presented before the start of any treatment.

Costa says the VTB has had wide-ranging effects on Ascension's treatment of lung cancer patients. "It has formalized our patient pathway and allowed us to better visualize and assess our program and goals," explains Costa. "Our lung cancer program has been elevated to a systematic, patient-focused approach. It has opened our eyes to doing things a different way. Now our GYN oncologists also want to use it in their specialty. Another physician wants to use it across the state to help rural providers who don't have access to a multidisciplinary team; it will be interesting to see where this goes next."

Assessment Area: Patient Access to Care

Costa says that Ascension approached its goal to enhance patient access to care by looking retrospectively at the previous year's caseload of lung cancer patients to gain a better understanding of the patient experience and treatment timeline. "That really helped us better understand what our program looks like from a patient's perspective," says Costa.

Ascension's lung cancer care team decided it could make the most impact by enhancing appointment availability, strengthening relationships with referring providers, and developing a formal strategy for internal reporting on referral patterns. To accomplish this, the Improving Care Coordination team developed a clinical pathway that defined care expectations. This resulted in a structured process to ensure patients receive timely and seamless care and provided a method to evaluate and measure the program.

As the team members developed and implemented strategies to accomplish the goals they outlined for themselves, they began to formulate and facilitate how lung cancer patients move throughout their system. This allowed the leaders of the lung cancer program to better define their expectations of care, evaluate and measure their program, and identify opportunities for improvement.

Subsequently, Ascension's lung cancer program developed a framework for patient care and a formal patient tracking process. As a result, the number of lung cancer patients offered navigation services increased, and the time from detection or confirmed diagnosis to first treatment decreased.

Costa says that evaluating patient patterns gave Ascension's lung cancer program a comprehensive view of its processes that it had not previously had. "I highly

recommend taking the time to evaluate how patients enter and move through your system," says Costa. "Is cancer identified incidentally, through a screening, or another way?"

Costa attributes many of the successes achieved by Ascension's lung cancer program to the ACCC Improving Care Coordination project grant and Model. "Having a grant and specific expectations helped us get this accomplished in our system," says Costa. "There can be a lot of barriers to making such large changes; but being able to use a tool such as the Model allowed us to evaluate our program and show leadership where we could improve. Physician champions contributed to the success of our projects. By looking at our projects from an outcome perspective, this enabled us to create a plan for effective change."

Genesis Cancer Care Center
Genesis Hospital, Genesis HealthCare System

Prove It: Using Data to Formulate Goals and Successes

Genesis HealthCare is an integrated healthcare delivery system based in Zanesville, Ohio. The system includes the not-for-profit Genesis Hospital in Zanesville, a network of more than 300 physicians, and multiple outpatient care centers throughout the rural region.

The largest healthcare provider in six counties in southeastern Ohio, Genesis Cancer Center offers patients medical oncology, radiation oncology, and integrated palliative care services. Genesis chose to develop quality improvement (QI) projects for two of the Model's 13 assessment areas: prospective multidisciplinary case planning and tobacco cessation.

Within the six counties served by Genesis, more than 22 percent of the population are smokers, versus approximately 18 percent nationally. During the 12-month Model testing period, 109 patients with lung cancer were treated at Genesis, 29 of whom were Medicaid/Dual Eligible. Of those 29 patients, 18 (60 percent) were active smokers; of those, 10 (56 percent) expressed a readiness to quit. This data demonstrated to Genesis' leadership the extent of the need for tobacco cessation services for their patients.

Assessment Area: Tobacco Cessation

While Genesis has had a lung cancer screening program for the past five years, the health system did not offer tobacco cessation services in its cancer center before participating in the ACCC Improving Care Coordination project. Today, Genesis Cancer Care Center screens each patient who comes through its doors for tobacco use, and it offers tobacco cessation services while the patient is in the cancer center.

Pebbles Thornton, RN, BSN, OCN, Director of Cancer Services, Palliative Medicine, and Hospice Care at Genesis, says Genesis Cancer Care Center was able to offer these services after getting four of its employees certified in smoking cessation training. "Pending available funding, we hope to have two additional employees certified next year," says Thornton.

"As a result of this effort, we have helped more patients quit tobacco," says Thornton. She explains that by incorporating questions about tobacco use and cessation readiness into each patient visit assessment, Genesis can now identify the patients who are ready to quit smoking. "We built questions about smoking into our review of systems questionnaire that every patient receives," Thornton explains, "and answers to that questionnaire are entered into our EHR."

While Genesis Cancer Care Center's new tobacco cessation services have given patients additional motivation to help them quit smoking, Thornton says the cancer center's limited resources make it difficult to keep up with demand for the counseling. "We run into the problem that the people we train in smoking cessation still work full-time giving direct patient care, so it's difficult for them to find time for all of their responsibilities," says Thornton.

On the positive side, coming out of the Care Coordination project, Genesis Cancer Care Center is now able to bill for its tobacco cessation counseling services, which will help make the program more sustainable in the long term. Also, if patients express a desire to quit, Genesis Cancer Care Center now has the means to provide same-day smoking cessation

"We learned the importance of collecting a specific set of data points and being able to report on outcomes. You can say we do something great, but, unless you prove it with data, that means nothing."

– Pebbles Thornton, RN, BSN, OCN, Director of Cancer Services, Palliative Medicine, and Hospice Care

services on site, including cessation medications from its retail pharmacy (as opposed to elsewhere within Genesis).

Assessment Area: Multidisciplinary Case Planning

Prospective multidisciplinary case planning is the second assessment area Genesis selected from the Model. Before participating in the program, physicians at Genesis Cancer Care Center held monthly tumor boards to discuss individual patient cases. Between these monthly meetings, Genesis' oncologists took a mainly ad-hoc approach to individual patient case planning. These informal consultations took the form of brief huddles held before patient appointments to discuss current treatment and status.

"Our multidisciplinary case planning model doesn't really fit into any of the description boxes out there," says Thornton. "As external groups [from the Model project] witnessed how we do things, they found that our way of doing it did not follow the Model. Most places schedule conferences at a set time where everyone comes together and participates either in person or virtually. With us, many times we have spontaneous huddles in which our physicians check in with, for example, the pulmonologist and the surgeon right before seeing the patient."

Thornton said this care planning model, though convenient to some providers, did not allow Genesis to effectively capture patient information, quantify services, or determine outcomes. "We were doing what needed to be done, but in our own way to meet the needs of patients in a hospital with not as many resources as a large urban health system," says Thornton.

Before participating in the Care Coordination project, Thornton says, given the frequency of its multidisciplinary "huddles," Genesis providers felt it sufficient to hold tumor boards once a month. During the course of testing the Model, Genesis increased the frequency of its tumor boards to biweekly. This decreased the average number of days from patient diagnosis to board presentation from 25 to 11.

"These more formal multidisciplinary conferences include approximately 15 people," says Thornton, "including oncologists, surgeons, oncology nurse navigators, and palliative care. In each conference, 10 to 12 cases are presented, depending on how many we've seen that week. Now that we're doing this twice a month, we have better collaboration among our providers, and referrals have sped up."

Thornton adds that Genesis' providers continue to huddle with one another for the purposes of consultation before patient appointments if necessary, but that communication is now supplemented with a more formal exchange of information. Thornton says Genesis' leadership is looking for additional ways to enable more efficient multidisciplinary collaboration. "We are currently investigating with our IT department the possibility of creating a virtual tumor board," says Thornton. "That would help us avoid the barrier of time constraints."

The Value of Data

Thornton says participating in the Care Coordination project has taught her and her team the importance of collecting and analyzing data to make a solid case for desired improvements. "We learned the importance of collecting a specific set of data points and being able to report on outcomes," says Thornton. "You can say we do something great, but, unless you prove it with data, that means nothing."

"In this project, we used the data we collected to make the case for holding tumor boards twice a month, and we were able to get funding to send more people to smoking cessation training," says Thornton. "We learned how to look broadly at our processes from an external point of view. It gave us the ability to identify where we needed to improve and take the steps to meet our goals."

Thornton says Genesis' participation in the ACCC Improving Care Coordination: A Model for Lung Cancer project has had a long-term effect on how she approaches her job: "Now I am always looking for data, figuring out how to make a case for the things we need by identifying where I want to be and how to get there."

Northwest Medical Specialties, PLLC

Meeting Patients Where They Are

A private, dual-specialty practice encompassing medical oncology and infectious disease physicians, Northwest Medical Specialties (NWMS) has five clinic locations serving the South Puget Sound area in Washington state. Each site is staffed with board-certified oncologists/hematologists, advanced registered nurse practitioners, physician assistants, and specially trained nurses and administrative staff.

The practice is one of the founding practices of the Quality Cancer Care Alliance Network, a clinically integrated oncology network of 20 practices that have championed practice transformation as the healthcare system transitions to value-based care. NWMS participates in both commercial value-based models and the CMMI Oncology Care Model (OCM). It therefore brought to the project experience with care coordination and an infrastructure for data collection.

The quality improvement project developed by NWMS to test the Model was focused on achieving decreased emergency room utilization by lung cancer patients insured through Medicaid. The QI project evaluated the practice's patient education, access to care management services, expanded clinic hours, and patient navigation for lung cancer patients with Medicaid. Key project staff for the QI project included a physician champion, executive-level champion, case manager, patient navigator, project point of contact, the practice's Director of Quality and Value-Based Care, and a data collection team of five patient care coordinators.

In early 2016, NWMS had identified the need to expand patient support services, and it had approved full-time positions for social work, care coordination, case management, and patient navigation. Reducing patient ER visits and hospital admissions was recognized as a primary practice goal.

Several factors influenced NWMS' decision to apply as a testing site for the ACCC Model, says Amy Ellis, Director of Quality and Value-Based Care, NWMS: "Patient navigation was already of great interest. We were already starting to scratch the surface. If we were to provide non-clinical navigation and RN navigation, could we reduce our hospital ER use?" NWMS believed that serving as a Testing Site would be an opportunity "to learn from ourselves and from others."

As an OCM participant, NWMS was already striving to reduce ER and hospital readmissions. In many ways, Ellis says, participating as a Testing Site for the ACCC Improving Care Coordination Model went "hand in hand" with the practice's OCM goals.

NWMS was also motivated to apply because of its comparatively small size as an independent community oncology practice. Support services, such as social work and patient navigation, are not reimbursed, and affording these additional FTEs is challenging. "If you only have an RN navigator, you potentially have someone paid at an RN salary helping patients with transportation," says Ellis. "We thought it would be a better use of nurses' time to spend all their time on clinical tasks." This would allow the lay navigator to help patients with barriers to care, such as obtaining housing and transportation, administering distress screening, and coordinating visits and appointments.

Assessment area quality improvement objectives:

- Calculate the proportion of patients who use NWMS Saturday Acute Care Clinic expanded hours.
- Summarize navigation attempts.
- Estimate the number of ER visits.

These objectives involved three of the Model's Assessment Areas: patient access to care, supportive care, and care coordination.

Analyze, Improve, Repeat

Participation as a Testing Site helped NWMS learn how to integrate lay navigation into the practice's oncology care team, adjusting the workflow process to provide multiple layers of support without creating redundancies. The QI project supported bringing resources together for this patient population. To identify qualifying patients, custom reports were built into the practice's electronic medical record (EMR). Because NWMS had previously targeted ER visits as an area for improvement, it already had a tracking process in place using PreManage and had implemented a care management platform to meet OCM requirements.

Among the lessons learned in testing the Model: Figuring out the workflow process between the case manager and the navigator so that there was no overlap or role confusion.

"In the beginning, we had a team that screened for eligible patients, and then notified the case manager and the lay navigator," recalls Ellis. "There was no workflow for who called the patient first. The case manager would call, and the navigator would call." Patients would wonder why they were receiving multiple calls. Establishing the workflow for the interaction between these roles addressed the problem. "April [the lay navigator] always calls first, and she explains her role and Teri's [the case manager] role to the patient." This created a warm hand-off between support staff and smoothed the patient experience.

"Patients have their own agenda. You have to meet them where they are."

– **Amy Ellis,** Director of Quality and Value-Based Care, NWMS

The practice often faced basic challenges in contacting its Medicaid patients, which is critical to understanding and eliminating barriers to care access. Through the Testing Site experience, NWMS learned to rethink its process for contacting this patient population, as these patients may not have a permanent home, address, or phone number. The patient navigator began trying to meet with patients in the infusion room. To improve communication/contact with difficult-to-reach patients, the navigator conducted drop-in visits during the patient's scheduled clinic visit.

To further ease access for this Medicaid population, NWMS had originally proposed utilizing remote navigation. "We wrote this picture-perfect [QI] proposal," says Ellis. "When you go to implement [your plan], you think, 'This is what should happen with the patient.' Patients have their own agenda. You have to meet them where they are. I moved away from the project with the mindset that we have to meet patients where they are to be successful."

One unexpected benefit from conducting the QI project "that we should have expected," says Ellis, "is that we became a project team." Their QI team included a physician champion, clinical manager, nurse, navigator, a single point of contact, and five staff responsible for data entry. "All of these people had to work seamlessly together," Ellis says. Another benefit from deploying the Model, she adds, is that "we got really good at figuring out how to communicate."

Continuing Impact

One year after the conclusion of the testing period, NWMS has kept the lay navigator model in place with two lay navigators and two RN case managers. The practice has a centralized triage with two first responders and two triage nurses and is continuing to scale the navigation program to all NWMS patients. Although the 12-month testing period did not result in a reduction in ER visits, NWMS has mined the QI project data to understand where opportunities to improve lie.

NWMS continues to track ER data to understand utilization trends and to seek solutions to the challenges of how best to meet these patients where they are. Another area NWMS would like to explore is possible approaches for improving patients' health literacy levels so that they are better motivated to participate in their own care.

As a step toward this, in early 2019 the practice implemented the Patient Activation Measure (PAM) survey. NWMS provides the 10-question survey during new patient orientation. The PAM survey gauges the patient's level of engagement in their healthcare, which NWMS anticipates will help to proactively assess patients more likely to have worse outcomes and flag those in need of more intensive support.

"I think it was extremely beneficial for our practice to participate as a Testing Site," say Ellis. "The support from ACCC...not just doing QI project but having the team support experiences outside of the practice. Because of the way we wrote our application and QI project, we had to create a very structured patient navigation program. We had to learn what navigation was, quality metrics in that space, that helped us. We had one clinical navigator before participating in the ACCC Care Coordination project. Testing the model through implementing a lay navigator helped NWMS learn how to build that program and formalize our navigation services."

REPLICABLE TAKEAWAYS

- 24-hour post-chemo infusion calls by nurse case manager to patients
- 24-hour post-hospital use calls to patients by nurse case manager
- Wellness screenings
- PHQ9
- NCCN Distress Thermometer
- Checking "PreManager" daily for ER use

Southern Ohio Medical Center, Southern Ohio Medical Center Cancer Center

Data Drives Process Improvement

Southern Ohio Medical Center (SOMC) in Portsmouth is a 234-bed non-profit healthcare organization serving rural southern Ohio and northern Kentucky. The hospital is located in Scioto County, an area classified by the Appalachian Regional Commission as economically distressed. The region has one of the highest smoking rates in the nation. Lung cancer incidence per 100,000 people in Scioto County is 71.8, compared to 67.2 (statewide) and 58 (nationwide). Lung cancer mortality rates per 100,000 people are 63 vs. 48 and 41 (statewide and nationwide, respectively).

The SOMC Cancer Center is accredited by the American College of Surgeons Commission on Cancer and has had a lung cancer screening program since 2015.

When the opportunity to apply to test the Care Coordination Model arose, the timing was ripe for SOMC, says Wendi Waugh, BS, RT(R)(T), CMD, CTR, Administrative Director of Cancer Services & Community Health and Wellness. "Several things were coming together within the organization," she recalls. "We had recently hired a talented thoracic surgeon, Dr. Jeremiah Martin. We'd started our lung-cancer screening program, but we didn't have many patients in our database. We wanted to reduce the stigma that lung cancer patients often experience, and we were passionate about identifying patients early when the patient's likelihood for cure was increased."

The cancer center had just finished the National Accreditation Program for Breast Centers (NAPBC) accreditation process, Waugh says, and fresh from that experience, "we recognized the difference engaging a team to focus on our breast cancer services had made. We had a physician champion in Dr. Martin, and we were looking for something to pull the team together." From the start, the SOMC Lung Health Leadership Team had commitment from leadership in coordinating departments (radiology, pulmonology, inpatient care) and buy-in for the QI project from the SOMC Executive Team.

Meaningful Measuring

Participating as a Testing Site for the Care Coordination Model "gave the team a good baseline to assess where we were with our program," says Waugh. The model also provided a framework for reference to look at future opportunities and set goals.

"We were already measuring detection-to-diagnosis and diagnosis-to-treatment elapsed days on our lung health dashboard prior to participating in the Care Coordination Model," says Waugh. "But it seemed like we had plateaued and the information was not granular enough to guide us to further improvement. I felt like we'd made the easy improvements." A critical area that remained unclear: Why and where were the delays in patients accessing care occurring?

Testing the Care Coordination Model offered SOMC the opportunity to conduct a QI project that could provide some clarity. In testing the Model, SOMC focused on the assessment area: patient access to care. The SOMC QI project would provide data on timeliness measures: detection-to-diagnosis (D to D) and diagnosis-to-treatment (D to T).

The project team at SOMC chose to study timeliness because they believed measuring and tracking of these metrics would be fairly easy to implement, and timeliness would serve as a surrogate for system efficiency. The QI project data could also potentially help support their requests for more resources and bring providers together to improve care for patients with lung cancer.

As Waugh and the team at SOMC discovered, however, measuring and tracking timeliness was not easy. The QI project required SOMC to create a more rigorous system for data measurement, abstracting data stored in different platforms, and to mount a significant team effort. "With the Model, we cast a wider net," says Waugh, "more discrete fields, better definitions. Our data went from giving us some information to giving us more accurate information."

Through the process of refining data collection and measurement, SOMC's QI project ultimately yielded a more reliable picture of the average time from detection-to-diagnosis and diagnosis-to-treatment for this patient population. "I learned so much from participating in testing the Model," says Waugh, "how to distinctly define dates, measures, and get all of us talking the same language."

Letting the Data Speak

The QI study testing the Model enrolled 105 participants (37% Medicaid Dual Eligibles, 40% Medicare, and 23% commercially insured). Medicare patients on average were older than age 70, while Medicaid patients were younger (median interquartile range [IQR], years). Nearly half (48%) of study patients were active smokers, 42% were former smokers, and 7% were never smokers.

SOMC's baseline data showed a median time from detection to diagnosis of 16 days, with no significant difference in timelines across insurance types. Diagnosis-to-treatment baseline data presented a similar picture: the time from diagnosis-to-treatment was not significantly different among different insurers.

The team at SOMC did identify a trend in their detection-to-diagnosis data: the more contact a patient had with the healthcare system, the longer the time to diagnosis. Simply

> **"What we created here gives us a real-time snapshot for the navigator to stay on someone who has had an abnormal finding."**
>
> **– Wendi Waugh, BS, RT(R)(T), CMD, CTR,** Administrative Director of Cancer Services & Community Health and Wellness

put, the more times the patients engaged with the healthcare system for any reason, the longer the delay to diagnosis. Fragmentation of care was one factor driving these delays.

Data from SOMC's QI project demonstrated positive results on three related quality measures:

- Clinical results tracked in EMR – 100% of study patients were captured (105/105)
- Bronchoscopy within 7 working days of decision to perform – 89.7% (35/39)
- Histologic subtype included on pathology report – 100% (102/102)

Waugh attributes a transformative programmatic impact to SOMC's participation in testing the Care Coordination Model. Prior to working with the Model, the SOMC care process for lung patients was fragmented, says Waugh. Learnings from conducting the QI project provided a framework for improvement and demonstrated how key navigation is to efficiency and to reaching patients.

Over the 12-month period that the SOMC team conducted its QI project using the Model, the program created a video spot for local TV with a different approach to encourage screening for lung cancer. Rather than focusing on negative health consequences, the video asked patients to reflect on what they value in their lives, and to consider screening so they can be there for their families and what matters most to them.

Although the focus of SOMC's QI project was measuring timeliness, working with the Model organically created a natural progression toward recognizing that additional navigation resources were needed. "Data showed that the patients were out there in the community," recalls Wendi Waugh. "The challenge was figuring out how to help patients come into the health system." Team building and team learning were positive side effects of working with the Model.

It became a complex project, says Waugh: "We learned a lot from the foundation for setting up [the QI project]. We still use that baseline spreadsheet that we developed during the Model testing period to track the measures we report out now."

"We had navigation on the screening side for lung cancer," says Waugh. "With the QI project findings, we were able to make the case to the executive team to add navigation to treatment and to assist those with incidental findings. We went from assisting a small percentage of our lung cancer population to assisting all of our lung cancer patients."

From refining the data collection and reporting process, navigators now use the tool to improve access, says Waugh. "What we created here gives us a real-time snapshot for the navigator to stay on someone who has had an abnormal finding." Through the testing experience, SOMC lung navigators now have a map to ensure that patients have "effective appointments" with a focus on how much can be scheduled in one day.

Reflecting on SOMC's experience in using the Model for QI, Waugh says, "I think it shaped our lung cancer care program. It helped us make the financial case to add lung navigation resources. It initiated the formation of a comprehensive lung cancer leadership team. The networking and value that we found continues today."

Since the conclusion of the testing project, several initiatives are underway at the direction of the lung health leadership at SOMC, including increasing access to smoking cessation support, enhancing access to clinical trials related to smoking cessation, and developing an organizational mechanism for providers to write an order for patients to stop smoking.

Testing the Model took a commitment of time and effort, and Waugh admits, "I really didn't know what we were getting into." It can be daunting to undertake this work, when "we're so pressed for time as administrators," she says, "but I think you just have to go for it. I'm happy to talk to anyone about the experience, because there's always something to be learned from each other."

REPLICABLE TAKEAWAYS

- Process mapping/following the patient can serve as a surrogate for patient access to care.
- Navigation is critically important, but will likely be slightly different at every program.

Virtual Toxicity Team Johns Hopkins University

Managing Immunotoxicities in a Virtual Space

This article explores Johns Hopkins University's unique approach to recruiting specialists outside the field of oncology to participate in its virtual immune-related Toxicity Team.

In 2015, when Jarushka Naidoo, MBBCh, began working at the Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins University, she joined one of the first institutions to use immunotherapies to treat intractable cancers. As she began treating her patients with immune checkpoint inhibitors, Dr. Naidoo—an assistant professor of oncology within the Bloomberg-Kimmel Institute of Cancer Immunotherapy—observed that after starting immunotherapy, select patients developed autoimmune disorders that required expertise outside the realm of oncology.

'It became obvious that there was a critical need to work closely with organ specialists," says Dr. Naidoo. "Many autoimmune diseases affect organs that oncologists don't specialize in."

Given the significant number of immunotherapy patients who were developing arthritis, Dr. Naidoo and her oncology colleagues, including Joanne Riemer, RN, BSN, senior research nurse within the Upper Aero-digestive Team at Sidney Kimmel Comprehensive Cancer Center, enlisted the expertise of Hopkins' rheumatologists to help diagnose and treat patients who were manifesting rheumatic immune-related adverse events (irAEs). This experience led the group to publish its first "algorithm" to help providers outside of Hopkins diagnose and manage patients who develop this side effect from immunotherapy. But since immunotherapies can affect any organ system, Hopkins' oncologists needed to tap into the expertise of other specialists as well. "We recognized the tremendous value a multidisciplinary team of organ specialists could bring to the treatment of patients experiencing adverse events," says Dr. Naidoo. She helped recruit other specialists, and the Johns Hopkins Immunotherapy Response Toxicity Team (IR-Tox Team) was born.

The Evolution of a Team

Hopkins' original toxicity team had representatives from eight medical specialties. Over the years, Dr. Naidoo helped recruit additional specialists, and the team grew. In addition to medical oncologists and oncology nurses, the team has specialists in rheumatology, endocrinology, cardiology, dermatology, neurology, hematology, pulmonology, ophthalmology, gastroenterology, and infectious disease. Each specialty is represented by two to four clinicians. Dr. Naidoo adds that her team also recognized the importance of adding allied health professionals—including pharmacists, radiologists, and pathologists—to the team. Team members help field the diagnostic and treatment questions posed by nurses and physicians who encounter irAEs in their patients.

The virtual element of Hopkins' toxicity team is a unique and important component of the group. Both referring oncology providers and IR-Tox Team members recognized at the outset that IR-toxicities can occur at unpredictable times. Given the size of the team, members needed an efficient method of triaging clinical questions as they were received. An electronic system would provide the flexibility and capability needed to call on individual organ specialists only when their specific expertise was required.

"At first, we just started adding to this group of people who we could call when necessary," says Dr. Naidoo. "Access to specialists and an ongoing dialogue between them and oncologists is critical. But we needed an easy-to-use method for matching queries with the team members who had the expertise necessary."

Going Virtual

Dr. Naidoo and Laura Cappelli, MD—assistant professor of medicine in the Division of Rheumatology at Johns Hopkins School of Medicine—created an electronic referral template that could be used by clinicians seeking consultation from Hopkins' IR-Tox Team. The form requests relevant patient information, including demographics, tumor type, immunotherapy regimen, and clinical course. Referrals are first accessed by the IR-Tox Team's oncologists, who either answer the question themselves or triage it to the appropriate specialist(s).

Members of Hopkins' virtual IR-Tox Team access questions and conversations via a password-protected email listserv. "Anybody who is part of the cancer center—any oncologist, oncology nurse, nurse specialist, physician assistant, or trainee—can refer to us," says Dr. Naidoo.

Hopkins' IR-Tox Team receives up to four referrals per day, totaling approximately 250 to 300 patients per year. Once a referral request is entered into the system, members

of the toxicity team make recommendations or leave comments, often leading to virtual discussions as different team members weigh in on individual cases.

Twenty-four hours after a referral has been submitted, the IR-Tox Team leaders send a summary of the recommendations or comments left by the team's members to the referring provider. Discussion about particularly complex cases may continue for longer than a day, in which case the team follows up with the referring provider. Dr. Naidoo says she is currently exploring how to formalize the team's responses so recommendations can be captured in patients' electronic medical records.

In a 2019 study, Dr. Naidoo and her colleagues evaluated the effectiveness of Hopkins' virtual toxicity team.[1] During an eight-month period in 2018, the team received 122 referrals, all of which they responded to within 24 hours. All surveyed providers who contacted the team said they used all or some of the team's recommendations, and most (74%) said they changed their patient management based on those recommendations.

Face to Face

Hopkins' IR-Tox Team complements its virtual interactions with monthly in-person meetings. There, members of the team discuss complex cases they previously addressed in the virtual environment. The gathering is also an opportunity for members to bring up clinical or research initiatives that may be relevant to the team's work. Riemer says team members educate one another on the immunotoxicities they see in their specialty areas. "We have offered CME-accredited irAE master classes," says Riemer, "in which each of the toxicity team specialists gives an overview of organ-specific toxicities and how they should be managed."

But while in-person meetings can be an effective platform for exchanging information and ideas, they are not always practical for a large multidisciplinary team. "And since many cases we receive are happening in real time, time is of the essence," says Riemer. "A monthly meeting won't help an acute patient. We need our electronic system to bridge that gap."

Current Limitations

Dr. Naidoo says the electronic referral system she has helped create can address potential adverse events quickly, with the referring physician making the ultimate patient care decision after receiving feedback. Although she believes telemedicine is an "obvious next step" for toxicity teams, Dr. Naidoo acknowledges that significant barriers remain. These include the uncertain availability of specific specialists, the difficulty of convening specialists on complex cases, and the unpredictability of irAE timing.

Ultimately, telemedicine may be the only method through which smaller cancer programs can access the expertise of a multidisciplinary toxicity team. "Many of our community colleagues do not have access to a pulmonologist who can perform a bronchoscopy or a GI specialist who can perform a colonoscopy at the drop of a hat," says Dr. Naidoo. "And many immunotherapy-treated patients need those services."

Dr. Naidoo recommends that cancer programs with fewer resources identify their most pressing needs and then seek out the specific specialists who can address them. "Perform a comprehensive audit by assessing your past referrals and hospitalizations and identifying the specific irAEs your patients develop," says Dr. Naidoo. "This can help prioritize which specialists can most help your patient population."

Dr. Naidoo also advises practices to reach out to specialists in their local areas and try to incentivize them to treat their patients. "That could take the form of hiring a specialist for a certain number of hours or giving them a clinic slot in your center," she explains.

Long-term Goals

As the number of immunotherapies increase and more patients are able to access them, more people will recognize the importance of multidisciplinary toxicity teams in cancer care. "The only way to adequately address this issue is to develop a critical mass of experts in irAEs and hire them to manage these patients," says Dr. Naidoo. "We need more organ specialists to service the needs of a growing group of patients. We need to create educational opportunities, such as immune-related toxicity fellowships."

But Dr. Naidoo admits that this long-term solution will take time. "We have to think outside the box for now," she says. The first step is to educate patients, providers, and family members about irAEs and the importance of multidisciplinary toxicity teams in cancer treatment. "To truly make this a practice-changing approach, we need to spread the word," Dr. Naidoo says. "By capturing our own program's data and examining our outcomes, Hopkins is taking steps to do just that." ▲

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Virtual Toxicity Team Jefferson Health

Networking for Health

This article explores how Jefferson Health is taking a unique approach to recruiting specialists outside the field of oncology to participate in an Immuno-oncology Working Group.

At Jefferson Health, detecting, diagnosing, and monitoring the irAEs that immunotherapy patients can manifest during treatment is a group effort in a virtual space. Rather than meeting in person at a designated location and time each week or month, the 11 members of Jefferson's Immuno-oncology Working Group meet online on an as-needed basis. Doing so, says Melissa Wilson, MD, PhD—associate professor of medical oncology at Thomas Jefferson University School of Medicine and clinical director of the biorepository—gives working group members the flexibility to respond to queries when they occur without having to shift their schedules.

'We communicate by phone, email, text, or we message one another in Jefferson's EMR," explains Dr. Wilson. "Everyone is very responsive, especially if we send them a question about a specific toxicity. They are very good about communicating their findings and their thoughts to us."

Dr. Wilson says Jefferson's Immuno-oncology Working Group, formed in late 2017, has specialist representatives from pulmonology, dermatology, gastroenterology, neurology, cardiology, nephrology, rheumatology, endocrinology, and hepatology. Which working group members are called upon when a case arises depends on the nature of the side effect in question. Dr. Wilson says that, typically, individual group members personally counsel the clinician who poses a question. "It's usually a one-on-one interaction unless the issue is multifactorial," she says. "Then everyone chimes in."

Dr. Wilson says working group members respond to referrals promptly, resolving them the same day they are received. She estimates that the group fields four to five referrals a week, totaling approximately 20 per month. For referrals that require a face-to-face patient consult, Dr. Wilson says several specialists have built patient slots into their clinic hours for irAE emergencies.

Building a Network

Like those of other healthcare systems, Jefferson Health's Immuno-oncology Working Group grew organically as oncologists using IO therapies reached out to their colleagues for consultation on the side effects they saw. "It grew from having to reach out to our specialist colleagues when we needed their expertise," says Dr. Wilson. "You start to learn who has research interests in this area, and you begin to connect with the individuals most likely to be interested in helping you."

But oncologists who want to assemble a multidisciplinary IO group may not always have colleagues in specialty departments. Tracy Virgilio, RN, MSN, CCRC, OCN—an oncology nurse manager and co-chair with Dr. Wilson of Jefferson's Immuno-oncology Working Group—says oncologists who are seeking expertise in a specialty with which they are unfamiliar should approach relevant department heads to try to identify the individuals most likely to have an interest in

treating immunotherapy adverse events. "If you start with someone enthusiastic about working with irAEs, you can build on that enthusiasm," says Virgilio.

Networking and building professional alliances in this area is key, affirms Virgilio, since irAEs can manifest in so many organs. Maintaining these relationships is vital," she stresses. "I was able to capitalize on our own built-in group recently when we opened an immuno-oncology clinical trial for patients with underlying autoimmune disorders. The trial requires a specialist from each organ site to be a PI on the study, and I was able to recruit them using connections I had already established in the working group."

Cultivating Contacts

Dr. Wilson recognizes that Jefferson Health is fortunate to have a wealth of specialty expertise from which to draw when dealing with irAEs. For oncologists who do not have a multi-specialty working group with which to consult, Dr. Wilson recommends designating the effort to physician champions who want to take on the responsibility of leveraging their professional networks for the purpose of cultivating resources for potential irAE consultations. "People are increasingly recognizing that immuno-oncology is a medical field in and of itself," says Virgilio. "Having someone who sees this and wants to forward that work would be a great spearhead for developing an immune-response team."

For smaller oncology practices unsure of where to look for specialist expertise for their immunotherapy patients, Dr. Wilson encourages them to contact nearby large medical centers. "Talk to the heads of the departments you are interested in and start networking," advises Dr. Wilson. "Identify a point person whom you can call and ask for advice about specific toxicities. Setting up calls and asking for introductions can help you build interest and momentum."

Creating Algorithms

Before gathering and making available the expertise of Jefferson's working group, Dr. Wilson says her colleagues began putting into place methods of alerting non-oncologists about the possibility of encountering irAEs in their patients. "First off, we built a flag into the EMR so, when patients called in, people could see whether or not they were on immunotherapy," says Virgilio. To help clinicians deal with irAEs once they were identified, oncologists at Jefferson developed and distributed algorithms for use by all of the health system's clinicians when they were faced with immunotherapy patients experiencing adverse events. "We recognized that not everybody would know how to deal with IO side effects," says Dr. Wilson. "Early intervention and management are essential to keep them from getting any worse. We needed a way to efficiently disseminate information when physicians are faced with these scenarios."

Dr. Wilson says the algorithms go beyond identifying irAEs; they also indicate care plans: "If a provider thinks there is an irAE, they can look at the algorithms to determine which specific tests to run, depending on the organ system that may be affected by these drugs. If they determine that the problem is a side effect, there are initial guidelines on management, which they can escalate to interventions depending on the severity of the situation."

As other clinicians have become aware of irAEs through the use of the algorithms, Dr. Wilson says more physicians have become interested in immunotherapies and their possible side effects. "We are asked to give talks on the topic," says Dr. Wilson. "One of our colleagues has given a grand rounds on irAEs, and more people are learning about our virtual tumor board. More of our specialists are being called on for their advice." Although Dr. Wilson is not collecting data on the impact of the efforts of the Immuno-oncology Working Group, she says that she has seen the number of ER visits and admissions in response to irAEs decrease. She says this is a result of more clinicians referring IO patients to same-day clinic visits rather than the emergency department (ED), and of Jefferson's "Call First" initiative, which instructs IO patients to first call their oncologist before heading to the ED.

Dr. Wilson says that, in the future, she can see the need for the Immuno-oncology Working Group to meet in person on a regular basis: "Perhaps something that's monthly or quarterly, in which all the doctors involved can discuss cases in general and share their own personal experience with this effort. Everybody's time is precious, but this effort is having a tremendous effect on our patients." ▲

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Virtual Toxicity Team Cleveland Clinic

It Takes a Village

This article explores how Cleveland Clinic is taking a unique approach to recruiting specialists outside the field of oncology to participate in immunotherapy multi-specialty immune-related adverse events (irAE) tumor boards.

According to Pauline Funchain, MD, the right champions are essential to attracting the interest of specialists in the adverse events that immunotherapy patients can manifest during treatment. The key, says Pradnya Patil, MD, is to recruit physician champions who are not oncologists.

Drs. Funchain and Patil co-chair the tumor board at Cleveland Clinic that addresses irAEs. When first assembling the tumor board, they found it difficult to maintain interest among the specialists they were targeting. "We kept trying to get a multidisciplinary team together, but we couldn't sustain it," says Dr. Patil. "It wasn't until someone outside of oncology championed our cause that other specialists began to take an interest."

'When we reached out to specialists ourselves, they'd agree that something needed to be done," adds Dr. Funchain. "But it didn't go any further than acknowledging these patients existed. It took rheumatologists getting interested in the immunotherapy side effects they were seeing in their own patients to spread the word. Once that happened, it catapulted the whole thing."

Dr. Funchain explains that while appointing specific champions can be beneficial to recruiting a multidisciplinary irAE team, it's ideal when champions are self-motivated. "For us, it happened organically," says Dr. Funchain. "We tried to get people to be champions for our board, but it worked better if they *wanted* to be champions, rather than us trying to put a crown on somebody."

Spreading the Word

Drs. Funchain and Patil launched Cleveland Clinic's monthly irAE tumor board in September 2017. Their goal was to obtain specialist opinions about the side effects their immunotherapy patients were experiencing and to review the latest literature from the rapidly evolving field.

The original irAE tumor board consisted of a handful of oncologists and rheumatologists with specific research interest in immune-related toxicities. Since then, the board has grown to include specialists in gastroenterology, endocrinology, cardiology, infectious disease, urology, pulmonology, and hepatology. Dr. Funchain says additional specialists sit in on meetings if their specific expertise is required. Approximately 15 to 20 people attend each meeting.

"We've tapped the knowledge of specialists who have dealt with natural autoimmune conditions that resemble what immunotherapies can do to patients," says Dr. Funchain. "They can pull tricks out of their hats that we as oncologists don't necessarily think of."

Dr. Patil adds that the tumor board draws attention to the more urgent care immunotherapy patients may require. "Autoimmune diseases tend to build gradually," explains Dr. Patil. "They don't happen overnight. But for some of these cancer patients, autoimmune toxicity does literally occur overnight, and trying to get an expert opinion right away can be a challenge."

Conveying that immediacy to specialists has proven problematic. Recruiting and retaining non-oncologists who appreciate the importance of quickly identifying and treating cancer patients experiencing immunotoxicities has helped other specialists understand why immunotherapy patients may require their services right away.

Making Connections

Each month, Cleveland Clinic's irAE tumor board meets to discuss an average of six to seven cases. Before the conference, Dr. Patil assembles a synopsis on each patient based on the information provided by his or her referring doctor. She reaches out to the appropriate specialists a week

before the meeting to alert them that their expertise will be needed. If an opinion is required before the board's scheduled meeting date, Dr. Patil asks for a recommendation upon receipt of her message, or—if necessary—she requests a patient appointment right away.

One of the things this tumor board has really done is help others realize that there are some cases that can't wait a month," says Dr. Funchain. "Now that we're several years into this effort, we've gotten some of our colleagues to save same-day spots if they are needed by our immunotherapy patients."

During the tumor board's monthly meetings, most members attend in person. "It's nice to have the specialists physically there," says Dr. Patil. "But sometimes people cannot join us in person due to scheduling conflicts. So we share a slide deck with them, and they join remotely."

Dr. Funchain agrees that professional interaction among participants has strengthened the effectiveness of Cleveland Clinic's irAE tumor board. The virtual conversations among board members that sometimes precedes in-person meetings can be invaluable, she adds: "Talking about the cases before and after we meet has led to discussions about how we can make the clinical practice better."

Soliciting Feedback

Dr. Funchain says she has personally seen the positive impact of the tumor board's recommendations on her melanoma patients. "The tumor board has been invaluable for our patients," she says. "We've had discussions about drugs that we never would have thought of otherwise." Being able to proactively solicit specialists' opinions has enabled Dr. Funchain and her colleagues to anticipate side effects before they occur and coordinate appointments with oncologists and specialists.

Most of the physicians who have referred cases to the irAE tumor board believe their patients have benefited from its recommendations. In response to a 2018 survey of referring physicians on their experience with the board, more than 66 percent of respondents reported a significant increase in their awareness of the scope and presentation of irAEs, and nearly 42 percent reported significantly increased confidence in diagnosing and managing certain irAEs.

Dr. Funchain and her colleagues are in the midst of compiling metrics to determine whether recommendations by tumor board members have influenced patient treatment and whether any subsequent clinical decisions have led to more positive outcomes. "We do get a sense that patient management after tumor board discussion does change to some degree," says Dr. Funchain, "but we haven't quantified that yet."

Educating One by One

For cancer programs that want to establish their own multidisciplinary irAE tumor board, Drs. Funchain and Patil recommend approaching the effort as a grassroots project and letting it grow organically. They emphasize the value of making personal connections with the specific specialists identified for recruitment.

"Medicine is like anything else," says Dr. Funchain. "If you sit down and talk to someone face to face, you make a much better connection than if you just send out an email saying, 'We've had these cases, would you be interested?' It's about starting a conversation."

When they set out to assemble their tumor board, oncologists at Cleveland Clinic adopted a divide-and-conquer approach in which they assigned themselves to specific specialties and then sought to connect with the specialists they wanted to recruit.

Making those personal connections, says Dr. Patil, ties into the education effort that many oncologists must undertake to expand understanding of immunotherapy drugs and how patients experience their side effects. To better accomplish this, oncologists at Cleveland Clinic have developed a CME course directed at non-oncologists to teach them about the management of immune-related toxicities in cancer patients.

But education doesn't always have to take a formal route. Dr. Funchain says she takes every available chance to educate the physicians she comes into contact with about immunotherapies and their side effects. She says such opportunities have presented themselves when she is contacted by emergency medicine physicians about oncology patients who present in the ER with irAEs.

"I explain that these are immunotherapy patients who can manifest anything that looks like an autoimmune disease,'" says Dr. Funchain. She keeps her explanations intentionally short, which can trigger follow-up questions. "People say, 'Oh, what's that?' which enables me to start a conversation that they've prompted."

Brief interactions such as these can lead to piqued interest and wider understanding among those who want to learn more. "At least the people who care enough to learn about it, they will ask," says Dr. Funchain. "And that's a start." ▲

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Houston Methodist Hospital, Houston Methodist Cancer Center, Texas Medical Center
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Delegate Rep: Jennifer Berry, DNP, RN, NE-BC
Website: houstonmethodist.org/cancer/locations/texas-medical-center/

Memorial Oncology & Hematology
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Delegate Rep: Amy Higinbotham, BSN
Website: memorialohio.com/locations/memorial-oncology-hematology

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Website: mercy.com/locations/hospitals/toledo/mercy-health-perrysburg-hospital

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Mercy Health-St. Elizabeth Boardman Hospital
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Website: mercy.com/locations/hospitals/youngstown/mercy-health-st-elizabeth-boardman-hospital

Mercy Health-St. Rita's Cancer Center
Lima, Ohio
Delegate Rep: Paul Clemments, BSRT (R)(T), MS
Website: mercy.com/locations/specialty-locations/cancer-care-oncology/oncology-specialists-of-st-ritas

Mercy Health-St. Vincent Holland Sylvania Cancer Center
Toledo, Ohio
Delegate Rep: Paul Clemments, BSRT (R)(T), MS
Website: mercy.com/locations/hospitals/toledo/mercy-health-st-vincent-medical-center

Scotland Memorial Hospital, Scotland Cancer Treatment Center
Laurinburg, N.C.
Delegate Rep: Paula Love, RN, BSN, CLNC
Website: scotlandhealth.org/medical-services/cancer-center-duke-health-affiliate

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Salt Lake City, Utah
Delegate Rep: Amy Pasmann, MS, RN
Website: utahcancer.com

2020 ACCC Oncology Reimbursement Meetings

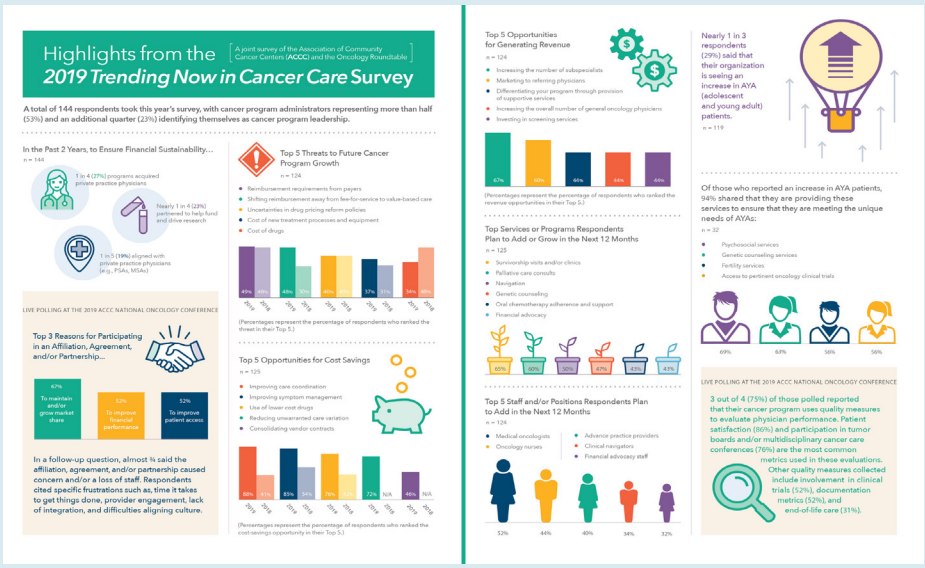
You will gain the tools you need to strengthen your program's operations, accelerate your knowledge in oncology business, and take on a rapidly changing healthcare landscape. At these one-day meetings:

- Review the latest trends in oncology coding and billing based on the CY 2020 Medicare HOPPS and MPFS Final Rules
- Assess financial strategies to track and improve the financial health of your cancer program or practice
- Gain insight on upcoming coding and reimbursement challenges related to financial counseling, compliance, and authorizations in medical and radiation oncology
- Identify opportunities to improve the financial navigation services at your practice or program.

Best of all, these essential meetings are FREE to ACCC and Oncology State Society members. Non-members are invited to attend at the low registration rate of $155. Register today at accc-cancer.org/ORM.

Discover the Latest Trends in Cancer Care

Now in its tenth year, the ACCC 2019 Trending Now in Cancer Care survey provides much-needed perspective on the strengths and challenges experienced by cancer programs across the country, as shared with us by more than 140 respondents. ACCC members can use this valuable information as a benchmarking tool and as justification for adding additional services. This year, members can also access comprehensive national report data and cohort comparative analyses online at accc-cancer.org/trends.



Some key highlights from this year's survey include:

- Nearly half of respondents reported that payer reimbursement requirements are a leading deterrent to cancer program growth.
- Almost 90 percent of respondents see improving care coordination as a top opportunity for cost savings.
- Fewer than half of respondents use telehealth to conduct tumor boards.

Download this year's Trending Now in Cancer Care infographic to learn what our members are saying and listen to the February episode of the CANCER BUZZ podcast, where we'll dive even deeper into the survey! accc-cancer.org/podcast.

Bristol-Myers Squibb provided funding to ACCC for the 2019 Trending Now in Cancer Care survey.

The Hairstylist Melanoma Challenge

BY SANDY ALLTEN, RN, OCN, CCRP

Though recent improvements in metastatic melanoma treatment are encouraging, we know that prevention or detection at an early stage remains the ultimate goal with this potentially deadly skin cancer.

In 2017 Neda R. Black, MD, published a research report in *JAMA Dermatology* on the promising work she and others had done educating hairdressers on the "ABCDE's"—a set of standardized criteria to detect melanoma—of the scalp, head, and neck.[1] As an oncology nurse, this innovative approach made so much sense to me. Who knows your head better than your hairdresser? If your hairdresser received training in the detection of skin cancers of the scalp, head, and neck, he or she could become the first line in detection.

First Contact

I reached out to Eyes on Cancer (eyesoncancer.org), an educational program developed by SkyMD, Inc., which collaborated on Dr. Black's project. SkyMD is a telemedicine-driven company that allows patients to upload photos of skin disorders to an online platform where a board-certified dermatologist can diagnose, propose treatment, and may even prescribe medication. Eyes on Cancer was founded by a husband and wife team, health professional Dean Foster, MD, and beauty professional Jeanne Braa Foster, who both knew that a collaboration between the health and beauty world could be beneficial. Its mission is to educate beauty professionals about skin cancer detection. The Fosters were extremely inspiring and introduced me by phone to their dynamic program manager Yvette Williams, who now runs the Eyes on Cancer program.

I learned that Eyes on Cancer provides a 20-minute online educational video about the different types of skin cancer with photos of each kind, a melanoma lesion photo reference card within the video, and an online 35-question post-test. When finished, hairdressers can print and display a certificate of completion in their salon.

The Eyes on Cancer video emphasizes that it is not the role of the hairdresser to diagnose skin cancer. The only goal is awareness. If a suspicious lesion is spotted, hairdressers are asked to encourage their client to follow up with a physician or dermatologist to get it checked out. Hairdressers can also offer to take a photo of the lesion if it is in a place that the client cannot see, like the back of the head or neck.

Passing It On

I decided to spread the word starting with my own hairdresser. I watched the video and then gave the link to my hairdresser, Lisa Lowe Gaddis, to complete. She agreed to watch it and has since become a wonderful ambassador for the training. She saved the photo page of skin cancer examples to her smart phone for easy reference when she is on the job. Lisa's family has been touched by cancer and she is proud to participate in this program.

"Saving lives is always in style," she says. Lowe Gaddis mentions that her clients tell her that they are not only grateful for a great haircut, they are thankful that she is looking out for their skin health, too. "Our clients know that we care about them … not just their hair," says Lowe Gaddis.

The idea for the Hairstylist Melanoma Challenge began in December 2018. It was easy for my hairdresser and I to participate in the Eyes on Cancer online class, quiz, and certification. If we could do it so quickly and easily, why not engage others to do it by challenging them on social media? I presented this idea to my local Oncology Nursing Society (ONS) chapter and to my employers at AdventHealth. Both groups enthusiastically endorsed the project. I thought the good-natured social media challenge of the successful ALS "Ice Bucket Challenge" would be a good model to adopt.

Setting the Challenge

Eyes on Cancer typically charges $10 for each hairdresser to take the class. AdventHealth Cancer Institute Daytona Beach applied for and received a grant from the Bill Walter III Melanoma Research Fund to pay for free unlimited use of the online program passcode (ONCRN) so that no one participating in the program would have to pay. The goal of this grant is to use the well-established Eyes on Cancer educational program to train as many hairdressers, oncology nurses, and AdventHealth staff members as possible.

Our next move was determining how we could spread the word about the Eyes on Cancer program. We engaged my local ONS chapter and AdventHealth employees to act as conduits to spread the word about the Hairstylist Melanoma Challenge. Eyes on Cancer would then document the numbers of hairdressers trained with our code.

The board of our local ONS Chapter, East Central Florida ONS, worked with our cancer program staff to make this a chapter mission project. ONS members were

encouraged to watch the video and take the test. Then, they were tasked with giving a coupon code to their own hairdresser for free registration to the online class. The hope was that once we engaged the hairdressers in our region to participate in the challenge, we would inspire other ONS chapters around the country to do the same.

AdventHealth Daytona's marketing department championed our cause and spread the word about the Hairstylist Melanoma Challenge in local newspapers and TV coverage. The East Central Florida ONS chapter reached out to other chapter presidents in northern Florida to join in the challenge.

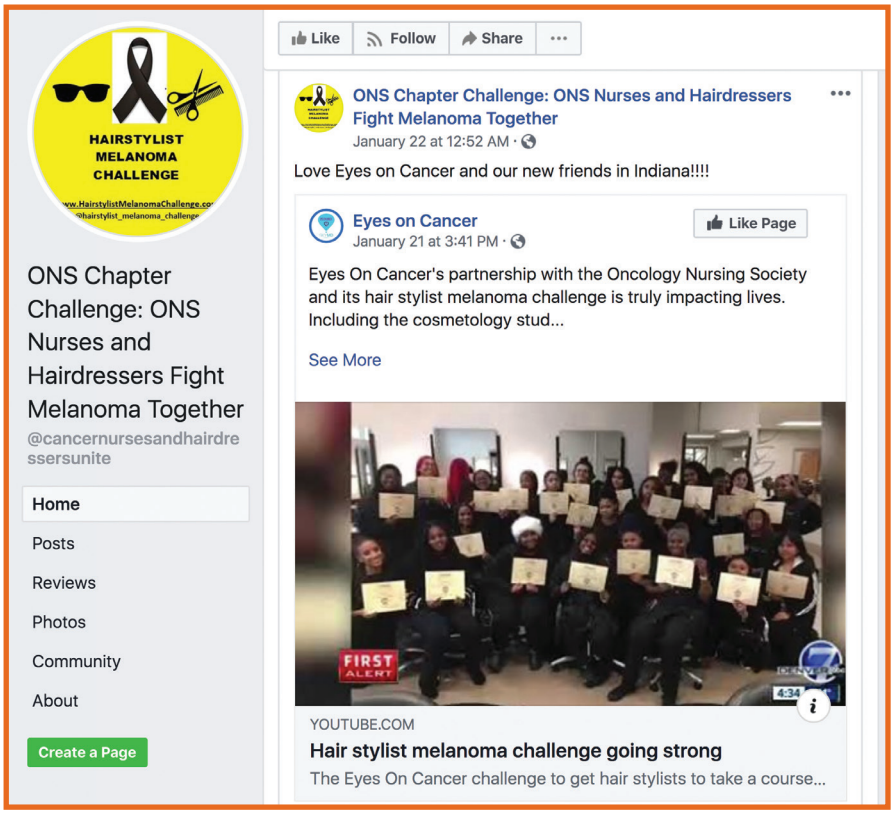
To encourage participation, we designed our own challenge website (HairstylistMelanomaChallenge.com) and Facebook page (facebook.com/cancernursesandhairdressersunite).

We originally thought that by having participants post a selfie with their certificate on our Facebook page, the challenge would catch on quickly. We have since found that people are participating but not always posting. Each month Eyes on Cancer gives us the name of all participants who use our code, so we can post those on our Facebook page.

At AdventHealth Daytona, we are following up the momentum of this challenge by offering a free skin cancer screening to all members of our community, including those hairdressers whom we have met through this project. In addition to benefiting our community, the Hairstylist Melanoma Challenge has brought programmatic benefits as well: AdventHealth Daytona is using the combination of the challenge and free skin screening as one of its community outreach projects for Commission on Cancer accreditation.

Gaining Momentum

I presented a poster on the Hairstylist Melanoma Challenge at the 2019 ONS Congress and received great feedback. Over and over we heard, "What a great idea!" Patty Higgins, RN, OCN, in Indiana heard about our project and immediately took the



Eyes on Cancer video class. She then started training beauty school students in her town. This is our dream in action.

There are currently 39,000 ONS nurses. If each ONS nurse encouraged his or her own hairdresser to participate, the numbers would be staggering. With approximately 39,000 hairdressers seeing potentially 6 to 12 clients per day, we could be affecting positive change in hundreds of thousands of people daily.

We are slowly contacting ONS chapter presidents around the country to see whether they are interested in joining the Hairstylist Melanoma Challenge. We urge ONS national to help us spread the word about this mission. Imagine what we could accomplish as a collective.

We continue to urge friendly competition between salons and have started to share our Hairstylist Melanoma Challenge at local beauty school programs. For example, we have had a wonderful response watching the video and talking about melanoma with the students of Daytona College.

Eyes on Cancer has educated more than 10,000 participants through its online video and test combination. The Hairstylist Melanoma Challenge has added 150 participants to that number in 2019. Eyes on Cancer's goal is to have 20,000 participants educated by the end of 2020.

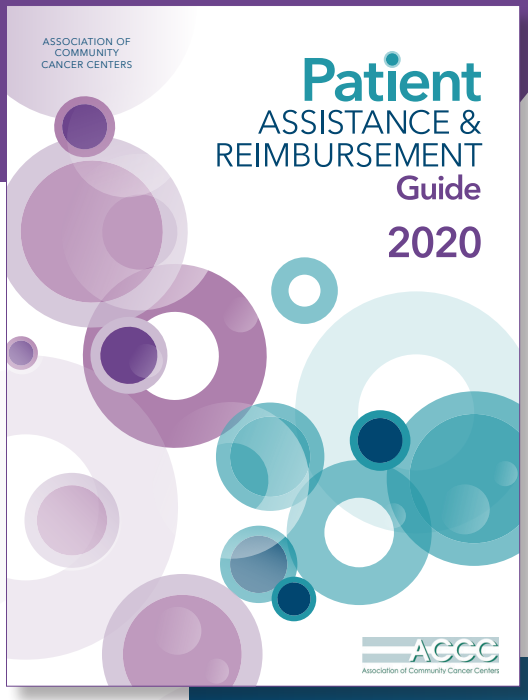
We invite ACCC members to join us! Please go to our website, enter the free code, watch the video, take the quiz, and then encourage others to join the challenge, too. Thirty minutes of your time could save a life, and saving lives is ALWAYS in style. OI

Sandy Allten, RN, OCN, CCRP, is a research coordinator at AdventHealth Daytona Beach.

Reference

1. Black NR, O'Reilly GA, Pun S, Black DS, Woodley DT. Improving hairdressers' knowledge and self-efficacy to detect scalp and neck melanoma by use of an educational video. *JAMA Dermatol.* 2018;154(2):214-216.

Help patients find the financial assistance they need.



Find the latest patient assistance information, including the addition of a table of contents that organizes medications by their administration type and an encompassing list of all oncology-related medications.

Download the most up-to-date version at accc-cancer.org/PatientAssistanceGuide

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** or call 301.984.9496. Join our social media communities; read our blog, ACCCBuzz; and tune in to our podcast, CANCER BUZZ.

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