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contents

DEPARTMENTS

Asking the Right Questions

BY JENNIE CREWS, MD, MMM, FACP

Across the continuum of oncology care, our patients' outcomes depend on many factors: living a healthy lifestyle, undergoing screening tests, receiving and adhering to treatment, and managing toxicities and comorbidities. These factors, in turn, depend on social determinants of health, such as access to care, safe housing, food security, and social support. Addressing the social determinants of health requires appropriate screening, involvement of multidisciplinary teams, extending payer benefits to these determinants, and providing services that fall outside of traditional medical care.

Within primary care, many professional societies are now recommending universal screening for social determinants of health. We are fortunate in oncology that routine distress screening is widely performed and often includes questions pertinent to these determinants. Yet, we have an opportunity to tailor questionnaires to better capture specific elements of social determinants of health, such as food security and housing needs. A recently reported survey of cancer patients in New York City showed that housing needs across six categories (cost, home loss, stability, conditions, accessibility, and safety) were often interrelated and emerged both before and after a cancer diagnosis.[1] A study of primary care patients found that 40 percent had food insecurity.[2] These studies highlight the need to ensure that we are asking the right questions of our patients. Fortunately, there are numerous validated social determinant screening tools that can enhance oncology screening tools.

With screening comes the responsibility to address identified needs. A survey of 154 physicians indicated that doctors are supportive of screening for social determinants of health, but 66 percent are not confident in addressing needs and believe that social workers are better equipped to do so.[3] The oncology multidisciplinary team is well positioned to address these issues with participation of nutritionists, navigators, and social workers. These professionals do an extraordinary job of creating internal programs or identifying community resources to meet patient needs and are extending that expertise in ways that specifically address social determinants of health. For example, 2019 ACCC Innovator Award recipient New England Cancer Specialists partners with a food bank to address food security issues.

Participation by government and private payers is also necessary, and their involvement must extend beyond covering access to medical care. Even in Canada, where universal healthcare is available, patients who screened positive for social determinants had lower utilization of health services and worse management of disease.[4] In the United States, payer involvement in social determinants of health is just beginning. United-Healthcare and the American Medical Association are partnering to standardize collection and integration of *International Classification of Diseases*, Tenth Revision data to assess these determinants. The Centers for Medicare & Medicaid Services now allows Medicare Advantage plans to cover meal delivery, transportation, and home cleaning services; however, lack of additional funding has dampened adoption and there is significant regional variability in funding for non-medical benefits to address social determinants of health.

Addressing the social determinants of health can lessen the burden of cancer, not only for those currently diagnosed but also for the 40 percent at risk due to modifiable lifestyle factors. Success depends on healthcare professionals, payers, government, and nonprofit agencies collectively acknowledging our responsibility and coming together to create solutions. OI

References
1. Phillips S, et al. "You have to keep a roof over your head": a qualitative study of housing needs among patients with cancer in New York City. *J Oncol Pract*. 2019;15:e677-e689.
2. Berkowitz SA, et al. Addressing basic resource needs to improve primary care quality. *BMJ Qual Saf*. 2016;25(3):164-172.
3. Schickedanz A, et al. Clinician experiences and attitudes regarding screening for social determinants of health in a large integrated health system. *Med Care*. 2019;57:S197-S201.
4. Katz A, et al. Association of the social determinants of health with quality of primary care. *Ann Fam Med*. 2018;16:217-224.

Chemotherapy Stewardship

BY ALI MCBRIDE, PHARMD, MS, BCOP

In response to the increasing complexity of oncolytic agents, the associated economic burden on the patient and health system, and the intricacies associated with alternative payment models (APMs), I suggest the need for widespread establishment of chemotherapy stewardship services. An example of effective stewardship practice in healthcare is antimicrobial stewardship, which aims to define appropriate antimicrobial agents for use in patients and decrease patterns of the emergence of resistance and cost. The Centers for Disease Control and Prevention states, "Antimicrobial stewardship interventions have been proven to improve individual patient outcomes, reduce the overall burden of antibiotic resistance, and save healthcare dollars."[1] Outside of curbing rates of resistance, I suggest that the foundational scope of chemotherapy stewardship mirror that of antimicrobial stewardship, with the goal of improving patient outcomes and controlling cost by decreasing waste and improving resource utilization.

Pharmacist review and intervention with patients in the outpatient setting has been shown to reduce the total cost of cancer care.[2] Specifically, pharmacists can prospectively review treatment plans to:

• Determine whether there are any clinical issues (dose reductions or modifications) that may lead to inappropriate therapy or augmented toxicity.
• Identify safety issues with chemotherapy and under- or over-utilization of supportive care medications.
• Review off-label use and appropriately referenced data to help improve the reimbursement process, reducing waste for the hospital system, and potentially saving patients from denial of treatment.
• Confirm that the appropriate structures and processes are in place to ensure that treatment regimens can be provided safely in the outpatient setting. Transitioning certain chemotherapy regimens from the inpatient setting to the outpatient setting can lead to cost reductions.[3]

These review methods are becoming increasingly important since the advent of APMs, which require education and counseling that pharmacists are uniquely qualified and positioned to provide.

Chemotherapy stewardship is a process in which a pre-selected list of chemotherapy agents is restricted to approval for use by the stewardship team. It should include:

• **Clinical Assessment:** Is the use of this agent within established evidence-based guidelines? Is there an established and recognized clinical benefit for use? If not, is there a published rationale supporting its use? Is supportive care maximized to prevent toxicity and the potential need for healthcare resources to manage adverse events? Is the dose appropriate based on organ function to prevent toxicity and the potential need for healthcare resources to manage sequelae?
• **Cost Assessment:** Is the agent the most cost-effective medication available to treat the patient's indication (while maintaining prescriber authority and autonomy)? Can the therapy be given in an ambulatory setting? Can the dose be rounded to the nearest vial size increment? Is there documentation of insurance approval? If not or if the patient has a burdensome co-pay, are programs available to help alleviate the financial burden to patients and the health system?

Pharmacy steward champions can also assess goal(s) of therapy and weigh the benefits of aggressive therapy as part of end-of-life care. In short, widespread adoption of oncology pharmacist-driven chemotherapy stewardship programs would help ensure safe and effective treatment of oncology patients, while managing limited healthcare resources. **OI**

References

1. CDC. Overview and evidence to support appropriate antibiotic use. Available online at: cdc.gov/antibiotic-use/healthcare/evidence.html. Last accessed April 22, 2019.
2. Han JM, et al. Clinical and economic impact of pharmacists' intervention in a large volume chemotherapy preparation unit. *Int J Clin Pharm.* 2016;38:1124-1132.
3. McBride A, et al. Implementation of a pharmacy-managed program for the transition of chemotherapy to the outpatient setting. *Am J Health Syst Pharm.* 2018;75(9):e246-e258.

fast

What's the Latest Buzz? Catch up on the latest episodes of ACCC's podcast, CANCER BUZZ. Episode 4: Survivorship Care After Immunotherapy discusses the transition from immunotherapy into post-treatment survivorship, how it differs from chemotherapy, and why coordination and communication among providers, patients, and caregivers is essential. In Episode 5: Rural Cancer Care learn about the challenges to care delivery in rural settings, and discover some of the innovative ways that providers are working to better serve this at-risk patient population.

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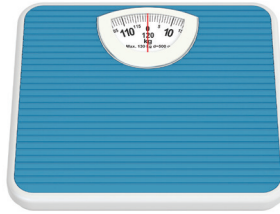
Obesity Rates in the U.S. Continue to Rise

- Adult obesity rates are at or above **35%** in 9 states: Alabama, Arkansas, Iowa, Kentucky, Louisiana, Mississippi, Missouri, North Dakota, and West Virginia. (In 1985, no state had an adult obesity rate higher than **15%**; by 2015, half the states were above 30%.)

- **7 states**—Florida, Kansas, Minnesota, Missouri, New Mexico, New York, and Utah—saw their adult obesity rates increase significantly between 2017 and 2018.

- Obesity levels are highest in Black and Latino communities, low-income, and rural communities, places where residents often have limited access to healthy options. Adult obesity rates for Latinos (**47%**) and Blacks (**47%**) are higher than among Whites (**38%**) or Asians (**13%**).

- **34%** of adults living in rural areas have obesity compared to **29%** percent of adults living in metro areas.

Source. The State of Obesity: Better Policies for a Healthier America 2019. Trust for America's Health and the Robert Wood Johnson Foundation. tfah.org/wp-content/uploads/2019/09/2019ObesityReportFINAL-1.pdf.

Are We Meeting the Needs of Our Cancer Patients?

- **53%** of cancer patients surveyed said they could have benefited from practical advice and support in dealing with the side effects of treatments.

- **36%** wanted better support in understanding long-term side effects of their treatment.

- **35%** of cancer patients wanted access to a cancer expert to act as an advocate.

- **31%** said they did not have an expert to talk to about worries and fears.

Source. The Wamberg Genomic Advisors Cancer Survey. wamberggenomic.com.
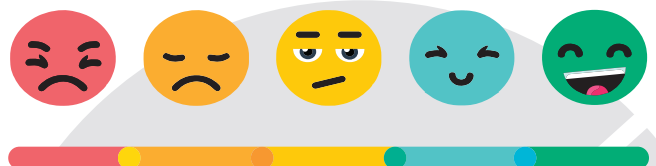
facts

Americans Stressed Over the Cost of Healthcare

- Healthcare costs are a major stress for Americans (**62%**)—second only to money (**72%**).

- The "biggest healthcare fear" among U.S. adults (**35%**) is losing healthcare insurance because of a pre-existing condition; overall, **62%** report having a chronic illness.

- The ability to pay for needed care (**35%**) is the "most pressing issue" in healthcare.

- Half (**48%**) said they received an unexpected medical bill they thought would be covered by insurance.

- Nearly **1 in 5** (**17%**) Americans cannot afford routine healthcare expenses, including prescription drugs.

- **69%** of U.S. adults are paying for significant healthcare expenses through a variety of means, including savings (**35%**), credit cards (**28%**), disposable income (**24%**), loans from family (**8%**), or a 401k withdrawal (**6%**).

Source. Transamerica Center for Health Studies. Sixth Annual Healthcare Survey: Stressed Out: Americans and Healthcare. transamericacenterforhealthstudies. org/docs/default-source/research/ tchs2018-healthcare-consumer- research-report.pdf.

5 Myths About Cancer Prevention

Myth 1. Cancer is often genetic—I can't do anything about it.

Myth 2. Drinking red wine is good for me.

Myth 3. Drinking coffee can cause cancer.

Myth 4. Eating organic fruits and vegetables offer extra protection against cancer.

Myth 5. Eating soy increases breast cancer risk.

Source. American Institute for Cancer Research. aicr.org.

Top 5 Healthiest Communities in 2019

1. Douglas County, CO
2. Los Alamos County, NM
3. Falls Church City, VA
4. Loudoun County, VA
5. Broomfield County, CO

Source. U.S. News and Aetna Foundation. usnews.com/news/ healthiest-communities.

Face Time?

- During the work day—physicians spent **27%** of their total time on direct, clinical face time with patients and **49%** of their time on EHR and desk work.

- While in the exam room with patients, physicians spent **53%** of their time on direct, clinical face time and **37%** on EHR and desk work.

- Outside of office hours, physicians spent another **1 to 2 hours** of personal time each night doing additional computer and other clerical work.

Source. Sinsky C., et al. Allocation of physician time in ambulatory practice: a time and motion study in 4 specialties. Ann Intern Med. 2016;165(11):753-760.
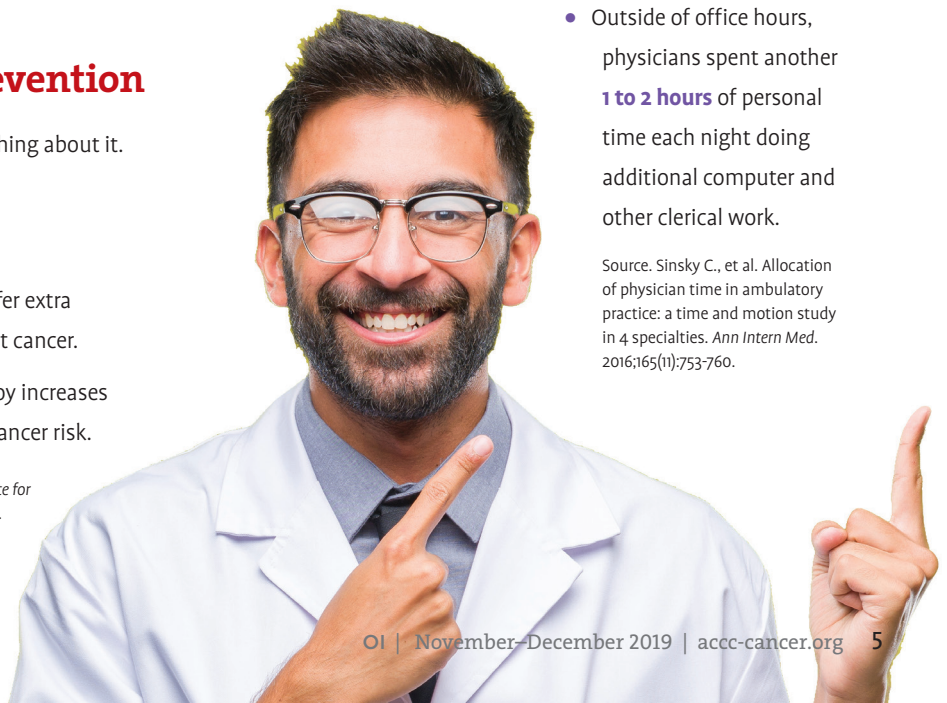
issues

ACCC Comments on 2020 Proposed OPPS and PFS Rules

BY CHRISTIAN G. DOWNS, MHA, JD

On Sept. 27, ACCC provided comments to the Centers for Medicare & Medicaid Services (CMS) on the agency's proposed CY 2020 Outpatient Prospective Payment System (OPPS) and Physician Fee Schedule (PFS) rules. CMS is expected to release the final CY 2020 Medicare payment rules in early November. Below are highlights from these comment letters.

Specific to the proposed OPPS Rule, ACCC recommended that CMS:

• Not finalize its proposal to reduce reimbursement to 40 percent of the OPPS rate for certain clinic visits furnished at excepted off-campus provider-based departments and reverse the policy that was implemented in CY 2019.

• Not finalize its proposal to continue to pay average sales price (ASP) minus 22.5 percent for separately payable drugs purchased under the 340B Program, including drugs furnished in non-excepted hospital off-campus provider-based departments.

• Finalize the Hospital Outpatient Payment Panel's recommendation to apply a status indicator of Q1 to CAR-T codes to enable them to be separately payable when no other service is performed.

• Not finalize its proposals with respect to the clinical laboratory date of service rule except that it should allow blood banks and centers to continue to bill hospitals.

• Not finalize its proposal to require hospitals to make public lists of gross charges and payer-specific negotiated rates.

• Not finalize its proposal to require prior authorization for certain outpatient department services.

In its letter, ACCC supports the proposal regarding changes in the level of supervision of outpatient therapeutic services in hospitals and critical access hospitals, but seeks clarification on how it will apply to chemotherapy and radiation oncology.

Specific to the proposed PFS Rule, ACCC recommended that CMS:

• Finalize its proposed revisions to the Transitional Care Management and Chronic Care Management services codes and payment to encourage further utilization of these services, reduce costs, improve patient outcomes, and ensure that healthcare professionals are appropriately compensated for services provided.

• Continue the payment freeze for radiation therapy G-codes for CY 2020. ACCC appreciates CMS's proposal to stabilize payment for radiation therapy services until such time as billing for radiation therapy services can be appropriately re-evaluated.

• Proceed with caution when proposing any bundled payments under the PFS, including possible expansion of the use of the monthly enhanced oncology services (MEOS) payment outside the Oncology Care Model (OCM), to ensure that any proposed model is thoroughly vetted to minimize any negative impact to patient access.

• Finalize its proposed changes to the evaluation and management (E/M) current procedural terminology codes and documentation guidelines, including the proposed revisions to the add-on G-codes for these services. ACCC believes that the changes to payment for E/M services finalized last year would have dramatically reduced reimbursement for E/M services to physicians by creating a single payment rate across four levels of E/M services. ACCC believes that adoption of the American Medical Association's guidelines for documentation of these codes will help ensure that physicians will be compensated at potentially more appropriate reimbursement rates.

• Propose simple, easy-to-implement rules governing notification of the options for infusion therapy services under the home infusion therapy benefit.

• Withdraw the payment reduction for non-excepted off-campus provider-based departments, which is supposed to be equivalent to the PFS rate for such services, but is instead proposed to continue to be set at 40 percent of the OPPS rate for the same services for CY 2020.

Read these comment letters in their entirety at accc-cancer.org/advocacy. OI

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

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The Time is Here! What You Need to Know for AUC Consultation

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

The wait is over. On July 26, 2019, the Centers for Medicare & Medicaid Services (CMS) released the requirements for appropriate use criteria (AUC) consultation for advanced diagnostic imaging exams. Currently AUC implementation is in a voluntary phase, which began July 1, 2018, and ends Dec. 31, 2019. Jan. 1, 2020, ushers in the testing and operations testing period. During this time, CMS will not deny any claims based on the submission of AUC reporting criteria. Beginning Jan. 1, 2021, the agency will begin denying payment to both the facility that provided the imaging *and* the interpreting provider if the required AUC elements (G-codes and modifiers) are not reported.

This AUC was created in response to the requirements of the Protecting Access to Medicare Act of 2014 (PAMA). The Act specifically requires CMS to establish a program to promote the ordering provider's utilization of AUC for advanced diagnostic imaging services. Advanced imaging services include diagnostic computed tomography, magnetic resonance imaging, and nuclear medicine exams, including positron emission tomography. Ordering physicians and practitioners ("ordering professionals") will be required to consult AUC for all advanced imaging studies billed under the Medicare Physician Fee Schedule, the Outpatient Prospective Payment System, and the Ambulatory Surgical Center Payment System, including those performed in a physician office, hospital outpatient department (including emergency department), independent diagnostic testing

facility, or ambulatory surgery center. This means that if your organization owns any advanced diagnostic equipment that is utilized for diagnostic studies, then the consultation and reporting requirements will apply.

AUC are designed to help clinicians select the most appropriate imaging study for patients with a particular diagnosis or patients presenting with specific symptom(s). CMS can only approve AUC that are developed or endorsed by provider-led entities, such as national professional medical specialty societies. In most cases the AUC will be evidence based. See Table 1, right, for the current listing of qualified provider-led entities as of June 2019.

Once a provider-led entity qualifies, all of the AUC developed or endorsed by that entity are considered to be "specified AUC" for purposes of the PAMA requirements.

An ordering provider (the referring physician or clinical staff member when delegated by and under the direction of the referring physician) will access the AUC through a clinical decision support mechanism; an electronic portal, such as a module in an electronic health record (EHR); or a web-based system. The clinical decision support mechanism will pull information about the patient from the EHR and/or the ordering provider will enter information and the clinical decision support mechanism will provide immediate feedback about the appropriateness of the proposed imaging exam. Table 2, page 10, is the most recent list of qualified clinical decision support mechanisms available at CMS. A list of

clinical decision support mechanisms with preliminary qualification as of June 2019 is found in Table 3, page 10.

At a minimum, each clinical decision support mechanism must include criteria for the following priority clinical areas, which are responsible for a significant percentage of advanced imaging exams paid by Medicare:

- Coronary artery disease (suspected or diagnosed)
- Suspected pulmonary embolism
- Headache (traumatic and non-traumatic)
- Hip pain
- Lower back pain
- Shoulder pain (to include suspected rotator cuff injury)
- Cancer of the lung (primary or metastatic, suspected or diagnosed)
- Cervical or neck pain.

The list will continue to expand in the future.

There are a few exceptions to note. The AUC consultation requirement does not apply to imaging exams performed on inpatients that are paid under Medicare Part A. It also does not apply to patients with emergency medical conditions as defined by the Emergency Medical Treatment & Labor Act, whether confirmed or suspected, or when the ordering physician or practitioner has received a hardship exception. Any ordering professional experiencing insufficient Internet access, EHR or clinical decision support mechanism vendor issues, or extreme uncontrollable circumstances (including natural or manmade disasters) will not be required to consult the AUC using a qualified clinical decision support mechanism. These circumstances will be

Table 1. Current Listing of Qualified Provider-Led Entities*
American College of Cardiology Foundation
American College of Radiology
Banner University Medical Group-Tucson University of Arizona
CDI Quality Institute
Cedars-Sinai Health System
High Value Practice Academic Alliance
Intermountain Healthcare
Johns Hopkins University School of Medicine
Massachusetts General Hospital, Department of Radiology
Medical Guidelines Institute
Memorial Sloan Kettering Cancer Center
National Comprehensive Cancer Network
Sage Evidence-based Medicine & Practice Institute
Society for Nuclear Medicine and Molecular Imaging
University of California Medical Campuses
University of Pennsylvania Health System
University of Texas MD Anderson Cancer Center
University of Utah Health
University of Washington School of Medicine
Virginia Mason Medical Center
Weill Cornell Medicine Physicians Organization

*As of June 2018. Source: cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Appropriate-Use-Criteria-Program/CDSM.html.

self-attested at the time the order is placed.

Assuming that medical necessity is met, CMS will pay for advanced imaging studies regardless of whether they meet appropriateness criteria during the consultation process. Eventually, CMS will identify the top 5 percent of ordering professionals who are consistently failing to follow AUC recommendations for studies involving the priority clinical areas outlined above. Under PAMA, these "outliers" will be required to obtain prior authorization for any advanced imaging studies they wish to order for Medicare patients. At present, lung cancer is the only oncology diagnosis on the priority clinical area list, but the list will be expanding, and it is anticipated that new oncology-related clinical conditions will be added to the list.

Beginning Jan. 1, 2020, CMS has indicated that claims processing systems will be prepared to accept claims with a Current Procedural Terminology code or Healthcare Common Procedure Coding System (HCPCS) C-code for advanced diagnostic imaging along with a line item HCPCS modifier. The modifier will identify what AUC level was followed or indicate an exception to the program. Table 4, page 11, lists the modifiers for reporting under the AUC program.

If a claim includes modifier ME, MF, or MG with the advanced diagnostic imaging service, a separate G-code is required to report the qualified clinical decision support mechanism that was consulted. CMS indicates that multiple G-codes can be reported on a single claim.

Each clinical decision support mechanism consulted by the ordering professional has a

Table 2. Qualified Clinical Decision Support Mechanisms*
AgileMD's Clinical Decision Support Mechanism
AIM Specialty Health ProviderPortal® (free tool available)
Applied Pathways CURION™ Platform
Cranberry Peak ezCDS
eviCore healthcare's Clinical Decision Support Mechanism
EvidenceCare's Imaging Advisor
Inveni-QA's Semantic Answers in Medicine™
MedCurrent OrderWise™
Medicalis Clinical Decision Support Mechanism
National Decision Support Company CareSelect™ (free tool available)
National Imaging Associates RadMD
Reliant Medical Group CDSM
Sage Health Management Solutions Inc. RadWise®
Stanson Health's Stanson CDS
Test Appropriate CDSM (free tool available)

*As of June 2018. Source: cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Appropriate-Use-Criteria-Program/CDSM.html.

Table 3. Clinical Decision Support Mechanisms with Preliminary Qualification*
Cerner CDS mechanism
Evinance Decision Support
Flying Aces Speed of Care Decision Support
HealthHelp's Clinical Decision Support Mechanism
Infinx CDSM
LogicNets' Decision Engines
New Century Health's CarePro

*As of June 2018. Source: cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Appropriate-Use-Criteria-Program/CDSM.html.

Table 4. HCPCS Modifiers for the AUC Program

HCPCS Modifier	Description
MA	Ordering professional is not required to consult a clinical decision support mechanism due to service being rendered to a patient with a suspected or confirmed emergency medical condition
MB	Ordering professional is not required to consult a clinical decision support mechanism due to the significant hardship exception of insufficient Internet access
MC	Ordering professional is not required to consult a clinical decision support mechanism due to the significant hardship exception of electronic health record or clinical decision support mechanism vendor issues
MD	Ordering professional is not required to consult a clinical decision support mechanism due to the significant hardship exception of extreme and uncontrollable circumstances
ME	The order for this service adheres to the appropriate use criteria in the clinical decision support mechanism consulted by the ordering professional
MF	The order for this service does not adhere to the appropriate use criteria in the qualified clinical decision support mechanism consulted by the ordering professional
MG	The order for this service does not have appropriate use criteria in the clinical decision support mechanism consulted by the ordering professional
MH	Unknown whether ordering professional consulted a clinical decision support mechanism for this service; related information was not provided to the furnishing professional or provider
QQ	Ordering professional consulted a qualified clinical decision support mechanism for this service and the related data were provided to the furnishing professional (effective dates: July 1, 2018-Dec. 31, 2019)

Table 5. G-Codes for AUC Program

G-Codes	Description
G1000	Clinical decision support mechanism Applied Pathways, as defined by the Medicare Appropriate Use Criteria Program
G1001	Clinical decision support mechanism eviCore, as defined by the Medicare Appropriate Use Criteria Program
G1002	Clinical decision support mechanism MedCurrent, as defined by the Medicare Appropriate Use Criteria Program
G1003	Clinical decision support mechanism Medicalis, as defined by the Medicare Appropriate Use Criteria Program
G1004	Clinical decision support mechanism National Decision Support Company, as defined by the Medicare Appropriate Use Criteria Program
G1005	Clinical decision support mechanism National Imaging Associates, as defined by the Medicare Appropriate Use Criteria Program
G1006	Clinical decision support mechanism Test Appropriate, as defined by the Medicare Appropriate Use Criteria Program
G1007	Clinical decision support mechanism AIM Specialty Health, as defined by the Medicare Appropriate Use Criteria Program
G1008	Clinical decision support mechanism Cranberry Peak, as defined by the Medicare Appropriate Use Criteria Program
G1009	Clinical decision support mechanism Sage Health Management Solutions, as defined by the Medicare Appropriate Use Criteria Program
G1010	Clinical decision support mechanism Stanson, as defined by the Medicare Appropriate Use Criteria Program
G1011	Clinical decision support mechanism, qualified tool not otherwise specified, as defined by the Medicare Appropriate Use Criteria Program

Table 6. HCPCS Advanced Imaging Procedure Codes

Magnetic Resonance Imaging

70336, 70540, 70542, 70543, 70544, 70545, 70546, 70547, 70548, 70549, 70551, 70552, 70553, 70554, 70555, 71550, 71551, 71552, 71555, 72141, 72142, 72146, 72147, 72148, 72149, 72156, 72157, 72158, 72159, 72195, 72196, 72197, 72198, 73218, 73219, 73220, 73221, 73222, 73223, 73225, 73718, 73719, 73720, 73721, 73722, 73723, 73725, 74181, 74182, 74183, 74185, 75557, 75559, 75561, 75563, 75565, 76498, 77046, 77047, 77058, 77059

Computerized Tomography

70450, 70460, 70470, 70480, 70481, 70482, 70486, 70487, 70488, 70490, 70491, 70492, 70496, 70498, 71250, 71260, 71270, 71275, 72125, 72126, 72127, 72128, 72129, 72130, 72131, 72132, 72133, 72191, 72192, 72193, 72194, 73200, 73201, 73202, 73206, 73700, 73701, 73702, 73706, 74150, 74160, 74170, 74174, 74175, 74176, 74177, 74178, 74261, 74262, 74712, 74713, 75571, 75572, 75573, 75574, 75635, 76380, 76497

Single-Photon Emission Computed Tomography

76390

Nuclear Medicine

78012, 78013, 78014, 78015, 78016, 78018, 78020, 78070, 78071, 78072, 78075, 78099, 78102, 78103, 78104, 78110, 78111, 78120, 78121, 78122, 78130, 78135, 78140, 78185, 78191, 78195, 78199, 78201, 78202, 78205, 78206, 78215, 78216, 78226, 78227, 78230, 78231, 78232, 78258, 78261, 78262, 78264, 78265, 78266, 78267, 78268, 78270, 78271, 78272, 78278, 78282, 78290, 78291, 78299, 78300, 78305, 78306, 78315, 78320, 78350, 78351, 78399, 78414, 78428, 78445, 78451, 78452, 78453, 78454, 78456, 78457, 78458, 78459, 78466, 78468, 78469, 78472, 78473, 78481, 78483, 78491, 78492, 78494, 78496, 78499, 78579, 78580, 78582, 78597, 78598, 78599, 78600, 78601, 78605, 78606, 78607, 78608, 78609, 78610, 78630, 78635, 78645, 78647, 78650, 78660, 78699, 78700, 78701, 78707, 78708, 78709, 78710, 78725, 78730, 78740, 78761, 78799, 78800, 78801, 78802, 78803, 78804, 78805, 78806, 78807, 78811, 78812, 78813, 78814, 78815, 78816, 78999

C-Codes

C8900, C8901, C8902, C8903, C8905, C8908, C8909, C8910, C8911, C8912, C8913, C8914, C8918, C8919, C8920, C8931, C8932, C8933, C8934, C8935, C8936

unique G-code for reporting on the claim form. Table 5, page 11, lists the G-codes for reporting under the AUC program.

CMS has also provided the full list of HCPCS advanced imaging procedure codes included in the AUC program. Table 6, above, lists the HCPCS codes included in the AUC program as provided by CMS beginning Jan. 1, 2020. As appropriate and necessary, the agency will add HCPCS codes to the list of advanced imaging procedures under the AUC as new codes are created and/or as changes to imaging are made.

Though AUC is ultimately a regulatory requirement, there is a bright side. Taking the time to perform the AUC consultation is defined by CMS as a high-weight improvement activity for the Medicare Access and CHIP Reauthorization Act (MACRA) quality program. Additionally, this activity is eligible for a 10 percent bonus point in the Promoting Interoperability performance category. Also, the Cost Display for Laboratory and Radiologic Orders is defined as a medium-weight improvement activity, which is also eligible for a 10 percent bonus point award in the Promoting Interoperability performance category.

Even though 2020 is a testing year and there will be no financial impact to the claims submitted to CMS for advanced diagnostic imaging service, all ordering professionals must be aware of AUC program requirements and commit to their role in the program. It is equally important that imaging facilities and interpreting physicians accurately report the modifiers and G-codes that are also performed. This teamwork will ensure accuracy and that reimbursement earned for the supported services through the AUC program is paid appropriately. OI

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tools

Approved Drugs

- On Sept. 26, the U.S. Food and Drug Administration (FDA) approved the use of **Darzalex® (daratumumab)** (Janssen Biotech, Inc., janssen.com) in combination with **bortezmib**, **thalidomide**, and **dexamethasone (Vtd)** as treatment for patients newly diagnosed with multiple myeloma who are eligible for autologous stem cell transplant.

- On Sept. 17, the FDA approved **Erleada® (apalutamide)** (Janssen Biotech, Inc., janssen.com) for patients with metastatic castration-sensitive prostate cancer. The drug was initially approved in 2018 for patients with non-metastatic castration-resistant prostate cancer.

- On Aug. 23, the FDA approved an abbreviated new drug application (NDA) for **fulvestrant injection** (Glenmark Pharmaceuticals, glenmarkpharma.com), in 250 mg/5 mL dose (a generic version of **Faslodex® Injection**) as a monotherapy for advanced breast cancer for women who have gone through menopause or have not received previous endocrine therapy or untreated, hormone receptor-positive advanced breast cancer before the disease advances.

- On Aug. 16, the FDA approved **Inrebic® (fedratinib)** (Celgene., Celgene.com) for adults with intermediate-2 or high-risk primary or secondary (post-polycythemia vera or post-essential thrombocythemia) myelofibrosis.

- On Sept. 17, the FDA granted accelerated approval to **Keytruda® (pembrolizumab)** (Merck, merck.com) plus **Lenvima® (lenvatinib)** (Eisai, eisai.com) for the treatment of patients with advanced endometrial carcinoma that is not microsatellite instability high or mismatch repair deficient, and who have disease progression following prior systemic therapy but are not candidates for curative surgery or radiation.

- On Aug. 15, the FDA granted accelerated approval to **Rozlytrek™ (entrectinib)** (Genentech Inc., gene.com) for adults and pediatric patients 12 years of age and older with solid tumors that have a neurotrophic tyrosine receptor kinase gene fusion without a known acquired resistance mutation or are metastatic or where surgical resection is likely to result in severe morbidity and have progressed following treatment or have no satisfactory standard therapy.

Drugs in the News

- AstraZeneca (astrazeneca.com) announced that the FDA has granted breakthrough therapy designation for **Calquence® (acalabrutinib)** for chronic lymphocytic leukemia.

- Novartis (novartis.com) announced that the FDA has granted breakthrough therapy designation for **capmatinib (INC280)** for patients with MET-mutated advanced non-small cell lung cancer.

- Calibr (scripps.edu/science-and-medicine/calibr) announced that the FDA has cleared its investigational NDA for **CCW702**, an immunotherapeutic for the treatment of patients with metastatic castration-resistant prostate cancer.

- Glenmark Pharmaceuticals (glenmarkpharma.com) announced that the FDA has granted orphan drug designation to **GBR 1342** for the treatment of patients with multiple myeloma who have received prior therapies.

- The Janssen Pharmaceutical Companies of Johnson & Johnson announced that the FDA granted breakthrough therapy designation for **niraparib**, an orally administered poly (ADP-ribose) polymerase inhibitor, for the treatment of patients with BRCA1/2 gene-mutated metastatic castration-resistant prostate cancer who have received prior taxane chemotherapy and androgen receptor-targeted therapy.

- Oncoceutics, Inc. (oncoceutics.com) announced that the FDA has accepted its investigational NDA for **ONC206** in adults with primary central nervous system neoplasms.

- Adaptimmune Therapeutics (adaptimmune.com) announced that the FDA has granted orphan drug designation to **SPEAR T-cells targeting MAGE-A4 (Adaptimmune's ADP-A2M4 program)** for the treatment of soft tissue sarcomas.

- EMD Serono (emdserono.com) announced that the FDA has granted breakthrough therapy designation for **tepotinib (MSC2156119J)** for patients with metastatic non-small cell lung cancer harboring MET exon 14 skipping alterations who progressed following platinum-based cancer therapy.

- Astellas Pharma Inc. (astellas.com) and Pfizer Inc. (pfizer.com) announced that the FDA has accepted and granted priority review to a supplemental NDA for **Xtandi® (enzalutamide)** to add an indication for the treatment of men with metastatic hormone-sensitive prostate cancer.

- BeiGene (beigene.com) announced that the FDA has accepted the NDA and granted priority review to **zanubrutinib (BGB-3111)** for the treatment of patients with mantle cell lymphoma who have received at least one prior therapy.

Approved Devices

- Akesis (akesis.com) announced that the company has received 510(k) clearance from the FDA for the **Akesis Galaxy™**, a gamma stereotactic radiosurgery, making the system available to clinicians in the United States.

- ProTom International (protominternational.com) announced that it has received 510(k) clearance from the FDA for its **Radiance 330® proton therapy system** installed at Massachusetts General Hospital in Boston, Mass.

- Profound Medical Corp. (profoundmedical.com) announced that the company has received 510(k) clearance from the FDA to market **TULSA-PRO®**, a transurethral prostate tissue ablation system, for ablation of prostate tissue.

Approved Genetic Tests and Assays

- Exact Sciences Corp. (exactsciences.com) announced that the FDA approved the company's noninvasive colorectal cancer screening test, **Cologuard®**, for eligible average-risk individuals aged 45 and older, expanding on its previous indication for individuals aged 50 and older.

spotlight

Central Peninsula Oncology
Soldotna, Alaska

Delivering quality cancer care to patients in their home community is the driving force behind Central Peninsula Oncology, a hospital-owned outpatient oncology clinic on the Kenai Peninsula in Alaska. Access to care in this community is often at the mercy of the weather.

The Kenai Peninsula protrudes from Alaska's south-central coast, just north of Kodiak Island. A single highway connects each town on the peninsula and stretches 150 miles through the Chugach Mountains from Soldotna to Anchorage, the nearest city. Winter months can bring travel to a standstill due to freezing temperatures and heavy blizzard conditions that can ground local flights for days and close the main highway. Though summer months offer respite, outbreaks of wildfires can threaten travelers and shut down access to roadways.

For patients with cancer and their families, the opening of Central Peninsula Oncology in 2017 has brought cancer services together in one location within Central Peninsula Hospital. Today, more than 95 percent of the area's patients with cancer receive care locally, with only about 5 percent needing referrals to Seattle, Wash., or other facilities in the "lower 49" for uncommon cancers or second opinions.

From the Ground Up
Located in the medical office building attached to the main hospital, Central Peninsula Oncology covers 5,620 square feet. Built in 2016, the outpatient clinic includes two procedure rooms and a 10-chair infusion center designed following the Planetree

patient-centric, healing environment guidelines. Spacious windows supply natural light throughout and offer breathtaking views of the Kenai Mountains. The infusion chairs are arranged so that patients can enjoy Alaska's natural wonders while receiving treatment, and small dividing screens create a sense of privacy.

"[We want patients to] to be comfortable during the little bit of time they have to spend with us," explains Shayne Pond, oncology/infusion director. The significantly larger infusion center allows for more space for patients but is still visible from the nurses' stations.

Though patients and staff benefit from the open space layout, initially it created an unforeseen challenge as staff adapted to covering more distance and providing care to a greater volume of patients in a larger area. However, the team responded quickly, establishing their own process and workflows to make effective use of the new space. The infusion center provides both oncology and non-oncology treatments to outpatients, including chemotherapy, blood transfusions, platelet transfusions, intravenous antibiotics, and hydration and electrolyte replacement. These services are individualized to meet the needs of each patient and his or her family.

Plans for launching an outpatient oncology clinic at Central Peninsula Hospital included recruiting a medical oncologist to lead the practice. Darren Mullins, MD, was brought on board in

2017. At the time, Central Peninsula Hospital had an infusion center, which administered oncology and non-oncology infusions, but there was no full-time medical oncologist on staff. With the help of the experienced infusion staff already on board and administration, Central Peninsula Oncology has grown to accommodate about 400 patients annually. To meet increasing patient demands, a satellite location has opened in Homer, Alaska, which provides care for patients farther south on the peninsula.

The community includes a small, independent oncology practice located across the street from the hospital; however,

the practice has limited office hours. Therefore, providing full-time cancer care to the 35,000-count community falls mainly on Dr. Mullins and the team at Central Peninsula Oncology.

As with other smaller oncology practices, staff members—clinical and non-clinical—take on multiple roles to provide the best multidisciplinary care they can. The practice is staffed with a medical oncologist, an oncology-certified nurse, seven chemotherapy-trained registered nurses, and an in-house lay navigator. The hospital's social workers are available to clinic patients if needed.

In order to provide comprehensive patient care, Central Peninsula Oncology has established working relationships with other oncology specialists, including a radiation oncology practice in Anchorage. Through an arrangement with the Anchorage group, radiation oncology services are provided at the Central Peninsula Hospital. Under the direction of a full-time radiation oncologist,

the patients have access to radiation treatment modalities, including external beam therapy, intensity-modulated radiation therapy, stereotactic body radiation therapy, and image-guided radiation therapy. Central Peninsula Oncology collaborates closely with these providers to facilitate the co-management of care in more challenging cases.

As patient volumes have increased, so have scheduled multidisci-plinary tumor board meetings, which are now held weekly. Ad hoc breast cancer tumor boards are as needed. These conferences usually bring together medical oncologists, radiation oncologists, general surgeons, radiologists, pathologists, and other surgical subspecialists for prospective patient case discussion. Patients' primary care physicians are also invited to attend.

A Spot for Snowbirds

The picturesque Kenai Peninsula, also known as "Alaska's playground," is a popular tourist destination. Spacious views, scenic drives, and opportunities for land and sea adventure bring visitors as well as vacationers with second homes in the area. Central Peninsula Oncology provides care for visiting patients with cancer or patients who are temporary residents during the summer months, so care coordination for these individuals is imperative.

Communication is key, shared Shayne Pond. Central Peninsula Oncology takes pride in its ability to care for these patients by facilitating the sharing of records and treatment plans between its own staff and the patient's provider at home.

Going Forward

As Central Peninsula Oncology continues to expand to meet patient demand, there is ongoing discussion on how to improve services and advance the delivery of quality cancer care to the community. Future goals include developing a formal affiliation with one or more tertiary cancer centers in Washington state, notably in Seattle. This next step will help Central Peninsula Oncology build a seamless referral network for patients with rare cancers and bring access to clinical trials to patients close to home. These formal affiliations will also allow the practice to broaden participation and resources for its tumor boards and possibly create opportunities to benefit from telemedicine to engage with more providers and access more resources.

Also on the horizon, the state of Alaska is looking to develop a program for all patient navigators throughout the state. This program will give navigators the opportunity to meet, share resources, and develop relationships to help cancer patients across the state. Going forward, Central Peninsula Oncology hopes that this program will widen the scope of resources available for local patients.

Achieving these goals will allow Central Peninsula Oncology to deliver more comprehensive cancer care to the Kenai Peninsula, while staying true to its mission to support patient access to quality cancer care close to home and family. [OI]

Select Supportive Care Services

- Access to American Cancer Society lay navigators
- Nutrition services
- Survivorship services

Approximate number of new analytic cases seen in 2018: 249

Breaking Down Silos

BY PAMELA R. PROMAN, MBA, RTT; WILLIAM D. JAMES, MHA;
AND NANCY H. JOHNSON, MSM

Revenue cycle tiers increase efficiency and reduce waste

Silos in healthcare delivery are marked by a longstanding history of creating system waste, reducing quality of care, and resulting in poor utilization of resources.[1] The danger inherent to the silo mentality within corporate structure relates to the barriers surfacing around knowledge sharing of best practices and innovations for change. Though not always intentional, silo mentality in departments, groups, and subgroups within an organization presents as operating in isolation without system thinking. The silo impact pushes departmental changes onto other areas of the health system. The isolation often results in the following:

- *Workflow fragmentation.* Individuals and departmental teams function within workflows that naturally tend to follow their "ideal" practice. When people are operating in silos without consideration of system connectedness, multiple workflows of varying efficacy develop and processes can become confused, especially when responsibilities change and people are asked to incorporate new elements into their workflow or integrate processes across departmental and group boundaries.
- *Communication barriers.* Notably, silos promote misunderstandings, diminish collaboration, and increase system waste with respect to efficient utilization of resources.[1] If groups do not know (or understand) the job functions or responsibilities

> Although healthcare delivery systems are complex, sometimes seemingly insignificant changes and lack of standardization create a domino effect with respect to errors, misinformation, and quality within clinical and financial systems.

of other groups, achieving tasks and goals becomes far more difficult. Additionally, groups need to understand how they connect with the overall system in order to foster improvements in information sharing and integration of services.
- *Lack of intellect sharing.* With silos come the segmentation of expertise. For any given problem, someone in the organization may have the solution, but the problem may not be solved if the individual with the problem is unaware of who

to ask for help. Opening communication between departments and individuals fosters knowledge translation and best practice sharing, an elemental driver for organizational success.

Although healthcare delivery systems are complex, sometimes seemingly insignificant changes and lack of standardization create a domino effect with respect to errors, misinformation, and quality within clinical and financial systems. Simple data entry errors, such as incorrect patient demographic information, substantially impact a health system's revenue cycle and may corrupt a patient's electronic health record (EHR). Additionally, the lack of information sharing impacts the ability of the clinical teams to function effectively with timely patient care. For example, in some cancer programs, palliative care providers may not have access to the same information that is available to radiation oncologists or medical oncologists. This discrepancy results in the duplication of patient assessments, wasted time, and patient dissatisfaction.

> Unnecessary bureaucracy and redundant workflow lead to *underutilization* of co-worker talent and limit opportunities for employees to work to full potential.

The leadership team of the Nancy N. and J. C. Lewis Cancer & Research Pavilion (LCRP) at St. Joseph's/Candler tackled the silo mentality, improving the integration of services from the free-standing cancer center into the healthcare delivery system. Following a thorough assessment of silos within the healthcare system, a critical area associated with clinical and financial metrics surfaced. Key performance indicators such as charge lag, month end close, patient registration, insurance identification and verification, and others were reviewed over the course of three weeks. Using LCRP's clinical EHR and billing data repository, LCRP's data analyst was able to translate leadership's inquiries into actionable areas for improvement, thus identifying the silos. Each opportunity was prioritized using a matrix to grade urgency and importance. LCRP uncovered four primary impacts of silo mentality in action: resource waste, incorrect denials, reduced cash flow, and increased risk for financial toxicity.

The Impact of Waste
Lean philosophy focuses on eight different types of "waste," meaning anything that does not produce value. At LCRP, three types of waste continued to surface: overproduction, under-utilized talent, and defects. In the case of LCRP, *overproduction* meant redundancies in paperwork and process resulting in poor resource utilization. One example comes from patient intake. Patients were filling out nearly identical patient intake packets for medical oncology and radiation oncology, sometimes on the same day, even though the departments were only a floor apart. This process resulted in unnecessary duplication of registration staff activities,

increased wait times, and greater patient dissatisfaction. Because these departments operated in silos that prevented communications, staff failed to understand the extent of duplicative workloads and its negative effect on patients. After identifying this issue, LCRP leadership gathered input from all departments tasked with patient-facing responsibilities and built a comprehensive patient intake packet that reduced staff labor redundancies and improved patient satisfaction by establishing one registration intake document.

Unnecessary bureaucracy and redundant workflow lead to *underutilization* of co-worker talent and limit opportunities for employees to work to full potential. For example, in LCRP's central billing office, the process for claim adjustments involved every single adjustment crossing the desks of five to seven employees prior to final approval. The redundancy became apparent through the evaluation performed by the central billing office Lean Six Sigma team. Using the current state month end process map that located and quantified time traps and capacity constraints, redundancies inherent to the adjustment approval process surfaced. Once identified, workflow changes were implemented, which significantly shortened the number of steps and amount of time between adjustment identification and application. Improvements like this reduced the month end close process by three business days.

Defects in this context refers to incomplete or limited procedures that lead to suboptimal results. Another example from the work of the central billing office Lean Six Sigma team concerns a tool called Advanced Claim Editing to generate clean claims. This tool requires regular maintenance; however, no one in the department was assigned this responsibility. As a result, the tool was largely useless despite its potential to greatly streamline claim adjustment workflow. The team rectified the process, assigned accountability, and relaunched the tool.

The Impact of Incorrect Denials
By examining the source of denied claims, LCRP leadership discovered that the majority were data entry errors associated with demographic information entered by the front desk personnel registering patients. The silo effect associated with the lack of clarity in communications and sharing of information surfaced as a contributing factor—each co-worker believed that his or her individual workflow was the correct workflow, any mistakes made went unchecked, and the health system, payer, and patient had to go through unnecessary appeals processes as a result. Split billing within the oncology services further contributed to denied claims. In split billing, professional services are billed through LCRP's central billing office and technical services are billed through the hospital's patient accounts department. The silo mentality of both billing entities created barriers to information sharing that resulted in claims denials from simple issues such as failure to communicate treatment authorizations. Given the turnover in these departments, it was difficult to keep both departments up to date on who to contact when billing questions arose.

The Impact of Reduced Cash Flow

Inefficiencies, a lack of communication, and a lack of focus on cash flow also harm the revenue cycle. This can be the result of both individual and department-wide silos. One example discovered related to co-worker objections to taking payments from cancer patients at the time of service, resulting in point-of-service patient responsibility being billed at a later date. This undesirable practice prevented co-workers from educating patients about their healthcare expenses and, thus, patients faced unexpected bills. Additionally, by proactively addressing co-payments at the time of service, patients with financial challenges can be seen by a financial navigator who will assist with potential resources. Without the rigorous attention to silo behaviors and mentality within the oncology services, this avoidance of point-of-service collection would not have been discovered.

The Impact of Increased Financial Toxicity

Financial toxicity affects both cancer patients and cancer programs. Prior to the silo identification and process improvement initiatives, financial toxicity existed as a significant opportunity for improvement at LCRP. Although limited financial navigation was offered, integration of LCRP clinical practice offices with financial navigation workflow was nonexistent. Across the oncology service line, several offices provided patients with incorrect contact information for billing inquiries, financial counseling, and other resources. Related navigation routines failed to efficiently address financial resources for patients and resulted in dissatisfaction, all compounded by the split billing process.

To address increasing financial toxicity, LCRP hired a financial navigator to help patients navigate the health system and the split billing process. During interdepartmental revenue cycle meetings designed to reduce silos, this co-worker requested a daily worklist that contained uninsured patients and any patients with outstanding balances. This report allows the financial navigator to prioritize patients with the most need for financial assistance and proactively assist, rather than relying on nurse navigators, patients, and providers for referrals.

The Role of Lean Six Sigma

To address systemic inefficiencies and silo mentality, St. Joseph's/Candler adopted Lean Six Sigma as a health system-wide process improvement philosophy. Following in suit, LCRP routinely launches Lean Six Sigma projects annually. The majority of staff are well versed in Lean Six Sigma principles, with LCRP's director of operations and one of the radiation physicians functioning as green belts, leading team projects. LCRP utilizes a "Triple I" approach to work improvement:

- Identify opportunities
- Investigate issues
- Improve processes and communication.

Service Line Analytic Meetings

In the early phases of addressing the silo mentality, data were deemed essential to establishing the metrics for change management. To better understand the current state of affairs and identify opportunities and issues, LCRP leadership organized around service line analytic meetings, or SLAMs. Biweekly meetings were co-chaired by the administrator of the oncology service line and LCRP's director of operations and included seven to eight regularly attending members. In addition to the revenue integrity managers involved in the charge approval process for specialties, a data analyst and a project manager attended the SLAMs. Capitalizing on knowledge sharing, critical thinking, and a flattened hierarchy for team interactions, the open sharing of diverse perspectives countered leadership groupthink and led to opportune and innovative strategies for change.

> As a strategy to prompt interdepartmental knowledge sharing across health system silos, the administrator of the oncology service line proposed a model for increasing and improving communications by placing renewed focus on the revenue cycle.

SLAM dashboards—customized reports generated by data analysts using up-to-date financial information—are routinely reviewed by the leadership team. Analyzing these dashboards can drive market opportunities and future strategic initiatives, pinpoint communication issues between internal and external providers, and inspire community outreach events.

Examples of dashboards (Figures 1-3, pages 20-21) include:
- Follow-up and new patient volumes.
- Treatment mix for radiation oncology and medical oncology.
- All charges across all locations—patient volumes that increase while charges remain stagnant point to fee schedule issues and the need to properly maintain the fee schedules. A decrease or and increase between 0 and 5 percent will not raise red flags; anything greater requires attention.
- Top 10 increasing and top 10 decreasing referring providers—The results drive activities to improve physician relationships with community providers.
- Individual provider volumes—By tracking provider productivity, solutions to promote equitable distributions of patients within a department can be realized and effective and timely care achieved.
- Physician vacations—Practice volumes are directly tied to physician availability. When physicians take vacations, revenues predictably drop. Failure to manage provider vacations contributes to months that may have significant volume and revenue shortages.

Figure 1. SLAM Dashboard Example 1

RadOnc A Total Txs

JUL · AUG · SEP · OCT · NOV · DEC · JAN · FEB · MAR · APR · MAY · JUN

◆ FY 2016 ■ FY 2017 ▲ FY 2018

RadOnc A IMRT Txs

JUL · AUG · SEP · OCT · NOV · DEC · JAN · FEB · MAR · APR · MAY · JUN

◆ FY 2016 ■ FY 2017 ▲ FY 2018

RadOnc A Complex & Simple Txs

JUL · AUG · SEP · OCT · NOV · DEC · JAN · FEB · MAR · APR · MAY · JUN

◆ FY 2016 ■ FY 2017 ▲ FY 2018

RadOnc A Cyberknife Txs

JUL · AUG · SEP · OCT · NOV · DEC · JAN · FEB · MAR · APR · MAY · JUN

◆ FY 2016 ■ FY 2017 ▲ FY 2018

RadOnc A HDR Txs

JUL · AUG · SEP · OCT · NOV · DEC · JAN · FEB · MAR · APR · MAY · JUN

◆ FY 2016 ■ FY 2017 ▲ FY 2018

Figure 2. SLAM Dashboard Example 2

Radiation Oncology A

NEW PATIENT · FOLLOW UP

◻ FY 2016 ◼ FY 2017 ◼ FY 2018

Radiation Oncology B

NEW PATIENT · FOLLOW UP

◻ FY 2016 ◼ FY 2017 ◼ FY 2018

RadOnc A New Patient Volume

JUL · AUG · SEP · OCT · NOV · DEC · JAN · FEB · MAR · APR · MAY · JUN

◆ FY 2016 ■ FY 2017 ▲ FY 2018

RadOnc B New Patient Volume

JUL · AUG · SEP · OCT · NOV · DEC · JAN · FEB · MAR · APR · MAY · JUN

◆ FY 2016 ■ FY 2017 ▲ FY 2018

Figure 3. SLAM Dashboard Example 3

Gynecologic Oncology New Patients
■ Dr. A ■ Dr. B

Gynecologic Oncology Surgery Volume
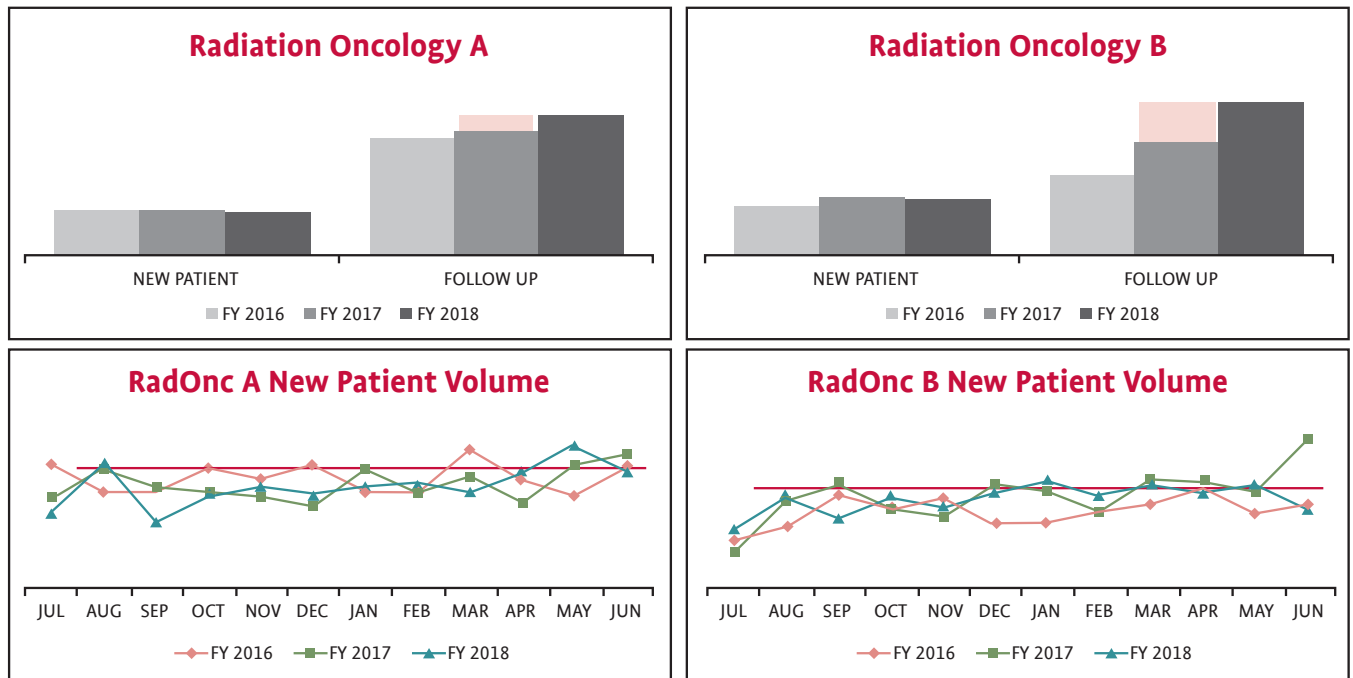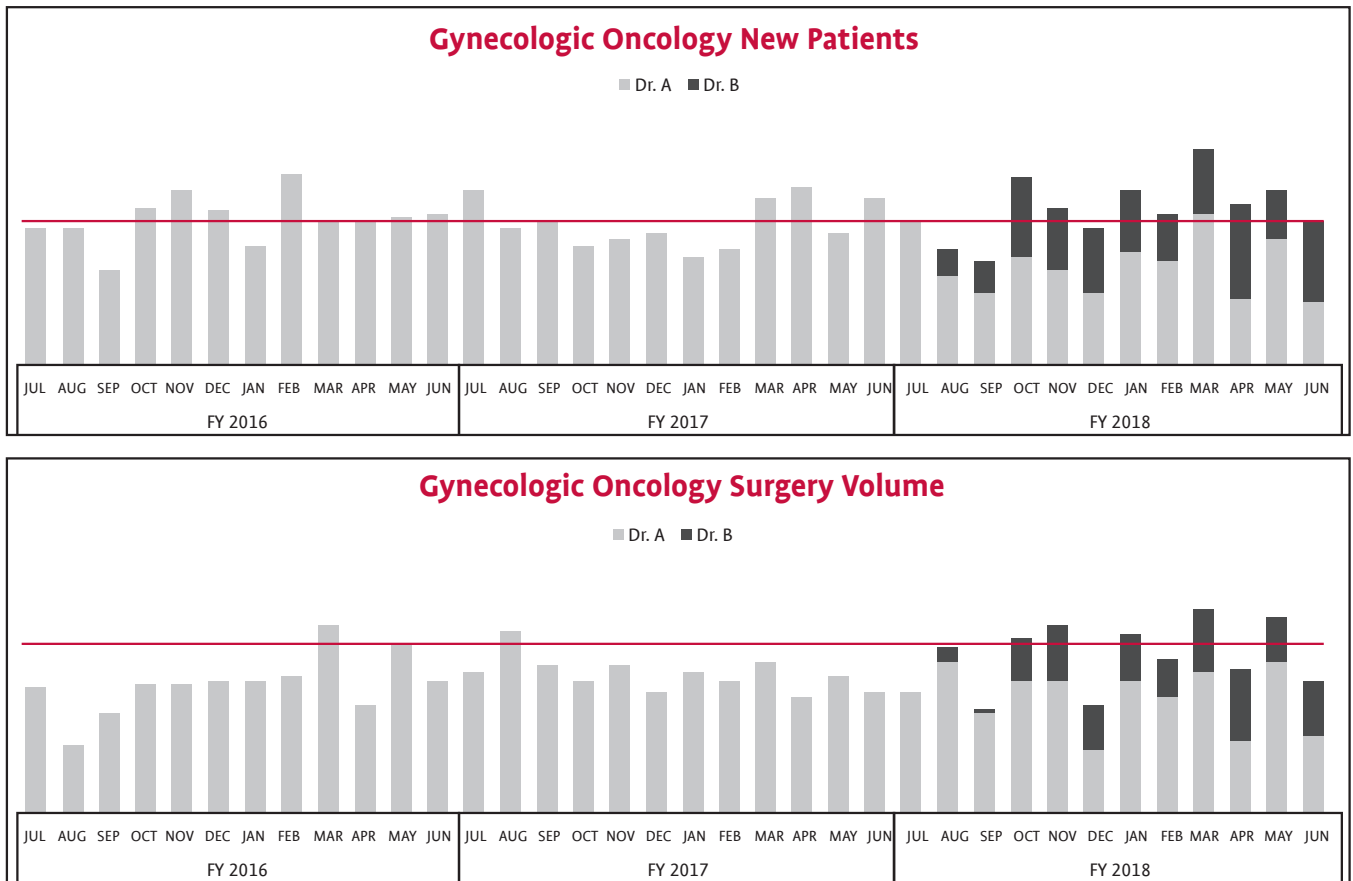■ Dr. A ■ Dr. B

(continued from page 19)

The Revenue Cycle Tier Model

As a strategy to prompt interdepartmental knowledge sharing across health system silos, the administrator of the oncology service line proposed a model for increasing and improving communications by placing renewed focus on the revenue cycle. The revenue cycle tier model, as it came to be known, served as a communication structure consisting of three tiers that meet at different intervals with different purposes. The director of operations and strategies meets with all three tiers and ensures communications from these teams is shared with the appropriate departments and/or staff members.

- **Tier I.** Participants in Tier I include department directors from finance, health information management, corporate compliance, all oncology service lines, pharmacy, and patient financial services. Participants meet quarterly to discuss big-ticket items such as the Centers for Medicare & Medicaid Services proposed rules, major software upgrades and initiatives, and quality metrics such as OP33 or OP35.

- **Tier II.** This tier consists of practice managers from the oncology service line, data analysts, and other mid-level administrative co-workers. Monthly meetings are held to explain what was discussed in the Tier I meetings; participants also review key performance indicators to help break down communication barriers and share knowledge across departments (see Figure 4, page 22).

- **Tier III.** Tier III includes ad hoc working groups of the frontline co-workers who are working with patients every single day. These co-workers are most often found to function in silos apart from one another; by sharing information both vertically and horizontally within LCRP's organizational structure, breaking down silos becomes a daily occurrence.

Breaking Down Silos with Process Improvement

As a result of the revenue cycle tier model and with the use of the Lean Six Sigma methodology, LCRP implemented structural and process improvement strategies that have had a significant

Figure 4. Key Performance Indicator Dashboard Example

RO KPI Visuals
— RadOncA — RadOncB — FY 18 Average
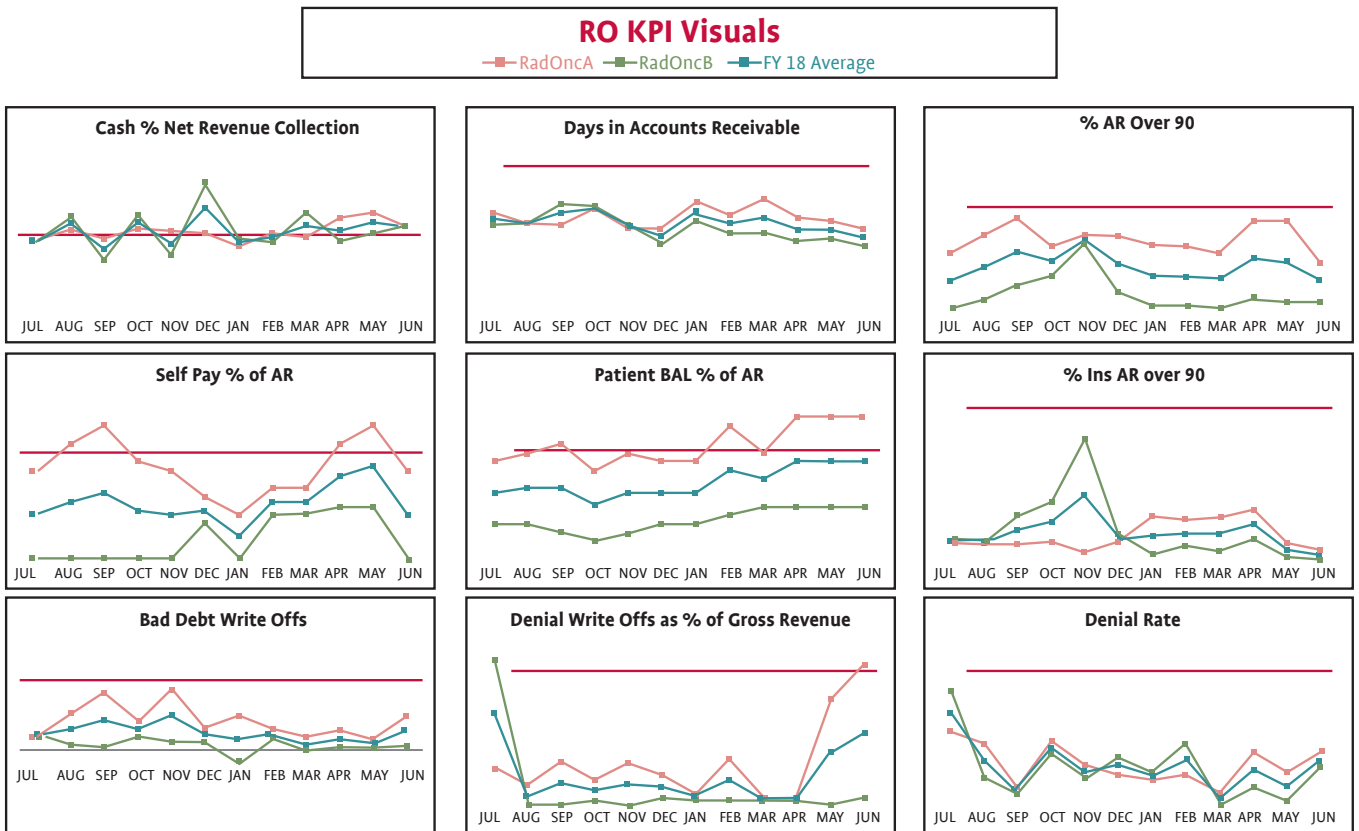
impact on the cancer center's financial health. For instance, through Tier I meetings, barriers between the clinical services area and the back-end financial team were eliminated by leveraging a monthly denials workgroup that addresses every denial the cancer center receives.

As previously noted, a significant source of denials and loss of revenue is associated with demographic data entry errors. By conducting a standardization project with five physician practices that focused on variations in workflow, notabl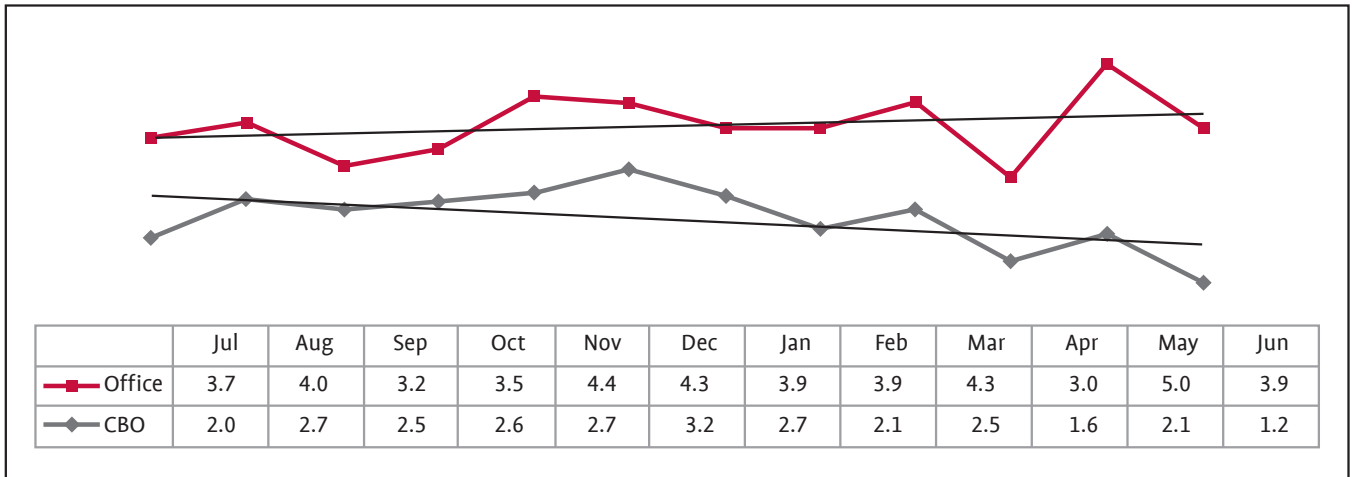e reductions in data errors were achieved. In 2016, 3,700 of 5,800 patients were registered with at least one demographic error (64.8 percent). Errors were defined as incorrect or missing date of birth, race, gender, ethnicity, address, phone number, language, marital status, and guarantor or insured party relationship. After implementing an ideal state workflow in the practices in 2017, we measured a month of patient registrations (Oct. 2 to Nov. 13) and found that errors had been reduced by 54.3 percent (18 of 172 patients showed data entry errors at registration). By engaging and educating frontline co-workers at weekly meetings, the leadership

team fixed the multiple errors that generated downstream problems in the revenue cycle and EHR documentation.

Through the SLAMs, a focus on departmental timelines for charge input, review, and approval prior to charge export surfaced (see Figure 5, right). Best practices in the medical and radiation oncology practices were carried over to improve practices within surgical oncology. Additionally, surgical oncology faced interdepartmental barriers associated with a time lag for completed pathology and operative reports. Although this delay remains a work in progress that is being addressed by the information services department, the problem would have gone undiscovered without a concerted effort to identify departmental silos.

Improving communications between management and co-workers on the front lines of activity is a major step in breaking down barriers. The flow of information from addressing vacation schedules to timing charge export schedules resulted in improvements that had an immediate impact on the revenue cycle. For example, a sudden increase in charge delays in November was discovered to coincide with the charge entry individual's vacation

Figure 5. Charge Lag Analysis for Surgical Oncology and Central Billing Office

	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun
Office	3.7	4.0	3.2	3.5	4.4	4.3	3.9	3.9	4.3	3.0	5.0	3.9
CBO	2.0	2.7	2.5	2.6	2.7	3.2	2.7	2.1	2.5	1.6	2.1	1.2

days. Fail-safes were then implemented to ensure that work continued despite co-worker absence. Another example of simple changes that have significant impact related to the process inefficiency identified and corrected within LCRP's central billing office regarding the timing of automatic charge exports. The co-worker responsible for inputting charges into claims had a work schedule of 7:00 am to 3:00 pm; however, the automatic charge export process began at 2:00 pm each day, leaving the co-worker with only one hour to process same-day charges. Due to the isolation surrounding the existing silo, the co-worker did not communicate the issue and believed that the process could not be changed. As a result, leadership was unaware of this significant inefficiency. To address the issue, leadership moved the charge export process up to noon, giving the co-worker three hours to complete same day charge import.

Active participation and ongoing reporting in the revenue cycle tier model are important to its continued success. For example, Tier II members requested a report to be auto-generated to include the following:

- Patients who do not have an active authorization or referral
- Patients who have an appointment scheduled between today and five days away
- Patients who have an active authorization or referral with an expiration date between today and five days away.

If co-workers receive a blank report, managers can congratulate their co-workers on a job well done. If the report yields results, co-workers are alerted to those patients who may have slipped through the cracks and will require some action prior to the time of service.

Closing Thoughts

Healthcare delivery systems are complex organizations with multiple stakeholders, each with a particular interest and focus. Successful integration of services, clinical and financial, is driven by proactive steps to break down barriers associated with the natural tendencies of areas to form silos. LCRP leadership aggressively tackled the silos identified within the cancer center, as well as those within the health system that impacted service line operations. The revenue cycle tier model served as a useful approach in the early efforts to address interdepartmental communications. Over the course of time, this model continues to evolve and has changed to meet the dynamic needs of the overall system. The ability to shift dynamically in a manner that is transparent, is fostered by trust, and fits the ongoing transformations of the health system is a testament to LCRP's foundational work to eliminate silos. As a result, the Nancy N. and J.C. Lewis Cancer & Research Pavilion is able to undergo continuous process monitoring and improvement without disrupting workflow and is able to evolve workflow processes.

A misconception about process improvement efforts is that they create efficiencies leading to layoffs. In LCRP's experience, no co-workers were laid off as the result of Lean Six Sigma projects. A reduction in process redundancies allows for the talents of co-workers to be used in more productive ways. When co-workers with these concerns understood the potential of process improvement coupled with job security, staff became part of the solution, even identifying other areas for employee contributions and improvements.

Creating and maintaining working groups is a key component of any process improvement effort. Collaborative groups allow co-workers in all departments and at all levels of expertise to ask questions, share information, and tackle significant problems. Through these interactions, silos are broken down and communication improves. LCRP leadership encourages other organizations to evaluate process and workflow, identify areas for improvements, continually monitor implemented solutions, and celebrate successful outcomes with all co-workers. **OI**

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Reference

1. Fralicx R. Strange bed (side) fellows: physician-finance collaboration: physicians and financial leaders are working together to solve health care's biggest challenges—cost and quality. *Healthc Financ Manage.* 2012;66(7):90-96.

Our Program At-a-Glance

The Nancy N. and J.C. Lewis Cancer & Research Pavilion occupies 56,000 square feet in Savannah, Ga. As part of St. Joseph's/Candler, the cancer center sees approximately 1,900 analytic cancer cases per year between its flagship Savannah location and at other locations throughout the Lowcountry of South Carolina and southern Georgia. The center offers radiation oncology, including the robotic Cyberknife; surgical oncology services through system-employed providers and private practices; and medical oncology services through a complement of private practitioners, professional service agreements, and joint ventures. Supporting the multidisciplinary and integrated clinical treatment teams are the supportive oncology services team (composed of nurse navigators, social workers and dieticians), genetic counseling services, survivorship care, and the outpatient palliative care service.

The Lewis Cancer & Research Pavilion is accredited by the American College of Surgeons, Commission on Cancer, and the National Accreditation Program for Breast Cancers. The Lewis Cancer & Research Pavilion's radiation oncology program is accredited by the American College of Radiology, and its South Carolina medical oncology practice is accredited by the American Society of Clinical Oncology's Quality Oncology Physician Initiative. LCRP is a major component of the Georgia Community Oncology Research Program and was recently (August 2019) selected by the National Cancer Institute for a six-year award as one of the National Cancer Institute's community oncology research programs.

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Cancer Care Considerations for Sexual and Gender Minority Patients

BY MANDI L. PRATT-CHAPMAN, MA, PHD, AND JENNIFER POTTER, MD
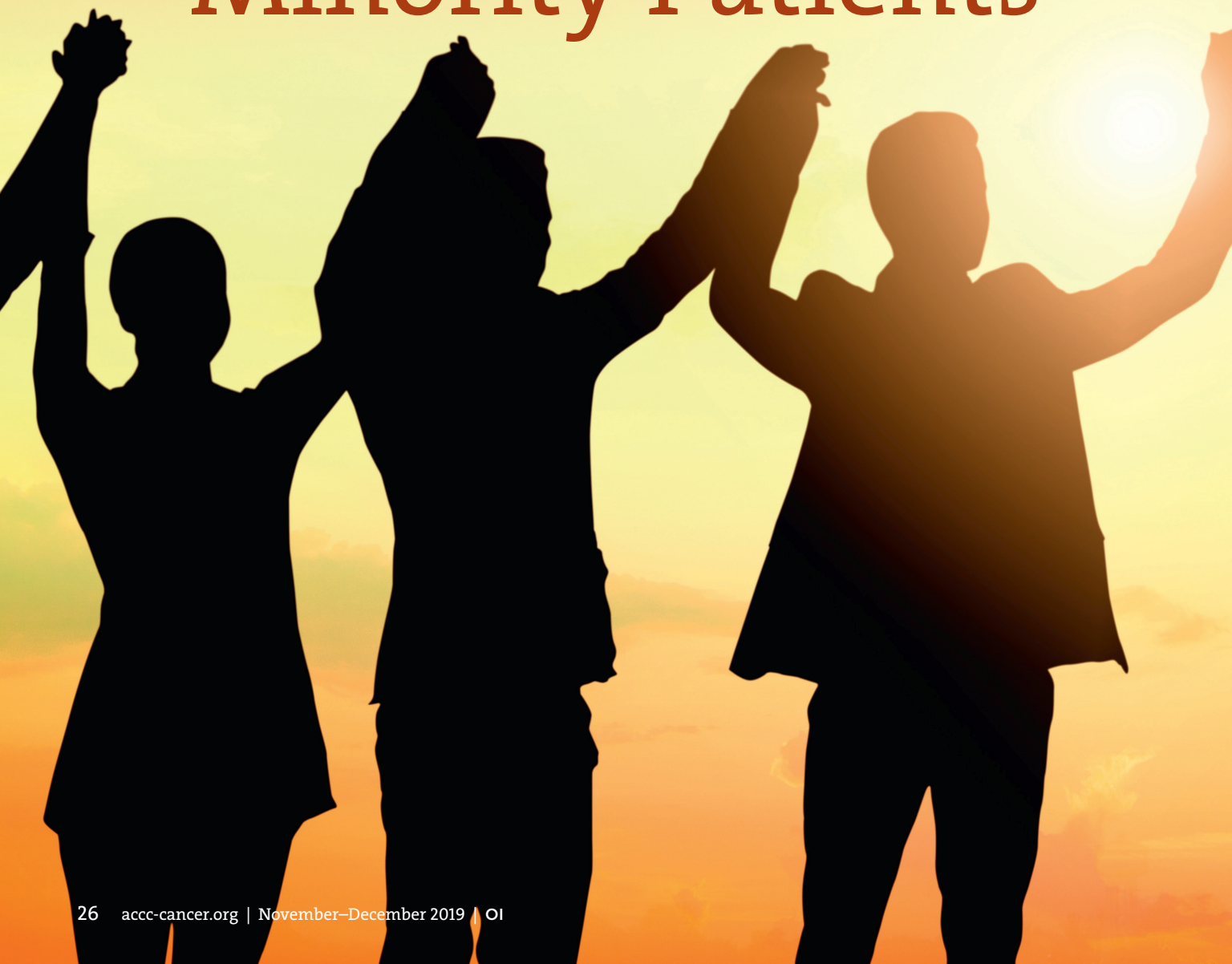
More than 5 percent of the U.S. population identifies as lesbian, gay, bisexual, transgender, queer, or intersex (LGBTQI).[1-3] Inclusively termed "sexual and gender minorities," LGBTQI people have unique health and healthcare needs that are not being met by most healthcare providers.[4] Emerging research has demonstrated poorer health promotion behaviors, healthcare avoidance, and health disparities among sexual and gender minorities due to chronic social stigma, past or anticipated discrimination, or outright denial of care.[5] Lack of healthcare provider cultural and clinical competence—including knowledge of and attitudes toward sexual and gender minorities, culturally affirming behaviors, and clinical management strategies—has a direct impact on sexual and gender minority patient experiences with healthcare, healthcare-seeking behaviors, and health outcomes.

In 2013 the World Health Organization described healthcare for sexual and gender minorities as inadequate: "Few healthcare providers or practitioners can provide adequate information, let alone comprehensive, safe, and appropriate services."[6] Specific to cancer care, the American Society of Clinical Oncology issued a position statement that called for five strategies to improve the health of sexual and gender minorities patients diagnosed with cancer, including improved patient and provider education, policy solutions, and inclusive research.[7]

> Lack of knowledge among healthcare professionals regarding the degree of stigma, bias, and unique challenges faced by sexual and gender minorities impacts all aspects of cancer care.

Healthcare providers want to know how to care for sexual and gender minority patients. In a recent national survey of oncologists at National Cancer Institute-designated cancer centers, 70.4 percent of respondents were interested in more education about the needs of sexual and gender minority patients.[8] Nevertheless, healthcare practitioners have few opportunities to learn about sexual and gender minority health.[9]

Fortunately, some online training has recently become available to healthcare practitioners.[10-12] Further, though the U.S. Preventive Services Task Force (USPSTF) is silent on recommendations specific to sexual and gender minorities, consensus-based guidelines exist for transgender cancer screening.[13] Various modalities

of training at different points in pre-clinical, clinical, and post-graduate education are optimal for learner self-reflection and application of new knowledge through skill-building.[14]

This article aims to partially fill this learning gap by summarizing clinical considerations across the cancer continuum of care and providing resources for providers interested in learning more about how to better serve sexual and gender minority patients.

Healthcare providers can do much to make sexual and gender minority people feel safe in the clinical environment. Visible signs of inclusion, such as brochures and posters that reflect sexual and gender minorities, as well as availability of relevant patient education information demonstrate that the environment is welcoming.

Impact of Social Context on Health

Lack of knowledge among healthcare professionals regarding the degree of stigma, bias, and unique challenges faced by sexual and gender minorities impacts all aspects of cancer care. Sexual and gender minorities have statistically higher rates of tobacco, alcohol, and substance abuse compared to heterosexual and cisgender (nontransgender) peers, increasing risks for cancer and chronic disease.[5] Sexual practice risk factors increase prevalence of sexually transmitted infections and HIV.[15] Sexual and gender minorities also experience access to care barriers, including discrimination, outright denial of care, and subsequent healthcare avoidance—which result in lower rates of cancer screening and higher rates of anticipatory anxiety.[5]

Maladaptive coping strategies may develop, in part, from chronic stress due to lack of visibility in healthcare data and legal discrimination. Overall, 21 states currently have religious exemption laws that allow individuals, organizations, and businesses to refuse services to sexual and gender minorities.[16] In addition, sexual and gender minorities remain largely invisible in national and state-level health data.[17] The proposed 2020 Census plans to capture same-sex households, but single sexual minorities and all transgender, genderqueer, and intersex people will remain uncounted.[17]

Invisibility of intersex people in mainstream society (approximately 1.7 percent of the population)[3] is even greater.[18] Research to optimize healthcare of intersex people is severely lacking, and education on what is known about intersex medical management is sparse in current medical school curricula.[9] Though only a portion of intersex people have ambiguous genitalia, it is vital to note that the longstanding practice of surgical intervention for ambiguous genitalia is not medically indicated and leads to unnecessary and painful lifelong repercussions—including high potential for additional surgeries and infections. In 2017 three former U.S. surgeons general called for a moratorium on intersex infant genital surgeries.[19]

Patient-Centered Communication

Often healthcare providers have not been taught basic terminology to communicate with sexual and gender minorities. Table 1, right, provides a list of basic terms that healthcare providers should know. Patient-centered communication for transgender people requires use of their correct name and pronouns. To provide affirming communication, opportunities for disclosure of gender identity are paramount.

Healthcare providers may not realize the extent to which sexual and gender minority people are harmed by hetero-presumptive or cis-presumptive care settings. Sexual and gender minorities may delay or refuse healthcare until needs are urgent out of fear of anticipated or past discrimination or mistreatment in healthcare settings.[5] For example, in the *2011 National Transgender Discrimination Survey*, almost 20 percent of transgender respondents reported having been refused medical care.[20]

Healthcare providers can do much to make sexual and gender minority people feel safe in the clinical environment. Visible signs of inclusion, such as brochures and posters that reflect sexual and gender minorities, as well as availability of relevant patient education information demonstrate that the environment is welcoming. Allowing patients opportunities to disclose sexual orientation and gender identity on intake forms and through open and non-assumptive dialogue is also crucial (see Figure 1, page 30). Most sexual and gender minority patients who are "out" to their providers must awkwardly correct hetero-sexist and cis-genderist assumptions from their healthcare providers.[15] Providers should listen carefully to the words that patients use. Affirming language includes referring to patients using their chosen names and pronouns, referring to body parts the way a patient refers to them, using gender-neutral language when gender is not clear, and minimizing hetero-presumptive and cis-presumptive language and policies. Affirming care requires attention from not only the practicing physician but the entire healthcare and administrative team, so all staff must receive training.

In terms of responsive clinical care, competent care means shifting from the mindset of male versus female cancers—and "women's health" centers—to assessment of cancer risk based on patient anatomy. Competent care also requires ongoing provider self-reflection on how personal beliefs and assumptions might affect patient access to and experiences of care.

Finally, lifelong learning is paramount. Sexual and gender minority patients—particularly those who are transgender or intersex—are often frustrated by having to teach their care providers over and over again about their healthcare needs. These patients need their provider(s) to already be knowledgeable about their healthcare needs. Proactively seeking information and edu-

Table 1. Basic Terminology

Bisexual: Person who has a sexual attraction to people regardless of sex or gender.

Bottom surgery: Gender-affirming surgical intervention on genitalia (could include a variety of procedures ranging from orchiectomy to vaginoplasty for transfeminine people or phalloplasty for transmasculine people; more commonly performed for transfeminine than transmasculine people in the United States due to complexity and cost of procedure as well as maturation of surgical technique).

Cisgender: Person whose gender identity aligns with their sex assigned at birth.*

Difference of sex development: Term that replaced "disorders of sex development."*

Disorders of sex development: Outdated term for many congenital conditions in which development of chromosomal, gonadal, and/or anatomical sex is atypical.

Gay: A person who primarily identifies romantic and sexual feelings toward same-gender persons.

Gender: Socially constructed term to describe characteristics perceived as "male" or "female."

Gender identity: Distinct from sex, the gender that a person feels through their lived experience.

Gender-affirming: Positive and affirming behaviors toward a person's gender and gender identity.

Gender dysphoria: Significant distress due to discordance between sex and gender identity.

Genderqueer: Challenging gender norms, including transgender and nonbinary/agender people.

Heterosexism: Beliefs and/or systems that assume that opposite-sex sexuality is the norm.

Homophobia: A range of negative reactions to same-gender attraction or behavior.

Intersectionality: The multiple ways in which an individual identifies in terms of sex, sexual orientation, race, ethnicity, socioeconomic experience, geography, and other personal descriptors

Intersex: Preferred term for people whose sex falls between male-typical and female-typical forms.

Lesbian: A nonheterosexual person who identifies primary romantic and sexual feelings toward women.

Queer: Umbrella term referencing nonmainstream sexual orientation and/or gender identity.

Sex: Sex karyotype and phenotype at birth.

Sexual orientation: Complex construct comprised of sexual identity, attraction, and behavior.

T: Short for testosterone.

Transgender: Individuals whose gender identities do not align with their sex assigned at birth.

Top surgery: Gender-affirming surgical intervention on breasts (reduction or removal for transmasculine people, enhancement for transfeminine people).

Transitioning: Process of adopting and/or affirming a gender identity different from sex assigned at birth; may but does not always include hormonal and/or surgical interventions.

Transphobia: Range of negative reactions toward gender-nonconforming people.

Two-spirit: Term used by some Native American communities for people who have both feminine and masculine qualities.

*Term is not universally embraced.

Figure 1. I Want You to Know … Intake Form

I WANT YOU TO KNOW...

My legal name is: _____   Please call me: _____

My pronouns are: _____   (ex. she/her, they/them, he/him)

I identify as a person who is: _____ , _____ & _____
                              race/ethnicity   sexual orientation   gender identity

I am most comfortable using this language or languages: _____

I believe in: _____ religion/faith

These are the people I want involved in my care (check all that apply):

☐ Spouse/Partner   ☐ Child   ☐ Friend   Anyone else?
☐ Parent   ☐ Sibling   ☐ Relative   _____

I would like them to be able to (check all that apply):

☐ Come to appointments   ☐ Ask for information, materials, and resources
☐ Come into the exam room   ☐ Discuss treatments
☐ Stay in the waiting room   ☐ Help make financial decisions
☐ Help make decisions   Anything else?
☐ Ask questions   _____

I WANT YOU TO KNOW...

Over the past three (3) months, I have been worried about:

☐ Transportation   ☐ School
☐ Childcare   ☐ Personal safety
☐ Housing   ☐ Insurance
☐ Money   ☐ Spiritual concerns
☐ Food   Anything else?
☐ Job or work   _____

Anything else you should know about me:

_____

GW Cancer Center   For more information, visit **gwcancercenter.com**

This document was developed by the George Washington University (GW) Cancer Center with support from the Pfizer Foundation.
Contents are solely the responsibility of the authors and do not necessarily represent the official views of Pfizer Foundation.

Table 2. Recommendations to Improve Communication with Sexual and Gender Minority Patients

1. Provide visual displays of inclusion in the clinical environment.

2. Provide a safe space for patients to disclose sexual orientation and gender identity.

3. Remember that you do not have to share the beliefs of your patients in order to ethically care for them.

4. Consider how your assumptions and reactions toward patients might affect their healthcare experience.

5. Use the words the patient uses—including chosen names, pronouns, and names for body parts.

6. Consider hormones, anatomy, and body composition rather than gender when making clinical recommendations.

7. Ensure that questions are clinically relevant and for the well-being of the patient.

8. Support the patient's chosen caregivers.

9. Apologize when you make a mistake.

10. Do your homework. Educate yourself on the health and healthcare needs of sexual and gender minorities.

cation on sexual and gender minorities' healthcare needs, asking clinically relevant questions, and apologizing when a mistake is made show that providers take their responsibilities as clinical caregivers seriously. Table 2, above, lists ten recommendations to improve communication with sexual and gender minority patients.

Cancer Prevention

Healthcare providers should screen for alcohol, tobacco, and other substance use among sexual and gender minority patients. Sexual and gender minorities are more likely to use and abuse substances compared to the general population.[5] Because gay bars were the only safe spaces for sexual and gender minorities for decades, a bar culture developed. In addition, tobacco companies heavily targeted sexual and gender minority communities in the 1990s, leading to higher rates of tobacco use among sexual and gender minorities.[21] There are few substance abuse and tobacco cessation programs tailored for sexual and gender minorities.[22] However, responsive interventions can build on evidence-based practices from the Substance Abuse and Mental

Health Services Administration.[23] Tailored programs should address the social context factors that are underlying drivers of substance abuse and take place in non-judgmental environments with affirming, patient-centered communication.[22,24] Social context factors include higher rates of family rejection, lack of social support, stigma, discrimination, and abuse.[22,24]

Though the human papillomavirus (HPV) vaccine is important for everyone starting at age 11 through 45, the risk for sustained HPV infection is more likely in people living with HIV—and men who have sex with men as well as transgender women have higher rates of HIV infection.[25] In addition, men who have sex with men, as well as anyone engaging in anal sex, have a heightened risk for HPV-associated anal cancer.[26] In short, all eligible people should be vaccinated, but risks may be higher among sexual and gender minorities in the long term.

Cancer Screening

Providers should recommend colorectal and lung cancer screenings to all sexual and gender minority patients as they would for any other patient—based on age and risk factors. The USPSTF recommends colonoscopy every 10 years; computed tomography colonography every 5 years; flexible sigmoidoscopy every 5 years; flexible sigmoidoscopy every 10 years with annual fecal immunochemical test (FIT), annual FIT, or fecal occult blood test screening; or FIT-DNA every 1-3 years for colorectal cancer for all average-risk people aged 55-75 years old.[26] The USPSTF recommends annual low-dose computed tomography screening for people aged 55-80 years old with a 30 pack-year history of smoking and who currently smoke or have quit within the past 15 years.[27]

Queer people who are not transgender or intersex should generally receive cancer screenings based on USPSTF guidelines for other cancers as well. One exception to this rule is anal cancer screening. Though there are no USPSTF guidelines for anal cancer screening, men who have sex with men and people living with HIV have an increased risk for anal cancer.[25,28] The European Society of Medical Oncology recommends that high-risk populations, defined as men who have sex with men and anyone who has anal intercourse, receive anal Pap testing and high-resolution anoscopy.[25] The American Cancer Society indicates no general recommendation for anal cancer screening but notes that men who have sex with men, women with cervical or vulvar cancer, and people living with HIV are at increased risk and that digital rectal examination can help to identify cancer early.[28] Transgender women of color bear a disproportionate burden of HIV and should be included as part of this high-risk population.[25]

It is important not to confuse sexual orientation and gender identity. Lesbian, gay, and bisexual people have a minority sexual orientation but do not necessarily have body parts or exogenous hormones that could alter cancer screening and clinical management recommendations. Cancer screening for transgender and intersex people can be confusing, because hormone balance, anatomy, and body composition may vary widely. No rigorous studies have been conducted to inform clinical practice for transgender or intersex individuals. However, the University of Cali-

fornia San Francisco has consensus-based guidelines for the care of transgender people. The university recommends, "As a rule, if an individual has a particular body part or organ and otherwise meets criteria for screening based on risk factors or symptoms, screening should proceed regardless of hormone use."[29] Specifically, breast, prostate, cervical, and endometrial/ovarian cancer screenings for transgender and intersex people merit discussion.

> Assessing hormone risks and hormone receptor status is important when creating treatment plans for transgender patients. The prospect of abandoning hormonal treatment in order to treat cancer can be extremely distressing to anyone on the transgender spectrum receiving hormonal treatment.

All transgender people are potentially at risk for breast cancer. A recent large population-based study in The Netherlands demonstrated that though hormone treatment for transmasculine individuals had a protective effect, breast cancer risk for transfeminine individuals using estrogen increased in a short period of time on hormones: 83 percent of breast cancer cases in these transgender women were estrogen positive.[30] Consensus-based guidelines from the University of California San Francisco indicate that breast cancer screening should be performed every other year for transfeminine people with 5 or more years of estrogen therapy who have achieved the age of at least 50.[31] Screening for transmasculine people should be individualized based on degree of breast tissue if breast reduction or bilateral mastectomy has been performed.[32]

Cervical cancer screening should be recommended by clinicians for anyone with a cervix. The USPSTF recommends Pap testing every 3 years for cisgender women in their 20s, which can continue on the same schedule through age 65 or Pap and HPV DNA co-testing or HPV testing alone every 5 years for cisgender women aged 30-65 years.[33] Transmasculine individuals may be less likely to receive cervical cancer screening than cisgender people even within a strongly affirming environment due to gender dysphoria.[34] Results of cervical cytology for transmasculine people can also appear unsatisfactory due to changes in histology resulting from testosterone.[35,36] Interventions to improve cervical cancer screening among transmasculine people are critically needed. Gender-affirming procedures should include clear communication regarding each step of the screening process, use of a smaller speculum, patient insertion of speculum if desired, use of water-based lubrication, and anti-anxiety medication when necessary.[36]

National guidelines recommend that cisgender women be informed about risks and symptoms of endometrial and ovarian cancer at the onset of menopause—and instructed to promptly report post-menopausal bleeding to their healthcare provider.[37] Routine screening for asymptomatic women is not recommended. No screening modality has yet been found to be effective.[38] Consensus guidelines recommend that transmasculine individuals who retain internal reproductive structures and who no longer have menses follow the same recommendations.[38]

For men aged 55-69 years, the USPSTF recommends that prostate cancer screening be an individual decision after discussing risks and benefits with their healthcare provider.[38] Healthcare providers need to remember to have these discussions with transgender women who retain a prostate and are therefore at risk for prostate cancer. Providers also need to know how to interpret prostate-specific antigen levels in this population, because levels are usually lower for transgender women on estrogen than for cisgender men: consensus guidelines recommend that a prostate-specific antigen of 1 ng/mL should be considered the upper limit of normal.[39] Table 3, right, outlines cancer screening considerations for transgender and intersex people.

Cancer Treatment

As mentioned above, hormones affect risk for cancer among transgender individuals. For example, estrogen increases risk of breast cancer for transfeminine people compared to cisgender males but not to the degree of cisgender females.[30] Assessing hormone risks and hormone receptor status is important when creating treatment plans for transgender patients. The prospect of abandoning hormonal treatment in order to treat cancer can be extremely distressing to anyone on the transgender spectrum receiving hormonal treatment. Some patients may choose to abandon cancer treatment, finding discontinuation of hormonal therapy unacceptable.[40] Professional psychosocial support should be provided to patients, with a focus on shared decision making after considering both the risks and benefits of discontinuing versus continuing hormonal therapy while undergoing cancer treatment.

Non-screenable cancers that show some risk among transgender people include meningioma and prolactinoma in transgender women.[41] However, only four cases of meningioma have been reported in the literature among transgender women and only eight cases of prolactinoma have been reported among transgender women.[41] Clinicians should note that given the elevated risk for HIV among men who have sex with men and transgender women, risk for Kaposis sarcoma and non-Hodgkin lymphoma should be considered based on symptoms.[24]

For intersex people, cancer risk factors depend on specific chromosomal status, specifically Y-chromosomal material and gonadal position.[42] For intersex people with no Y-chromosomal material (those with congenital adrenal hyperplasia), cancer risk is not greater than that for non-intersex people.[43] Testicular cancer is greater in postpubertal people with androgen insensitivity syndrome who have undescended testes.[42] Risk of germ cell tumors in patients with androgen insensitivity syndrome with undescended

Table 3. Cancer Screening Considerations for Transgender and Intersex People

Cancer Screening	Transfeminine	Transmasculine	Intersex
Breast	Screen per USPSTF guidelines for women if estrogen exposure is ≥5 years and age is 50+.	If top surgery has been performed, individualize screening based on amount of breast tissue and risk profile. If top surgery has not been performed, screen using USPSTF guidelines for women.	Individualize screening based on amount of breast tissue and risk profile.
Cervical	Not indicated	Screen per USPSTF guidelines for women if cervix is retained. Gender dysphoria is strong and gender-affirming precautions should be taken. Histological changes for people on testosterone may result in false positive screening.	Screen per USPSTF guidelines for women if cervix is present.
Endometrial and ovarian	Not indicated	If bottom surgery, not indicated. If no bottom surgery, inform of risks and symptoms; encourage patient to report unexpected bleeding.	Inform patients with a uterus of risks and symptoms. Encourage patient to report unexpected bleeding.
Prostate	Individualize based on risk factors, (e.g., ≥50 years old, African American) and benefits. Prostate-specific antigen 1 ng/mL is upper limit of normal if patient is on estrogen therapy.	Not indicated	Research is insufficient to provide recommendation. Individualize based on risk and benefits if patient has a prostate.

testes can be as high as 50 percent.[42] Gonadoblastoma is almost entirely limited to intersex people with undescended testes.[42] Treatment for these conditions includes informed consent for radical gonadectomy. Comprehensive genetic screening of Y-chromosomal material with genetic counseling is important for these patients.

Hormonal and chromosomal considerations are not limited to transgender and intersex people at risk for or diagnosed with cancer. A recent review of sex-based differences in cancer outcomes found that 53 percent of clinically actionable genes (60/114) had sex-based signatures.[43] Differential efficacy of cancer therapeutics based on sex chromosomes and hormone status may have enormous implications not only for transgender individuals on cross-

sex hormones and those anatomically discordant with their natal chromosomal signature but for cisgender men and women as well.[43]

Despite the elevated risk for some cancers among sexual and gender minorities, current National Comprehensive Cancer Network (NCCN) guidelines do not include clinical management considerations for sexual and gender minority patients specifically. Additionally, a recent survey of NCCN panel members found that most panelists had no plans to address these considerations in future guidelines.[44] Given the dearth of information in the clinical literature to inform cancer care management, this may appear reasonable. However, a growing body of sexual and gender minorities research demonstrates that behavioral risks, anatomical

Table 4. Clinical Guidelines, Advocacy, and Legal Resources

Association of American Medical Centers Sexual and Gender Minority Health Resources: aamc.org/initiatives/diversity/lgbthealthresources

Center for Excellence for Transgender Health: transhealth.ucsf.edu

Endocrine Treatment of Gender-Dysphoric/Gender-Incongruent Persons: An Endocrine Society. Clinical Practice Guideline 2017: academic.oup.com/jcem/article/102/11/3869/4157558

Gay and Lesbian Medical Association: glma.org

GW Cancer Center. "Addressing the Need for LGBTQI-Affirming Care: A Focus on Sexual and Gender Minority Prostate Cancer Survivors": cancercenter.gwu.edu/news/prostate-cancer-awareness-month-resources

InterACT, Advocates for Intersex Youth: interactadvocates.org

National Center for Transgender Equality: transequality.org

Lambda Legal: lambdalegal.org

LGBT Cancer Network: cancer-network.org

National LGBT Health Education Center: lgbthealtheducation.org

Sage, Advocacy & Services for LGBT Elders: sageusa.org

World Professional Association for Transgender Health: wpath.org

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features, hormone balance, and chromosomal risk factors of sexual and gender minorities affect cancer risk and treatment efficacy. Furthermore, sexual and gender minorities have unique psychosocial support needs. Therefore, collection of sexual orientation and gender identity data across all areas of health research is critical to inform future care for patients diagnosed with cancer and other conditions.

Cancer Survivorship

Cancer survivorship can be uniquely challenging for sexual and gender minorities given heteronormative assumptions. For example, a clinical assumption that every person who has breast surgery will want breast reconstruction can be disaffirming to genderqueer individuals and sexual minority women. A qualitative study of genderqueer patients with cancer who had bilateral mastectomy or a hysterectomy showed that for some patients surgery constituted both cancer treatment and gender-affirming care.[45] Another study showed that some lesbians resented pressure to conform to social expectations for breast reconstruction.[46] For these patients, assumptions that all patients want cisgender female breast reconstruction or that a hysterectomy is unwelcome contradicts the tenets of patient-centered care.

Compared to straight counterparts, queer prostate cancer survivors have reported worse urinary, bowel, and hormonal symptoms; worse mental health; and greater fear of recurrence.[47] Erectile dysfunction and other late effects of treatment result in differential experiences for men who have sex with men compared to their straight male peers, regardless of whether the patient is anal penetrative or receptive.[47] Current pharmaceutical options to treat erectile dysfunction for prostate cancer survivors are inadequate for men who have sex with men.[47,48] The GW Cancer Center offers a guide to help healthcare professionals support queer prostate cancer survivors. "Addressing the Need for LGBTQI-Affirming Care: A Focus on Sexual and Gender Minority Prostate Cancer Survivors" includes a checklist for monitoring care preferences, relationship concerns, sexual dysfunction, urinary dysfunction, bowel dysfunction, and other long-term and late effects.[48] See Table 4, above, for a link to this online guide, as well as other resources for continued learning.

Conclusion

Sexual and gender minorities need and deserve patient-centered care. Lack of provider competence in caring for sexual and gender minorities is due, in part, to lack of education and lack of evidence-

based clinical care guidelines. Graduate school education on sexual and gender minority health and healthcare needs and ongoing practitioner continuing education are needed. Collection of sexual orientation and gender identity data is vital in cancer care and research in order to improve evidence-based guidelines in the future. Though we await evidence to inform better clinical and supportive care for sexual and gender minorities, this article provides some resources and strategies to provide affirming care for sexual and gender minority patients based on what is known now. ◼OI

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References

1. Gates GJ. How many people are lesbian, gay, bisexual and transgender? Available online at: williamsinstitute.law.ucla.edu/wp-content/uploads/Gates-How-Many-People-LGBT-Apr-2011.pdf. Published April 2011. Last accessed August 13, 2019.

2. Flores AR, Herman JL, Gates GJ, Brown TNT. How many adults identify as transgender in the United States. Available online at: williamsinstitute.law.ucla.edu/research/how-many-adults-identify-as-transgender-in-the-united-states/. Published June 2016. Last accessed August 13, 2019.

3. Viloria H. How common is intersex? An explanation of the stats. Available online at: intersexequality.com/how-common-is-intersex-in-humans/. Last accessed August 13, 2019.

4. Obedin-Maliver J, Goldsmith ES, Stewart L, et al. Lesbian, gay, bisexual, and transgender-related content in undergraduate medical education. *JAMA*. 2011;306:971-977.

5. National LGBT Health Education Center. Providing inclusive services and care for LGBT people. Available online at: lgbthealtheducation.org/wp-content/uploads/Providing-Inclusive-Services-and-Care-for-LGBT-People.pdf. Last accessed August 13, 2019.

6. World Health Organization. Improving the health and well-being of lesbian, gay, bisexual and transgender persons. Available online at: ghwatch.org/sites/www.ghwatch.org/files/B133-6_LGBT.pdf. Published May 14, 2013. Last accessed August 13, 2019.

7. Griggs J, Maingi S, Blinder V, et al. American Society of Clinical Oncology position statement: strategies for reducing cancer health disparities among sexual and gender minority populations. *J Clin Oncol*. 2017;35(19):2203-2208.

8. Schabath MB, Blackburn CA, Sutter ME. National survey of oncologists at National Cancer Institute-designated comprehensive cancer centers: attitudes, knowledge, and practice behaviors about LGBTQ patients with cancer. *J Clin Oncol*. 2019;37:547-558.

9. Pratt-Chapman ML. *Getting Sexual and Gender Minority Health "Into the Brick and Mortar": A mixed methods implementation study* [dissertation]. Doctor of Philosophy in Translational Heath Sciences Dissertations. Paper 1. https://hsrc.himmelfarb.gwu.edu/smhs_crl_dissertations/1. Published September 13, 2019. Last accessed October 4, 2019.

10. Seay J. Feasibility and acceptability of an online LGBT cultural competency training for oncologists: the COLORS training. Paper presented at: 11th AACR Conference on the Science of Cancer Health Disparities in Racial/Ethnic Minorities and the Medically Underserved; November 2-5, 2018; New Orleans, LA.

11. Pratt-Chapman ML, Harvey AC. Preliminary outcomes from a pilot health equity learning intervention in a national sample of cancer care organizations: the TEAM training. Paper presented at: AcademyHealth 11th Annual Conference on the Science of Dissemination and Implementation; December 3-5, 2018; Washington, DC.

12. National LGBT Health Education Center. Webinars & video training. Available online at: lgbthealtheducation.org/lgbt-education/webinars. Last accessed August 13, 2019.

13. Duetsch MB, ed. *Guidelines for the Primary and Gender-Affirming Care of Transgender and Gender Nonbinary People*. Available online at: transcare.ucsf.edu/guidelines. Published June 17, 2016. Last accessed August 13, 2019.

14. Akella D. Learning together: Kolb's experiential theory and its application. *J Manage Organ*. 2010;16:100-112.

15. Radix A, Maingi S. LGBT cultural competence and interventions. *Semin Oncol Nurs*. 2018;34:80-89.

16. Movement Advancement Project. Religious exemption laws. Available online at: lgbtmap.org/equality-maps/religious_exemption_laws. Published 2019. Last accessed August 13, 2019.

17. U.S. Department of Commerce, Economics, and Statistics Administration. Questions planned for the 2020 Census and American Community Survey. Available online at: assets.documentcloud.org/documents/4426784/Planned-Questions-2020-Acs.pdf. Published March 2018. Last accessed August 13, 2019.

18. Viloria H. *Born Both: An Intersex Life*. New York, NY: Hachette Books; 2017.

19. Elders MJ, Satcher D, Carmona R. Re-thinking genital surgeries on intersex infants. Available online at: palmcenter.org/wp-content/uploads/2017/06/Re-Thinking-Genital-Surgeries-1.pdf. Published June 2017. Last accessed August 13, 2019.

20. Grant JM, Mottet LA, Tanis J, et al. *Injustice at Every Turn: A Report of the National Transgender Discrimination Survey*. Washington, DC: National Center for Transgender Equality and National Gay and Lesbian Task Force; 2011. Available online at: transequality.org/sites/default/files/docs/resources/NTDS_Report.pdf. Last accessed August 13, 2019.

21. Washington HA. Burning love: Big Tobacco takes aim at LGBT youths. *Am J Public Health*. 2002;92:1086-1095.

22. Hicks D. The importance of specialized treatment programs for lesbian and gay patients. *J Gay Lesbian Psychother*. 2000;3(3):81-94.

23. Substance Abuse and Mental Health Services Administration. Evidence-based practices resource center. Available online at: samhsa.gov/ebp-resource-center. Last accessed August 13, 2019.

24. Ceres M, Quinn GP, Loscalzo M, Rice D. Cancer screening considerations and cancer screening uptake for lesbian, gay, bisexual, and transgender persons. *Semin Oncol Nurs*. 2018;34:37-51.

25. Glynne-Jones R, Nilsson PJ, Aschele C, et al. Anal cancer: ESMO-ESSO-ESTRO Clinical Practice Guidelines for diagnosis, treatment and follow-up. *Ann Oncol*. 2014;25(suppl 3):iii10-iii20.

26. U.S. Preventive Services Task Force. Final recommendation statement: colorectal cancer: screening. Available online at: uspreventive-servicestaskforce.org/Page/Document/RecommendationStatementFinal/colorectal-cancer-screening2. Last accessed August 13, 2019.

27. U.S. Preventive Services Task Force. Final recommendation statement: lung cancer: screening. Available online at: uspreventiveser-vicestaskforce.org/Page/Document/RecommendationStatementFinal/lung-cancer-screening. Last accessed August 13, 2019.

28. American Cancer Society. Can anal cancer be found early? Available online at: cancer.org/cancer/anal-cancer/detection-diagnosis-staging/detection.html. Published November 13, 2017. Last accessed August 13, 2019.

29. Deutsch MB. General approach to cancer screening in transgender people. Available online at: transcare.ucsf.edu/guidelines/cancer-screening. Published June 17, 2016. Last accessed August 13, 2019.

30. de Blok CJM, Wiepjes CM, Nota NM, et al. Breast cancer risk in transgender people receiving hormone treatment: nationwide cohort study in The Netherlands. *BMJ*. 2019;36:l1652.

31. Deutsch MB. Screening for breast cancer in transgender women. Available online at: transcare.ucsf.edu/guidelines/breast-cancer-women. Published June 17, 2016. Last accessed August 13, 2019.

32. Deutsch MB. Screening for breast cancer in transgender men. Available online at: transcare.ucsf.edu/guidelines/breast-cancer-men. Published June 17, 2016. Last accessed August 13, 2019.

33. U.S. Preventive Services Task Force. Final recommendation statement: cervical cancer: screening. Available online at: uspreventive-servicestaskforce.org/Page/Document/RecommendationStatementFinal/cervical-cancer-screening2. Last accessed August 13, 2019.

34. Peitzmeier SM, Reisner SL, Harigopal P, Potter J. Female-to-male patients have high prevalence of unsatisfactory Paps compared to non-transgender females: implications for cervical cancer screening. *J Gen Intern Med*. 2014;29:778-784.

35. Wesp L. Ovarian and endometrial cancer considerations. Available online at: transcare.ucsf.edu/guidelines/ovarian-cancer. Published June 17, 2016. Last accessed August 13, 2019.

36. Rollston R. Promoting cervical cancer screening among female-to-male transmasculine patients. Available online at: fenwayhealth.org/wp-content/uploads/TFIP-28_TransMenCervicalCancerScreeningBrief_web.pdf. Last accessed August 13, 2019.

37. U.S. Preventive Services Task Force. Final recommendation statement: ovarian cancer: screening. Available online at: uspreventive-servicestaskforce.org/Page/Document/RecommendationStatementFinal/ovarian-cancer-screening1. Last accessed August 13, 2019.

38. U.S. Preventive Services Task Force. Final recommendation statement: prostate cancer: screening. Available online at: uspreventive-servicestaskforce.org/Page/Document/RecommendationStatementFinal/prostate-cancer-screening1. Last accessed August 13, 2019.

39. Wesp L. Prostate and testicular cancer considerations in transgender women. Available online at: transcare.ucsf.edu/guidelines/prostate-testicular-cancer. Published June 17, 2016. Last accessed August 13, 2019.

40. Coyote IE, Spoon R. *Gender Failure*. Vancouver, BC, Canada: Arsenal Pulp Press; 2014.

41. Braun H, Nash R, Tangpricha V, et al. Cancer in transgender people: evidence and methodological considerations. *Epidemiol Rev*. 2017;39:93-107.

42. Kathrins M, Kolon TF. Malignancy in disorders of sex development. *Transl Androl Urol*. 5:794-798.

43. Yuan Y, Liu L, Chen H, et al. Comprehensive characterization of molecular differences in cancer between male and female patients. *Cancer Cell*. 2016;29:711-712.

44. Hudson J, Schabath MB, Sanchez J, et al. Sexual and gender minority issues across NCCN guidelines: results from a national survey. *J Natl Compr Canc Netw*. 2017;15:1379-1382.

45. Taylor ET, Bryson MK. Cancer's margins: trans* and gender nonconforming people's access to knowledge, experiences of cancer health, and decision making. *LGBT Health*. 2016;3:79-89.

46. Wandrey RL, Qualls WD, Mosack KE. Rejection of breast reconstruction among lesbian breast cancer patients. *LGBT Health*. 2016;3:74-78.

47. Hart TL, Coon DW, Kowalkowski MA, et al. Changes in sexual roles and quality of life for gay men after prostate cancer: challenges for sexual health providers. *J Sex Med*. 2014;11:2308-2317.

48. GW Cancer Center. Addressing the need for LGBTQI-affirming care: a focus on sexual and gender minority prostate cancer survivors: a guide for health care professionals. Available online at: cancercenter.gwu.edu/news/prostate-cancer-awareness-month-resources. Published 2017. Last accessed August 13, 2019.

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Partnering with Data Analytics to Promote Survivorship Care Plan Success

BY ANDREA ROWE, BS, RHIT; ALICIA ROSALES, LCSW, OSW-C;
AND CHRISTOPHER WEED

In 2016 there were an estimated 15.5 million cancer survivors living in the United States. This number is expected to grow to more than 20 million before 2026. During the past 20 years, patient survivor advocates and national organizations have encouraged cancer survivors to take an active role in their health journey after treatment. This includes requesting a survivorship care plan from their oncology providers.

The survivorship care plan is the patient's guide to life after cancer. It outlines the treatment the patient received; recommendations for surveillance, follow-up, and care coordination; and the long-term risks related to treatment. In 2007 the Institute of Medicine (now the National Academy of Medicine) released *From Cancer Patient to Cancer Survivor: Lost in Transition*, a report that outlines the struggles cancer survivors face when treatment ends. The report encouraged all cancer survivors to request a survivorship care plan from their oncologist.[1] During the past decade, several national oncology organizations such as the National Comprehensive Cancer Network, the American Society of Clinical Oncology, and the American College of Surgeons have followed suit with clinical recommendations and accreditation requirements related to survivorship care planning.

With these recommendations, the survivorship care plan became part of the standard of cancer care. Oncology programs have invested in both clinical and non-clinical resources to meet

> In addition, most oncology programs are so consumed with developing and implementing survivorship care that they have paid little attention to actually tracking and reporting their survivorship care plan compliance.

and accurately report on this standard. Comprehensive reporting on compliance requires a cohesive, open, and dedicated relationship between two teams: the clinical team and the report development team. This article outlines how one oncology program is pushing through the inherent challenges to find success with delivering and reporting on survivorship care planning.

In Pursuit of Standard 3.3

When the Commission on Cancer (CoC) released an updated version of the *Cancer Program Standards* in 2012, including a new standard for survivorship care planning, oncology programs that sought accreditation had to make new strategic investments

in staff and program support.[2] "Standard 3.3: Survivorship Care Plan" is one of the most challenging new standards for CoC accreditation to date. Up to 80 percent of cancer program leaders have identified Standard 3.3 as one of the most difficult to achieve.[3] In 2014 a CoC survey of program participants revealed that only 37 percent of programs felt "completely confident" that they would be able to implement Standard 3.3 by 2015.[4]

The relevant literature cites multiple implementation difficulties among cancer programs attempting to achieve Standard 3.3, such as limited staffing, lack of reimbursement, limited integration of an electronic health record (EHR), and more. In addition, most oncology programs are so consumed with developing and implementing survivorship care that they have paid little attention to actually tracking and reporting their survivorship care plan compliance.

Survivorship at MSTI

St. Luke's Mountain States Tumor Institute (MSTI) began building its survivorship program with evaluation and reporting in mind. MSTI is a multidisciplinary, medium-sized, hospital-based community cancer center with five outpatient clinics stretching across southern Idaho. MSTI sees approximately 3,500 new analytic cases a year; that is, cases that are both diagnosed and treated at MSTI. The multidisciplinary care provided by the cancer center includes surgical oncology, medical oncology, and radiation oncology services provided by both employed and contracted physicians. MSTI also has a robust supportive oncology program that promotes integrated survivorship care (see Figure 1, below).

MSTI has provided survivorship care plans to patients since 2010. Initially, the cancer program focused on patients with breast cancer; it has since been expanded to include patients with all cancer types who meet the criteria for survivorship care plans outlined by the CoC. MSTI nursing staff identify patients who are likely to be eligible for survivorship care when they begin treatment with curative intent. Oncologists and primary registered nurses track those patients throughout their treatment and discuss survivorship with them at their first follow-up appointment after treatment is completed.

Reporting Challenges

MSTI's survivorship care plan program has taken a proactive approach to ensure that eligible patients are identified early, which has required a significant investment in time and resources. When MSTI first began providing survivorship care plans, its oncology service line was using a different EHR than the rest of the health

Figure 1. Supportive Oncology Wheel
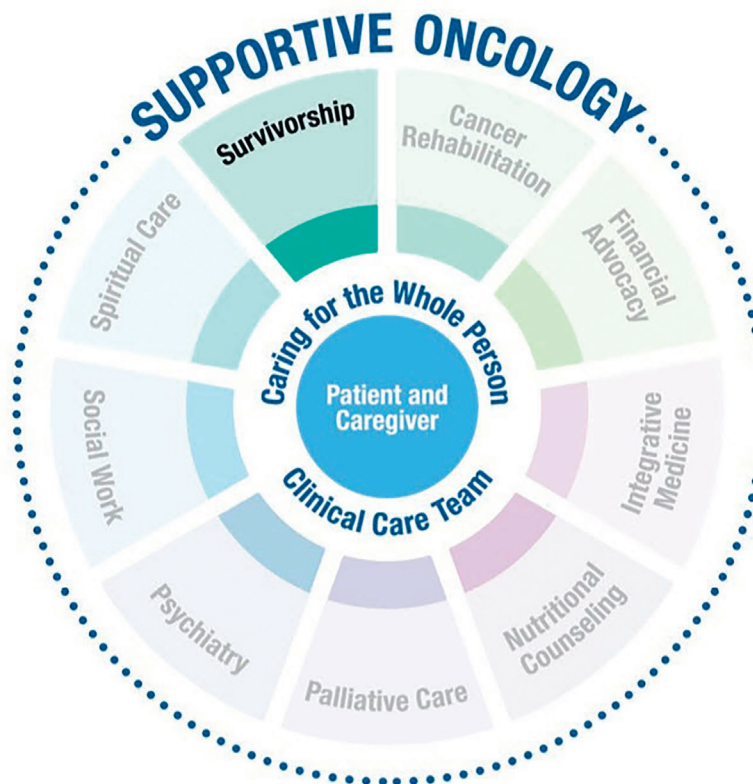
system. This made the evaluation of the survivorship program a highly manual process in which tracking and reporting required many staff hours.

The process required the oncology team to create a custom report within the EHR to identify when cancer patients had completed radiation or infusion chemotherapy. As such, reporting capabilities were highly limited and unable to identify the patients receiving oral chemotherapy or those treated with definitive surgery only. The report was also not able to filter out patients with advanced disease or those receiving therapy with palliative intent. Each patient the report did identify was reviewed manually by a clinical team member to determine eligibility for the survivorship care plan program. Patients who were eligible were marked accordingly and tracked to ensure that orders were placed and that patients attended their survivorship appointments.

Though the program was generally successful, the process had limitations and was time consuming. Compliance calculations were essentially an educated guess, defined as the number of survivorship care plans delivered divided by the number of analytic cases closed by the tumor registrars during the same period. There was no way to identify eligible patients who may have been omitted by the report; the clinical team could only base compliance calculations on the information provided by the report and the tumor registry.

New EHR, New Approach
In October 2016 St. Luke's Health System implemented a single system-wide EHR spanning all care settings. The EHR incorporates a foundation reporting function that can identify patients who complete chemotherapy, report the number of days lapsed since the end of treatment, and report whether a survivorship care plan has been delivered to a patient. But this foundation report was unable to identify patients undergoing radiation or patients who had surgery only. It also could not provide any analytics or high-level summary data with which to evaluate program compliance with survivorship care plan delivery.

After using the new EHR for six months, it became clear to the oncology staff that the foundation reporting available could not provide the necessary data to report survivorship care plan compliance to the CoC. That was going to require additional resources and support from the report development team, which needed to understand each of the variables necessary to create a meaningful survivorship compliance report. Accordingly, the survivorship program manager began meeting regularly with the report developers to create a more comprehensive reporting capacity.

The Report Development Process
The maintenance required for the ongoing, accurate reporting of survivorship care plan compliance meant that oncology staff and the report development team had to approach the project as a continually evolving one. Workflows would need to be modified on an ongoing basis to meet the multidimensional needs of both patients and clinicians. Thus, the relationship between the clinical team and the report development team had to be built on a solid foundation.

Step 1: Define Your Goal
Any report development process typically begins with a request for data. The report development team meets with the requester to discuss the desired parameters of the report. These parameters should include the purpose of the report, the data elements needed, defined metrics, visualizations needed, workflows involved, and EHR build specifics. The development of the report can then begin. The requester and the report development team typically work through several iterations of the report until the requester accepts it as complete and accurate.

In this case, the report development team needed to appreciate the complexities of the survivorship workflow, understand the clinical indicators for survivorship, know how eligible patients are identified in the EHR, and understand which documentation to look for. Report development team members also had to know the key reporting metrics required by the CoC. This information helped the team understand that a broad range of patients with various diagnoses undergoing different types of treatment are eligible to receive survivorship care plans. Being able to identify which specific patients should receive a survivorship care plan from the long list of patients within the system-wide EHR was the development team's first priority.

Step 2: Define Your Patient List
The reporting process requires report developers to first identify all patients in the EHR who have a cancer diagnosis. This initial data pull yields the names of tens of thousands of patients. Report developers then determine disease stage. Patients with stage IV disease are removed, because they do not meet the CoC eligibility criteria for survivorship. Next, report developers identify patients who have received cancer treatment within the past two years. Treatment is defined as chemotherapy, radiation therapy, and/or surgery.

The report development team meets with the survivorship program manager to review and validate their results after each revision of the report. Ultimately, the team identifies the appropriate patients and creates a list of individuals with cancer diagnoses who are treated with curative intent by completing surgery, chemotherapy, or radiation therapy with no additional treatments planned.

Step 3: Verify Data Elements
Developing a survivorship care plan report requires significant collaboration and validation between the clinical team and the report development team. The underlying data are unique and disparate, and data elements are entered into the EHR in a variety of ways, depending on treatment type and intent. The workflow associated with each treatment modality is also unique to each treatment scenario. For example, providers often select a diagnosis code from a pre-populated list of diagnosis descriptions that may be close to the patient's diagnosis but not the most accurate. Though the provider notes or text documentation for the patient are always the best source of clinical information, notes or text do not offer discrete data fields for the report development team to pull from. The team must rely on discrete data entered into the appropriate tables and fields built into the EHR.

Step 4: Identify Eligible Patients

Though discrete fields are critical for accurately identifying patients with eligible diagnoses, the variability within diagnosis descriptions makes it difficult to ensure the accurate identification of patients. Report developers must identify all potentially eligible diagnosis codes and descriptions and remove any that are ineligible. This includes identifying any benign diagnoses that may be incidentally included, such as patients with chronic malignant hematology who remain on treatment indefinitely.

The survivorship program manager should also identify metastatic cancers within the patient list because they, too, are ineligible for survivorship due to advanced disease. As an example of how difficult this can be, diagnosis descriptions have multiple variations of the word "metastatic," including "metastasis," "metastases," and "metastasized." These permutations must be verified and accounted for within the report.

Step 5: Track Delivery Metrics

Once a list of eligible patients is generated from the EHR, report developers associate additional data elements with the patients listed. These include the variables associated with their treatment, including treatment start and end dates, care team data, diagnosis and staging information, and other elements. Developers then use treatment end dates to calculate due dates for survivorship care plan delivery. Once a survivorship care plan has been delivered to a patient, the report should track the delivery date and method of delivery (in person or by mail). Report developers can group delivered survivorship care plans by the number of months it took to deliver the plan compared to the treatment end date.

Step 6: Account for Different Scenarios

To break down all potential scenarios within the clinical workflow, the report development team works with the clinical team to understand business rules, assign logic, and create the metrics required by the CoC. These workflows are dependent on the treatment plan for each patient. For example, patients may begin with surgery and never have additional treatment. In this case, the end of therapy is defined as the date of surgery, and the survivorship care plan delivery due date is calculated as six months after the date of the surgery. Some patients proceed to chemotherapy and radiation therapy, whereas others may have only one or the other. Still other patients are placed on long-term maintenance drugs; in that case, the survivorship care plan delivery due date is calculated as 18 months from the diagnosis date.

The survivorship program manager and the report development team meet regularly to flesh out each scenario and identify example patients within the EHR to determine when and how survivorship orders are to be placed. This allows report developers to correctly identify end-of-treatment dates for patients within each scenario. Deviations from the standard workflow inevitably occur, and report developers must be able to identify all potential deviations and their impact on the data. Some examples of deviations from the standard workflow include:

- The survivorship appointment was ordered and canceled.
- The patient did not attend the survivorship appointment.

- The patient declined the survivorship appointment, and the survivorship care plan was mailed.

Delivery Stats for All Eligible Patients, Figure 2, right, summarizes the variation in the survivorship care plan delivery workflow.

Step 7: Account for Elements of the Report

One of the most daunting aspects of survivorship care reporting is that it crosses the entire continuum of the cancer care experience. Among others, all of these elements must be included in the report:
- Cancer diagnosis date
- Identification of treatment intent
- Staging (or lack thereof in a structured field)
- Oral chemotherapy treatment via medications processed through the MSTI clinic or hospital
- Oral chemotherapy treatment via mail order
- Radiation treatment
- Chemotherapy infusion treatment
- Surgical treatment/intervention
- Hospice (as an exclusion)
- Survivorship appointment
- Delivery of the survivorship care plan
- Follow-up appointments

Maintaining the Report

Ongoing maintenance of reports that span the continuum of care, such as survivorship, means that the report development team is working on a continually evolving project. In other words, the work is truly never done because the manner in which patients receive care and clinicians provide care is constantly advancing. Workflows are modified to meet the multidimensional needs of both the patient and the clinician, and the report refinement process is ongoing. These impending changes demand that the relationship between the clinical team and the report development team be built on healthy and respectful communication.

It is essential that the report development team and survivorship program manager meet frequently to review data and ensure that the report is accurately capturing the care delivered and documented. The MSTI team meets monthly, at which time its members discuss variable ongoing issues. Accurately capturing clinical workflows and understanding their impact on the report's data is a frequent topic of discussion. The clinical team continually identifies additional patients who need to be removed from the list and creates exclusionary criteria that the report development team incorporates into the report.

Break-fixes are one of the foremost reasons the relationship between the clinical team and the report development team must be strong. When the report "breaks," it is no longer completely accurate, and the report development team must determine the scope and full impact of the break. The two teams depend heavily on one another to identify the problems creating the break, such as missing data or patients who are included when they should be excluded.

For example, a break-fix could occur when the names of several oral chemotherapy patients with blank survivorship care

Figure 2. Adult Survivorship Care Plan Delivery for All Eligible Patients for All Sites
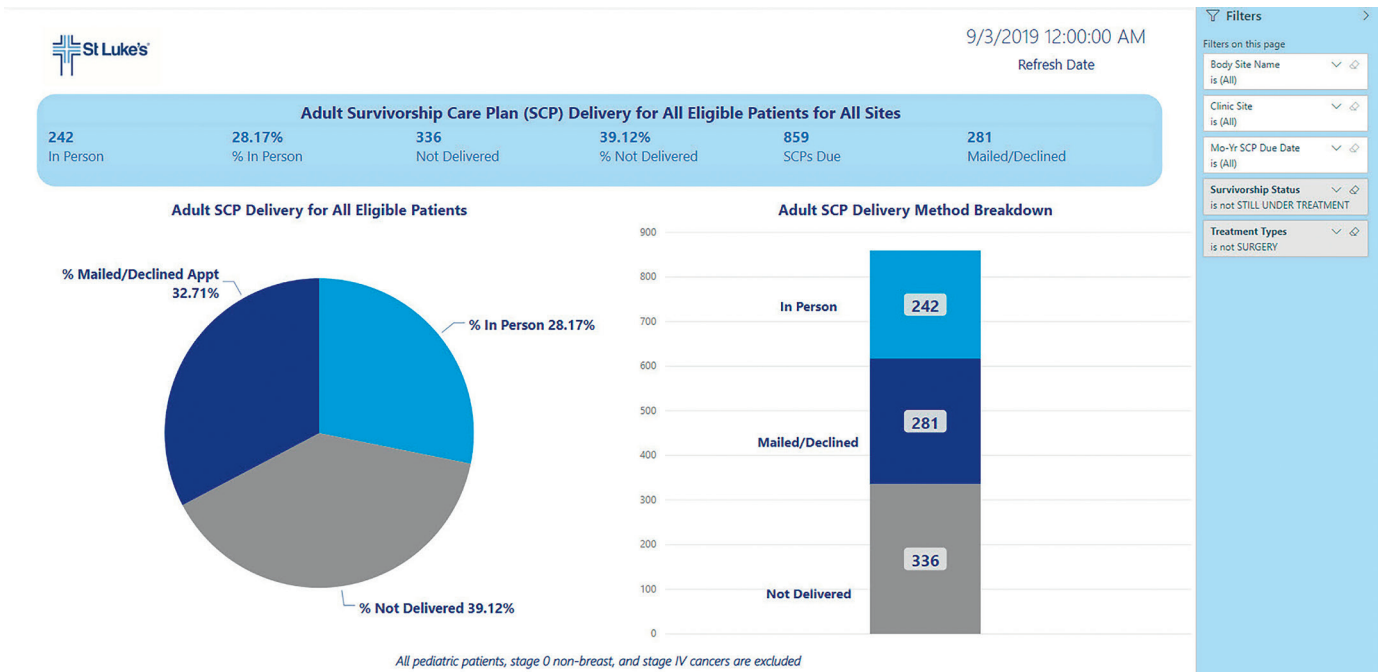
plan due dates appear in the data. (Oral chemotherapy at MSTI is handled by the oral chemotherapy pharmacy team, so the necessary pharmacy team members must be pulled into the conversation to identify what changed in the workflow and documentation process.) Once this break-fix is detected, report developers troubleshoot possible reasons for the missing due dates and communicate their findings to the survivorship program manager. The two teams then meet and review example patients within the EHR to determine their next steps.

Immediate communication is essential when a team member identifies something that may be broken or missing. Some break-fixes are minor, whereas others can require an extensive rebuild. The report development team should approach any potential break-fix in a systematic manner:

- Troubleshooting
- Scoping the break
- Modifying the report
- Validating changes made to the report
- Conducting user acceptance testing or validation
- Overseeing final approval to keep the fix in place.

Any changes to EHR build or clinical workflows should be communicated to the report development team early in the process so that it is able to proactively modify the report to account for any changes. The report development team can also make rec-

ommendations to ensure that data are captured via discrete structured fields rather than free text fields, which can breed inconsistency.

The clinical team needs to be engaged in the use of structured fields very early in the build and workflow development process so that team members understand the impact on reporting—regardless of whether the reporting need is related to regulatory or accreditation requirements. Structured fields also allow for consistent identification of patient populations for treatment purposes and identifying opportunities for improving the care provided to the patient.

Report Visualizations

Maintaining a survivorship care plan is a complex process, making it difficult to visualize in a meaningful way. But it is essential to turn the data collected in the report into actionable information that informs clinical and management team decision making. To do this, it helps to evaluate the needs of your intended audience and collect the relevant metrics to help them visualize the information relevant to them. Simple visualizations are typically easier to understand.

The current version of the MSTI survivorship report contains a high-level summary page that depicts compliance with Standard 3.3. In CoC Compliance Summary, Figure 3, page 44, the column chart on the right depicts survivorship care plan delivery broken

Figure 3. Summary of the Commission on Cancer Compliance with Adult Survivorship Care Plan Delivery for All Sites

All pediatric patients, stage 0 non-breast, and stage IV cancers are excluded
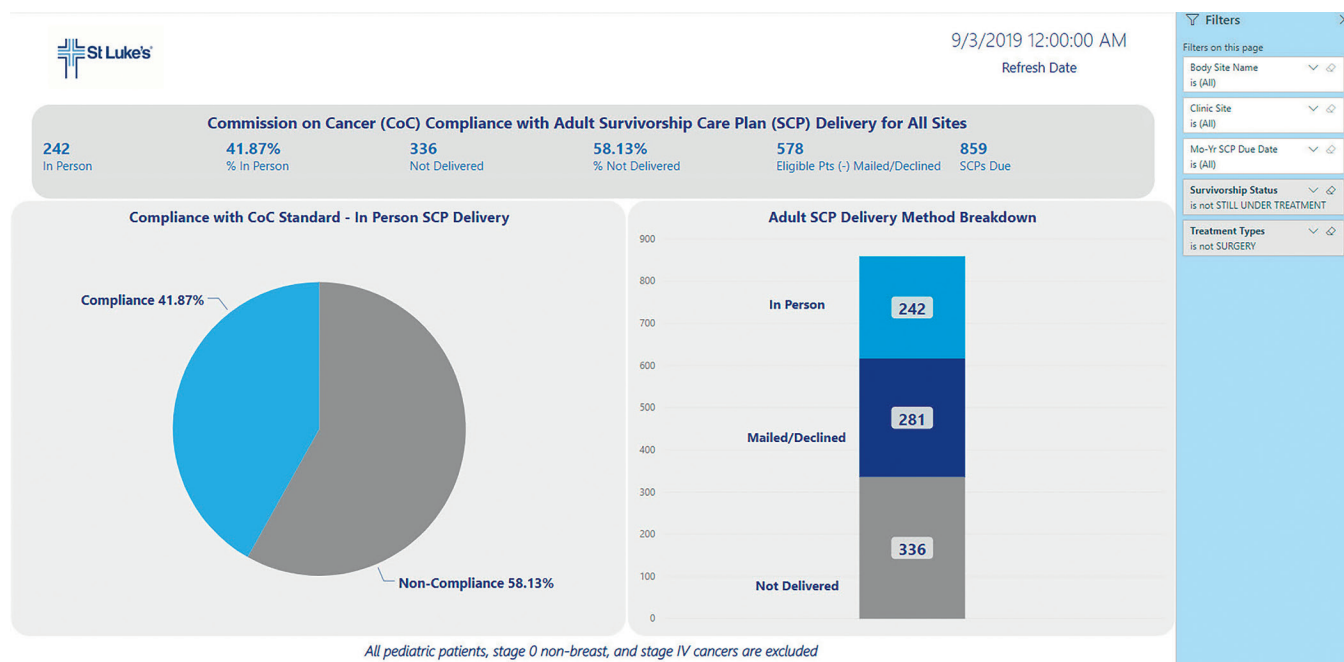
down by delivery method. Delivery in person is the preferred delivery method and part of the standard's compliance calculation. The pie chart on the left shows the count and percentage in compliance compared to the count and percentage in noncompliance. This high-level summary is intended to help management and leadership quickly determine compliance status.

Slicers allow the audience to further define the patient population to pinpoint areas requiring more focus. Filters include clinic site, survivorship care plan due date (based on treatment end date), survivorship (care plan) status, treatment type (including various treatment combinations), and cancer site. (Note: Not all filters are depicted in Figure 3.)

Clinical staff use the report to identify patients who need a survivorship care plan delivered. The patient lists summaries in Figures 4A-4C, right, provide the detail necessary for clinical staff to facilitate delivery by the survivorship care plan due date or mark the patient's plan as not needed. Filters are also available within these summaries, including final treatment date, survivorship-ordered appointments, last updated by staff name, and survivorship appointment status. (Note: Not all filters are depicted in Figures 4A-4C.)

The survivorship report can also produce other specific summaries. Figure 5, page 46, shows the percentage of survivorship care plans delivered on time (within six months of final treatment) and cumulative delivery statistics. This summary is actionable and directs the clinical staff to a list of patients that need to have

their survivorship care plans delivered. Figure 6, page 47, is a report for the survivorship program manager that shows both cumulative and trended delivery of survivorship care plans, as well as CoC compliance statistics.

Figure 7, page 47, is a physician-specific summary that provides insight into the surgery-only patient population. Before the MSTI team created this customized report, the clinical teams had not been able to appropriately identify surgery-only patients. The survivorship program manager will work collaboratively with surgical groups in the future to include their patients in the survivorship care plan delivery process.

The report also provides delivery statistics trended over time to easily visualize whether delivery statistics are moving in the right direction. Figure 8, page 48, shows the percentage of overall survivorship care plans delivered—regardless of delivery method. Figure 9, page 48, breaks out delivery of survivorship care plans in person, mailed, and/or declined and then shows trending data of in-person delivery. Figure 10, page 49, shows the percentage of survivor care plans that were delivered on time or by the due date.

Though most people tend to respond well to visual representation of data, others prefer to interpret raw data in a table form; all reports show data in both formats to help all staff digest information and be prepared to effect change when necessary.

Figure 4. Master Lists for (A) Adult, (B) Pediatric, and (C) Surgery Only Patients

(A)

(B)

Figure 4. Master Lists for (A) Adult, (B) Pediatric, and (C) Surgery Only Patients (continued)

(C)

Figure 5. High-Level Performance Improvement Summary – Adult Survivorship Care Plans to Be Delivered

Figure 6. High Level Management Summary – Adult Survivorship Care Plans Delivery Statistics

St Luke's

ADULT SURVIVORSHIP CARE PLAN (SCP) DELIVERY STATISTICS
HIGH LEVEL MANAGEMENT VIEW
All pediatric patients, stage 0 non-breast, and stage IV cancers are excluded

9/3/2019 12:00:00 AM
Refresh Date

60.88%
% Delivered Overall YTD

523
Delivered Overall

859
Total Eligible Pts

SCP Delivery Stats with Actionable Patient List via Drill Through

CLINIC SITE	CARE PLAN BEYOND DUE DATE	CARE PLAN NEEDED	DELIVERED	Total
BOISE	117	2	170	289
FRUITLAND	43		80	123
MERIDIAN	56	1	133	190
NAMPA	28		88	116
TWIN FALLS	88	1	52	141
Total	332	4	523	859

Stage	Eligible Pts
	456
Stage I	270
Stage II	125
Stage III	116
Stage Unknown	28
No Stage Recommended	23
Stage 0	11
WHO Grade IV	1
Total	859

Delivery Statistics to Date (Rolling 12 Months)

39.12% % Not Delivered YTD | **336** # Not Delivered | **859** Total Eligibile Pts

51.46% % Delivered On Time YTD | **442** # Delivered On Time | **859** Total Eligible Pts

28.17% % Delivered In Person YTD | **242** # Delivered In Person | **859** Total Eligible Pts

32.71% % Mailed/Declined YTD | **281** # Mail/Declined | **859** Total Eligible Pts

Delivery Trends
% Not Delivered
% On Time
% In Person (of Total Eligible Pts)
% Mailed/Declined

Compliance Calculation
% In Person (CoC Compliance)

CoC Compliance
41.87% % Delivered In Person YTD

242 # Delivered In Person

578 Eligible Pts (-) Mailed/Declined

Filters
Filters on this page
Clinic Site is (All)
Survivorship Status is (All)
Survivorship Delivery M... is (All)
Treatment Types is not SURGERY
Survivorship Appt Statu... is (All)
SCP Last Updated By is (All)
Calendar Year SCP Due I... is (All)
Mo-Yr SCP Due Date is (All)
PercentDeliveredMailDec... is (All)

Figure 7. High Level Summary - Surgery Only

St Luke's

Clear Filters

Surgery Only High Level Summary

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SCP Delivery Percentages

13.59% % Delivered in Person | **19.61%** % Delivered Overall | **80.39%** % Not Delivered

Deilvery Stats per Surgical Specialty with Drill Through

Physician Specialty	Distinct Patients	Not Delivered	Delivered
Urology	155	110	45
General Surgery	152	135	17
Gynecologic Oncology	81	48	33
Otolaryngology	32	32	
Colon and Rectal Surgery	22	22	
Thoracic Surgery	22	22	
Obstetrics and Gynecology	20	19	1
Plastic Surgery	16	11	5
Internal Medicine	6	6	
Gastroenterology	3	3	
Neurosurgery	2	2	
Pulmonary Disease	2	2	
Hand Surgery	1	1	
Orthopedic Surgery	1	1	
Total	515	414	101

SCP Delivery Status

70 In Person

31 Mailed/Declined

414 Not Delivered

Stage	Distinct Patients
	373
Stage 0	5
Stage I	87
Stage II	46
Stage III	16
Stage Unknown	46
Total	515

Filters
Filters on this page
Survivorship Status is (All)
Treatment Types is SURGERY

All pediatric patients, stage 0 non-breast, and stage IV cancers are excluded

Figure 8. Adult Survivorship Care Plans Delivered Overall: All Sites

ADULT SURVIVORSHIP CARE PLANS (SCPs) DELIVERED OVERALL: ALL SITES

St Luke's

Legend: SCPs Due • SCPs Delivered — Percent SCPs Delivered

Mo-Yr SCP Due Date	SCPs Delivered	SCPs Due	Percent SCPs Delivered
Sep-18	61	79	77.22%
Oct-18	44	69	63.77%
Nov-18	46	61	75.41%
Dec-18	44	71	61.97%
Jan-19	30	50	60.00%
Feb-19	53	80	66.25%
Mar-19	33	53	62.26%
Apr-19	46	91	50.55%
May-19	52	85	61.18%
Jun-19	48	81	59.26%
Jul-19	40	83	48.19%
Aug-19	30	69	43.48%
Total	**523**	**859**	**60.88%**

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All pediatric patients, stage 0 non-breast, and stage IV cancers are excluded

Filters
Filters on this page
Body Site Name is (All)
Clinic Site is (All)
Treatment Types is not SURGERY

Figure 9. Adult Survivorship Care Plans Delivery by Method Over Time: All Sites

ADULT SURVIVORSHIP CARE PLAN (SCP) DELIVERY BY METHOD OVER TIME: ALL SITES

St Luke's

Legend: In Person • Mailed/Declined — Percent Delivered In Person

Mo-Yr SCP Due Date	In Person	Mailed/Declined	Percent Delivered In Person
Sep-18	25	36	58.14%
Oct-18	16	28	39.02%
Nov-18	19	27	55.88%
Dec-18	20	24	42.55%
Jan-19	13	17	39.39%
Feb-19	20	33	42.55%
Mar-19	12	21	37.50%
Apr-19	23	23	33.82%
May-19	24	28	42.11%
Jun-19	31	17	48.44%
Jul-19	22	18	33.85%
Aug-19	20	10	33.90%
Grand Total	**242**	**281**	**41.87%**

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All pediatric patients, stage 0 non-breast, and stage IV cancers are excluded

Filters
Filters on this page
Body Site Name is (All)
Clinic Site is (All)
Treatment Types is not SURGERY

Figure 10. Adult Survivorship Care Plans Delivered Within 6 Months of Final Treatment: All Methods for All Sites

ADULT SURVIVORSHIP CARE PLANS (SCPs) DELIVERED WITHIN 6 MONTHS OF FINAL TREATMENT: ALL METHODS FOR ALL SITES

St Luke's

● SCPs Due ● SCPs Delivered within 6 Mo — Percent SCPs Delivered within 6 Mo

Mo-Yr SCP Due Date	SCPs Delivered within 6 Mo	SCPs Due	Percent SCPs Delivered within 6 Mo
Sep-18	49	79	62.03%
Oct-18	36	69	52.17%
Nov-18	33	61	54.10%
Dec-18	33	71	46.48%
Jan-19	27	50	54.00%
Feb-19	47	80	58.75%
Mar-19	29	53	54.72%
Apr-19	40	91	43.96%
May-19	45	85	52.94%
Jun-19	43	81	53.09%
Jul-19	36	83	43.37%
Aug-19	27	69	39.13%
Total	**442**	**859**	**51.46%**

Filters on this page
Body Site Name is (All)
Clinic Site is (All)
Treatment Types is not SURGERY

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Refresh Date

All pediatric patients, stage 0 non-breast, and stage IV cancers are excluded

Final Thoughts

The report development team is working toward a more optimized version of the survivorship report for the future. Currently, the report is updated—or refreshed—on a monthly basis. Ideally, the team hopes to update the report on a daily basis, potentially in real time. The team is also creating more efficient methods for processing the large volume of data pulled from the underlying tables within the EHR.

Keep in mind: clinical and report development teams do not always speak the same language, which can impede progress and negatively affect outcomes. But in the case of survivorship care plan delivery, teams can find common ground in the needs of the patient. By focusing on patient-centered care, clinicians can help non-clinical teams appreciate the impact of survivorship care plans on care, and report developers can help clinical teams identify gaps in clinical practice. Working together, the two teams can construct a framework to improve the sharing of information and the successful delivery of survivorship care plans to patients so that they can better plan for their future. The report's objective data can also serve to drive clear and consistent communication with organizational leaders to prioritize improvement efforts and resource allocation. ◐

Andrea Rowe, BS, RHIT, is a business intelligence analyst/developer; Alicia Rosales, LCSW, OSW-C, is an oncology service line program manager; a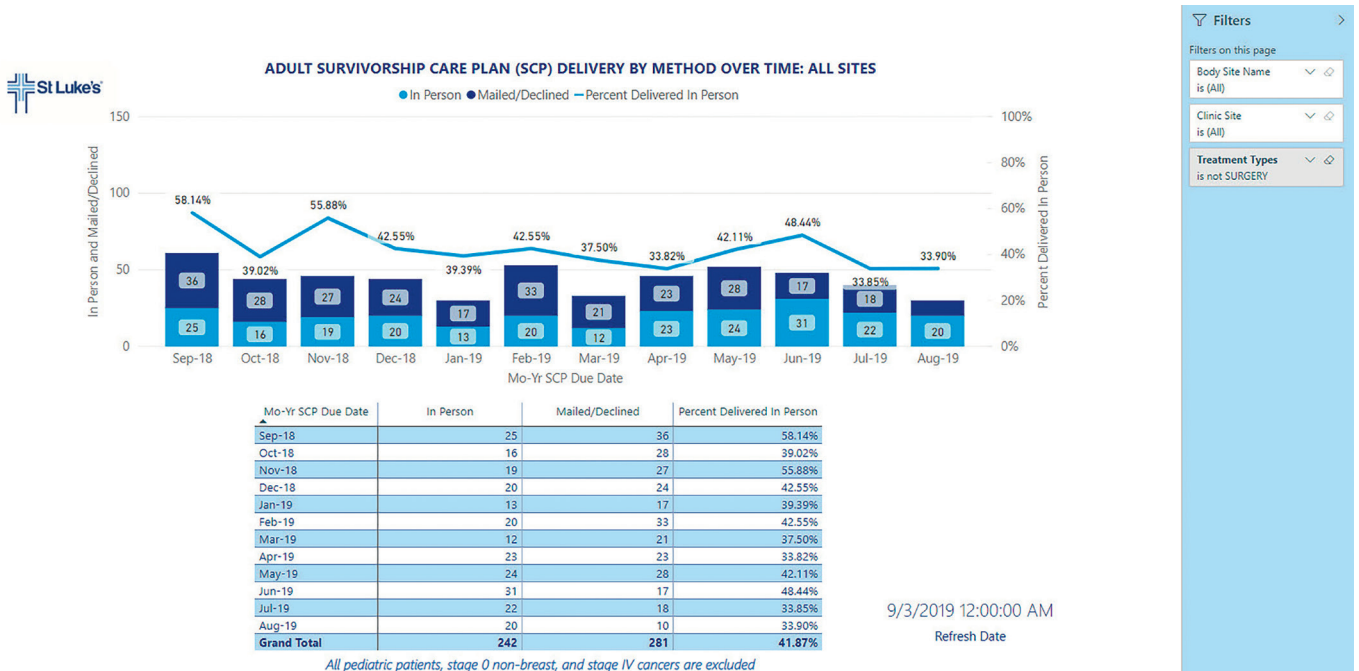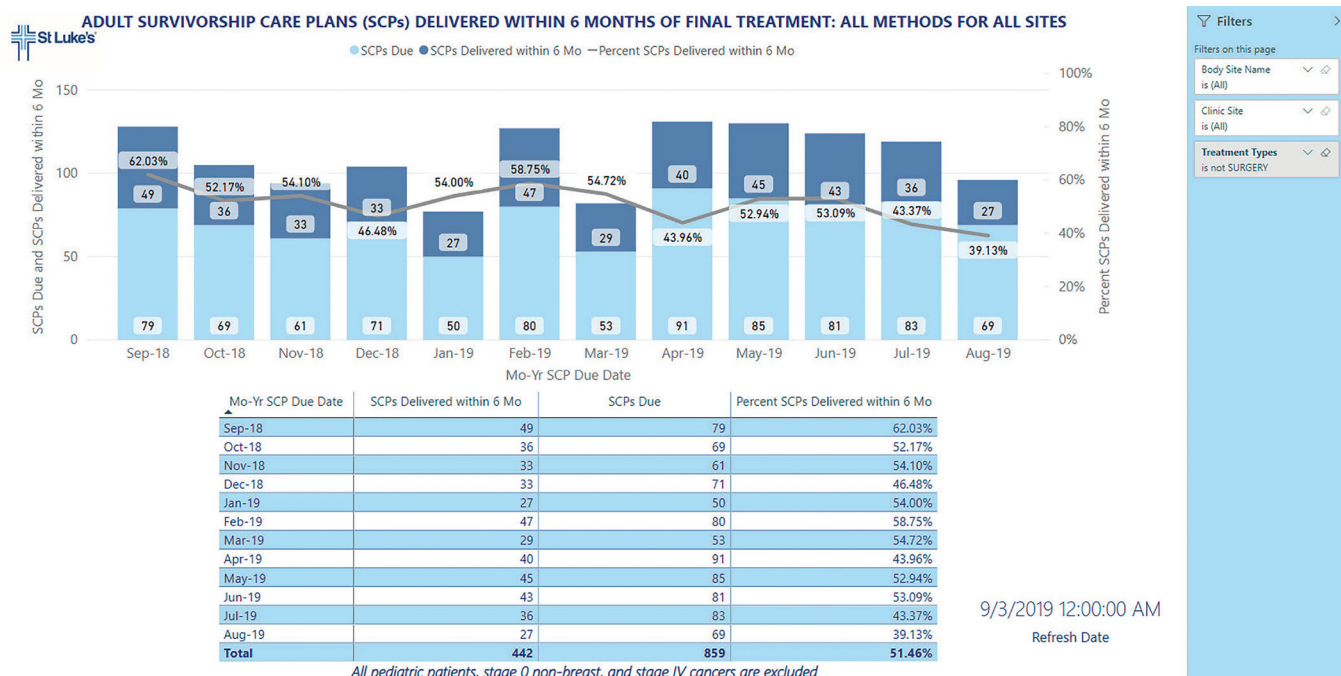nd Christopher Weed is a talent insight analyst/developer at Mountain State Tumor Institute and Digital and Analytics, St. Luke's Health System, Boise, Idaho.

References

1. Institute of Medicine, National Research Council of the National Academies. *From Cancer Patient to Cancer Survivor: Lost in Transition.* Washington, DC: National Academies Press; 2006.

2. American College of Surgeons Commission on Cancer. *Cancer Program Standards: Ensuring Patient-Centered Care.* Version 1.2.1. Chicago, IL: American College of Surgeons; 2012.

3. Association of Community Cancer Centers, Advisory Board. *2017 Trending Now in Cancer Care Survey.* Available online at: accc-cancer. org/home/learn/publications/Trends/2017-trending-now-in-cancer-care-survey. Last accessed April 1, 2019.

4. Deline M. The CoC clarifies the survivorship care plan standard: what you need to know. Available online at: advisory.com/research/oncology-roundtable/oncology-rounds/2014/09/the-coc-clarifies-the-survivorship-care-plan-standard-what-you-need-to-know. Published August 6, 2018. Last accessed September 11, 2019.

Engaging the Community to Improve Patient-Centered Care for Inflammatory Breast Cancer

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TERRY ARNOLD; AND NADINE J. BARRETT, PHD, MA, MS

Breast cancer remains the most common cancer diagnosis among women in the United States, affecting one in eight women today. Inflammatory breast cancer is a little-studied but highly lethal breast cancer subtype, accounting for more than 10 percent of all breast cancer deaths.[1] The aggressive characteristics of inflammatory breast cancer and the late stage at which it is typically diagnosed lead to poor survival outcomes.[2,3] Inflammatory breast cancer is unique from other breast cancers in that it is diagnosed based on a clinical presentation that is described as the rapid onset of breast erythema and edema occupying at least one-third of the breast with or without a breast mass.[1] Given this non-classic presentation of breast cancer, patients are often misdiagnosed or treated inappropriately.

According to National Comprehensive Cancer Network guidelines, all inflammatory breast cancer patients without metastases at the time of diagnosis should be treated with trimodal therapy, including chemotherapy, surgery, and adjuvant radiation.[4] But even this aggressive therapy is not a definitive cure, because many patients go on to develop local or distant recurrences. However, evidence has shown that treatment with timely guideline-concordant care can dramatically improve survival among patients with inflammatory breast cancer.[5,6]

The individuals involved in the diagnosis, treatment, and long-term care of patients with inflammatory breast cancer include a diverse set of people, including patients, patient advocates, clinicians, researchers, and community and national organizations. To improve awareness about inflammatory breast cancer, promote education about the disease, and advocate for patient-centered care, these individuals must collaborate in order to identify gaps that prevent appropriate diagnosis and treatment and identify ways to engage the inflammatory breast cancer community to enhance awareness and patient support.

Through a community engagement session and focused interviews, researchers from Duke University School of Medicine held a consortium to help stakeholders identify barriers to inflammatory breast cancer awareness, diagnosis, and appropriate treatment.

The Duke Consortium for Inflammatory Breast Cancer formed in the winter of 2014 when a group of basic, translational, and clinical investigators; research administrators; and patient advocates with diverse research and clinical interests from Duke University, the University of North Carolina at Chapel Hill, NC State University, and North Carolina Central University came together as part of an interdisciplinary initiative at the Duke University School of Medicine. Based on an analysis of the strengths, weaknesses, challenges, and opportunities available at Duke University and the local community to address the unique features and challenges of inflammatory breast cancer research and patient care, the group ratified the critical need for a multidisciplinary and cohesive effort in North Carolina, an ethnically and economically diverse state with 100 counties and home to the Research Triangle Park and multiple institutions of higher education, comprising a major hub for research, medicine, and education. The consortium is committed to the goal of translating research into action and held its first meeting on Feb. 28, 2018 at Duke University.[7] The meeting included researchers,

Based on participant responses from the community engagement session and post-meeting interviews, researchers identified three concepts related to the unique needs and challenges facing stakeholders in inflammatory breast cancer treatment and research: (1) barriers to timely diagnosis and treatment, (2) strategies for community engagement, and (3) the need for provider education.

practicing physicians, patients, advocates, and community stake-holders. The consortium consisted of three sessions occurring on the same day that addressed:

1. Global partnership in the clinical management of inflammatory breast cancer
2. Research challenges and opportunities in inflammatory breast cancer
3. Engaging advocates and community partners to improve inflammatory breast cancer research and education

Participants pre-registered for the meeting, attendance was recorded, and attendees were not compensated. Facilitators obtained approval from the institutional review board for the study of human subjects.

Community Engagement Session
During this session, facilitators led conversations to identify and address critical needs in inflammatory breast cancer clinical care and outreach. Small groups of three to eight participants—along with group facilitators and/or notetakers—discussed the following open-ended questions:

- What gaps prevent the timely diagnosis and appropriate treatment of inflammatory breast cancer?
  How can you advocate for inflammatory breast cancer awareness and work with local community health providers to become part of patient care?
- Identify ongoing grassroot/programmatic efforts in your community. How are you advocating in your community? How are you supporting patients and survivors?
- How can we partner to promote philanthropy for research and awareness?

Post-Meeting Interviews
After the community engagement session, researchers contacted representative patients (from whom written consent was received), group facilitators, and community partners to give more in-depth responses to the following questions:

- From the interactive session, do you remember themes that stood out to you?
- Do you remember a story that stood out to you?
- What was your overall impression of the session?

Two additional questions were included for foundation leaders:

- What challenges are you facing right now?
- What are your greatest strengths as an inflammatory breast cancer or breast cancer foundation?

Thematic Analysis
Researchers recorded and transcribed conversations from the community engagement session for the purpose of qualitative analysis to identify key themes across core domains. The researchers aggregately analyzed participant responses using qualitative data analysis software. Three coders independently analyzed data and identified initial codes and emergent themes. An in-depth review of responses allowed the development of initial codes that were then refined by consistent cross-checking and team discussion. Coders met to examine and compare emergent themes across each core question. When one team member derived a different code than the other team members for a particular response, the team discussed the response and came to a group consensus.

Themes were highly aligned across coders. A thematic analysis using a systematic, multi-step, rigorous process as outlined by Braun and Clarke was conducted to ascertain, compare, and contrast key concepts and emerging themes across the responses.[8] Grounded theory shaped the design and analysis of the research.[9]

Conference Attendance and Follow-Up Interviews
In total, 174 people attended the Duke Consortium for Inflammatory Breast Cancer meeting. Of the attendees, 28 percent were local community members (patients, patient advocates, and North Carolina government representatives); 15 percent were healthcare providers (physicians and nurses); 15 percent were Duke Cancer Institute or Duke University School of Medicine staff; 13 percent were research and clinical faculty representing both local and national academic and medical institutions; 9 percent were trainees (undergraduate and graduate students as well as postdoctoral fellows); and 16 percent were other community stakeholders. Following the meeting, researchers contacted representative patients, advocates, and community stakeholders and conducted seven in-depth interviews.

Analysis of Concepts from the Community Engagement Session
The community engagement session findings for major themes and most commonly reported subthemes are summarized in Table 1, right.

A total of 506 unique responses were recorded. Responses to the four questions from the community engagement session were tabulated and translated into word clouds. The size of the words was weighted by the frequency of the words used (Figure 1, page 54). The top five word frequencies were as follows:

1. IBC (inflammatory breast cancer): 3 percent ($n = 53$)
2. Community: 1.5 percent ($n = 27$)
3. Patient: 1.5 percent ($n = 27$)
4. Cancer: 1.5 percent ($n = 26$)
5. Support: 1.5 percent ($n = 26$)

Emerging Themes
From the participant responses, six major themes were identified:

- Strategies for community outreach: 43.3 percent
- Barriers to timely diagnosis and treatment: 29.4 percent
- Need for education: 16.4 percent
- Fundraising: 6.3 percent
- Legislative processes: 1.4 percent
- Other: 3.0 percent

The major themes were then subdivided into patient/community level, provider level, and organizational level as appropriate (see Table 1).

Table 1. Summary of the Parent Themes and Most Commonly Reported Subthemes from the Community Engagement Session

Theme	Frequency	Percentage of Theme[a]	Percentage of Level[b]
Strategies for community outreach	241		
Patient/community level	109	45.2	
Media-related outreach	30		27.5
Patient-specific programs	30		27.5
Provider level	51	21.2	
Create research agenda/grant writing	21		41.2
Need for education	236		
Patient level	28	11.9	
Provider level	107	45.3	
Lack of education among providers	85		79.4
Inaccurate profile (e.g., age, pregnancy)	14		13.1
Organizational level	2	0.85	
Barriers to timely diagnosis and care	175		
Patient level	75	42.9	
Rural location/distance to treatment center	16		21.3
Lack of social support (e.g., lack of child-care, family needs, work responsibilities, religion)	15		20.0
Organizational level	41	23.4	
Lack of access to appropriate treatment or inability to get a timely appointment	19		46.3
Lack of a central source of information	9		22.0
Fundraising	32		
Legislative process/priorities	7		
Other	15		

[a] Values represent the percentage of responses coded to the patient/community, provider, and organizational levels.
[b] Values are the percentage of responses coded for subthemes under each level.

Figure 1. Word Cloud from the Community Engagement Session, Inclusive of All Responses


Figure 2, below, depicts the percentage of responses for community outreach strategies, barriers to timely diagnosis and appropriate treatment, and education when categorized according to patient/community, provider, and organizational levels. Participant responses demonstrate a need to initiate community outreach efforts, primarily at the patient/community and provider levels (45.2 percent and 21.2 percent, respectively). No responses in the community outreach theme were coded at the organizational level. Respondents indicated that barriers to treatment and care were greatest at the patient/community level (42.9 percent), followed by the organization level (23.4 percent). No responses in the barriers theme were coded at the provider level. For education, the highest percentage of responses indicated a need to educate providers (45.3 percent), followed by the patient/community (11.9 percent) and the organization (0.85 percent).

Barriers to Timely Diagnosis and Treatment

According to participants in the community engagement session (Figure 3, right), the primary barrier to timely diagnosis and appropriate care is residence in a rural community/distance from

Figure 2. Responses for Primary Themes of Barriers, Education, and Community Outreach at the Patient/Community, Provider, and Organizational Levels.
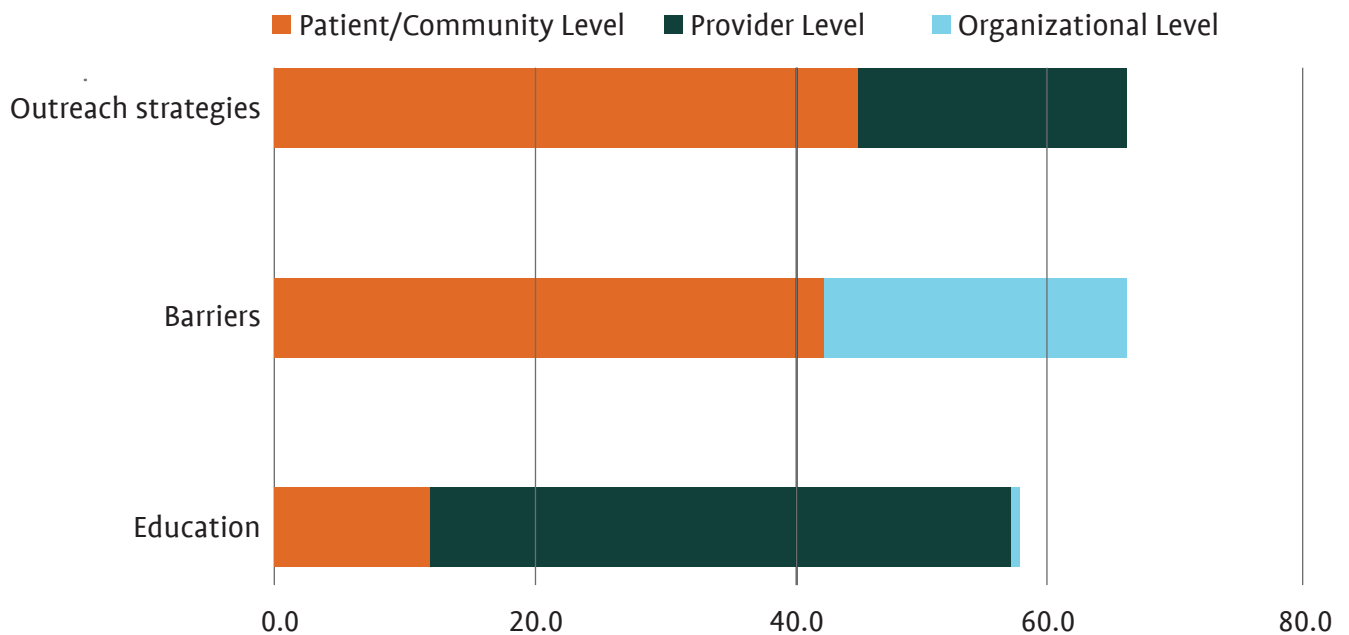
Note: The participants' responses were coded via the Braun and Clarke methodology. Numerous responses were assigned more than one thematic code.

a treatment center (21.3 percent). Almost one-fifth of respondents indicated that a lack of social support for responsibilities, such as juggling childcare and work duties, was a common barrier to care, followed by fear of diagnosis or treatment, financial concerns, and issues with insurance coverage (15.8 percent each). Barriers at the organizational level included limited or lack of access to an appropriate treatment center/an inability to schedule a physician appointment (46.3 percent), lack of standard of care for patients (20 percent), lack of a central source of information about inflammatory breast cancer (22.0 percent), and a lack of patient navigation (8.9 percent).

Strategies for Community Outreach

Participant suggestions for outreach strategies (Figure 4, page 56) identified multiple ways to engage community members, including media involvement (e.g., social media, TV, and brochures, totaling 27.5 percent), patient-specific programs (e.g., programs incorporating testimonials/stories and support programs, totaling 27.5 percent), churches or faith-based outreach (13.8 percent), and outreach to families and caregivers (10.1 percent). Suggestions for outreach at the provider level included

strategies such as creating an inflammatory breast cancer research agenda/grant writing (41.2 percent), building/strengthening academic and community partnerships (13.7 percent), and attending conferences and meetings (11.8 percent).

Need for Education

There were no subcategories at the patient/community and organizational levels. However, Figure 5, page 56, indicates that the primary issues among providers are a lack of education on inflammatory breast cancer (79.4 percent), misdiagnosis due to patients not fitting the typical profile for breast cancer (13.1 percent), and lack of communication between physicians and patients (7.5 percent).

Discussion

Based on participant responses from the community engagement session and post-meeting interviews, researchers identified three concepts related to the unique needs and challenges facing stakeholders in inflammatory breast cancer treatment and research: (1) barriers to timely diagnosis and treatment, (2) strategies for community engagement, and (3) the need for provider education.

Figure 3. Responses for Barriers That Prevent Timely Diagnosis and Appropriate Treatment at the Organizational and Patient Levels
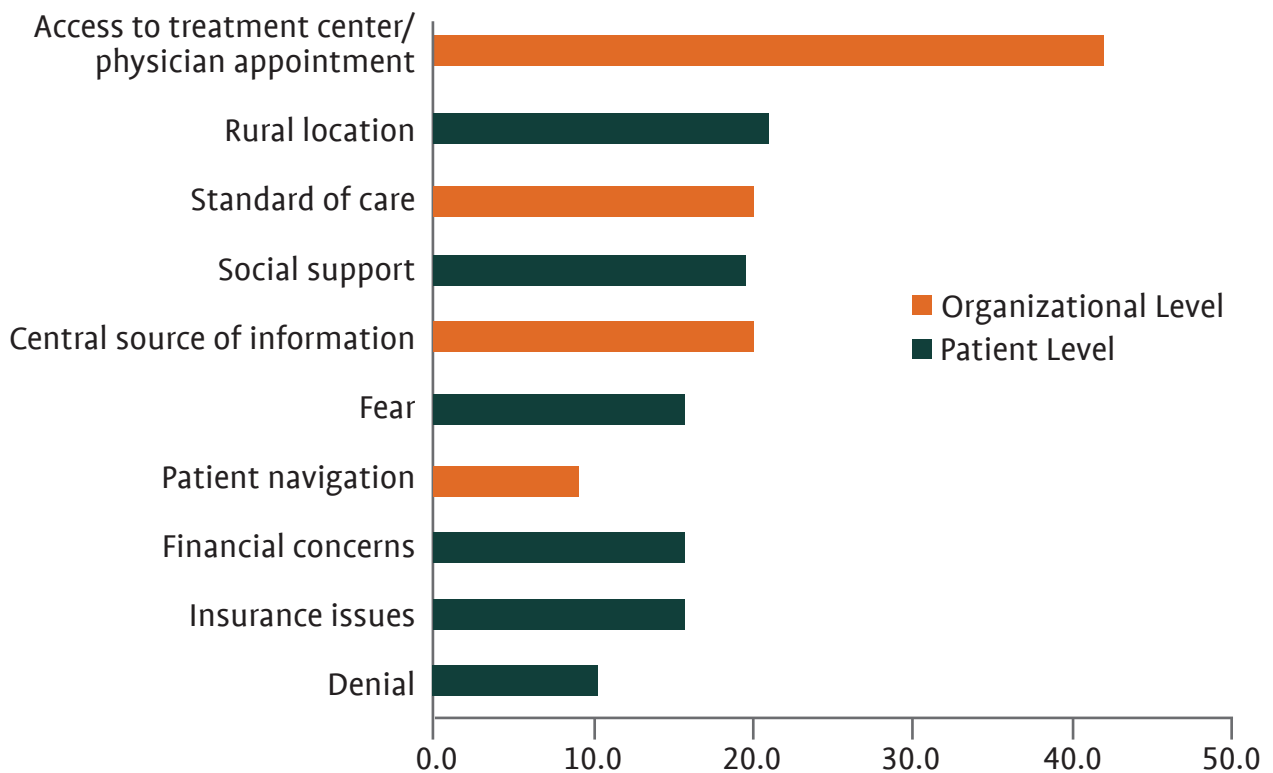
Note: No responses were coded at the provider level.

Figure 4. Responses for Community Outreach Strategies about Inflammatory Breast Cancer at the Provider and Patient/Community Levels

Legend:
- Provider Level
- Patient/Community Level

Categories (top to bottom):
- Research/grant writing
- Media-related outreach
- Academic/community partnerships
- Patient-specific programs
- Conferences/meetings
- Faith-based outreach
- Families and caregivers
- Advocacy groups/networks
- Health fairs
- Employers/schools

X-axis: 0.0, 10.0, 20.0, 30.0, 40.0, 50.0
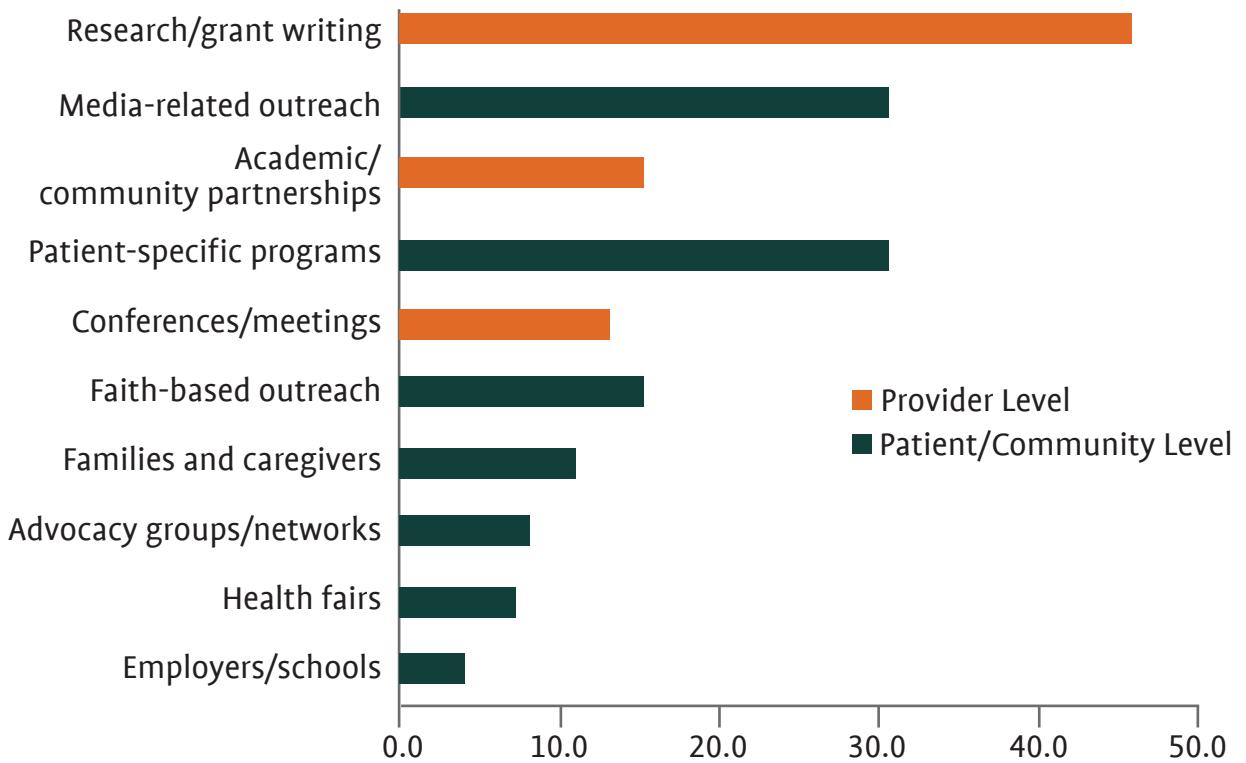
Note: No responses were coded at the organizational level.

Figure 5. Education Subthemes at the Provider Level

Categories (top to bottom):
- Lack of physician education
- Inaccurate profile (age, pregnancy, etc.)
- Lack of physician/patient communication

X-axis: 0.0, 20.0, 40.0, 60.0, 80.0, 100.0
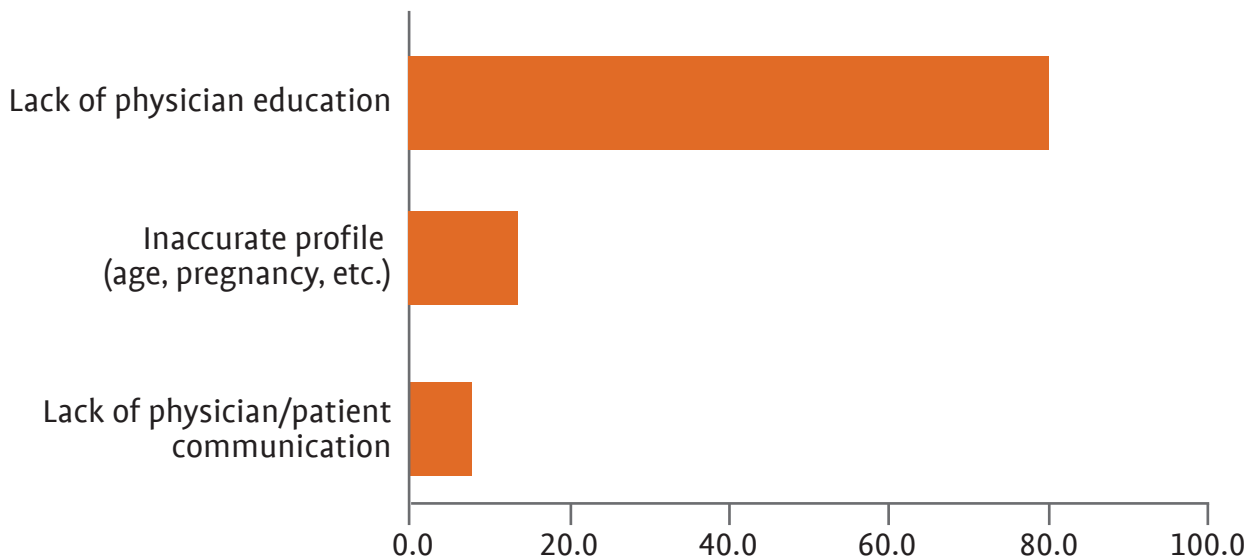
Note: No subcategories were coded for the patient/community and organizational levels.

These concepts are further described below with illustrative quotes. Table 2, page 58, outlines a proposed strategic plan to address these primary themes.

Barriers to Timely Diagnosis and Care

Guideline-concordant care for breast cancer patients includes multimodal therapy, which translates into a significant number of diagnostic tests, increased risk for potential complications, and prolonged time away from work.[10] Two patients described the number of tests and need for support throughout therapy:

I had a PowerPort inserted in my left chest wall; had an ECHO [echocardiogram] of my heart; had lab work; had an ultrasound of my right axilla lymph nodes (which resulted in me having a lymph node biopsy—also cancerous); and attempted to have a PET [positron emission tomography] scan, which my insurance denied, so I had CT [computed tomography] scans of chest, abdomen, and pelvis plus a bone scan.

I can't deny that the effects of dose-dense chemotherapy were debilitating for me. I am thankful my mom came to stay with us because I could barely take care of myself, let alone my son.

Our analysis shows that problems with travel, social support, and insurance all contributed to delays in diagnosis and treatment. A 2003 report from the Institute of Medicine (now The Academies of Medicine) identified rural residence as a potential risk factor for health disparities, and studies have shown that patient survival and outcomes may vary based on area of residence.[11] For example, Hausauer et al. reported that invasive breast cancer incidence decreased by 13.8 percent among middle-aged women living in urban areas, but for similarly aged women living in rural areas, incidence decreased only 7.5 percent.[12] Compared to women who have breast cancer and live in urban areas, women who live in rural areas and are further away from treatment centers are more likely to undergo mastectomies.[13–15]

Although there is a lack of research surrounding social support and inflammatory breast cancer per se, social well-being in women with breast cancer has been linked to better quality of life and increased immune function, including improved CD8+ T-cell percentage and counts, natural killer cell activity, and lymphocyte proliferation.[16-21] Recent literature has shown that the amount and quality of social support varies throughout the cancer experience. For example, in women newly diagnosed with breast cancer, social support from both providers and family dropped significantly within the first year.[22] Patients with inflammatory breast cancer also tended to be younger and had a higher incidence in under-represented minorities, particularly black women.[23-25] There is potential for greater disease burden because treatment is often more aggressive, and with likely family and work demands, social support is even more critical.

Finances also emerged as a barrier to treatment and care, which is closely related to insurance issues, such as denials for coverage of tests or a lack of insurance coverage altogether. To our knowledge, no studies have focused on the economics of inflammatory breast cancer treatment and care; however, literature

suggests that metastatic breast cancer can result in steep patient costs. Data on privately insured women diagnosed with metastatic breast cancer from 2003 to 2008 showed that the incremental annual total healthcare costs per patient were $5,100 for inpatient care, $37,231 for outpatient care, and $1,037 for prescription drugs.[26] Though the median income in the United States is $55,775, the median income in North Carolina is $47,884, allowing little money for living expenses.[27] Data from a study conducted at Duke University Medical Center indicated that among insured patients with cancer actively receiving chemotherapy or hormonal treatment (71 percent of study participants were diagnosed with breast cancer), 42 percent reported a significant or catastrophic financial burden. To save money, 24 percent of all participants avoided filling prescriptions, and 19 percent partially filled prescription drugs.[28]

> Feedback from the community engagement session indicated that patients often receive multiple misdiagnoses before finding a physician who correctly recognizes inflammatory breast cancer. Many healthcare providers often mistake inflammatory breast cancer symptoms for mastitis and prescribe antibiotics for a period of time, delaying diagnosis and appropriate treatment

Strategies for Community Engagement

There was a strong consensus among participants during our interactive session about the inclusion of community members in the development, decision making, and/or implementation of programs that affect them. Recently, the National Cancer Institute mandated the inclusion of community outreach and education for National Cancer Institute-designated cancer centers, requiring actionable programs outlining how centers can make an impact on the populations they serve.[29] Since 2012, the Duke Cancer Institute, through the Office of Health Equity and Disparities, has engaged patients, providers, and caregivers in strategic planning and collaboration to enhance cancer services, identify research opportunities, provide critical services to improve cancer outcomes, and reduce disparities. Data from these strategic planning and collaboration efforts are expected to assist in developing inflammatory breast cancer-specific outreach and education programs for effective co-learning and partnership building among

Table 2. Proposed Strategic Plan to Improve Patient-Centered Care for Patients with Inflammatory Breast Cancer	
Identified Themes	**Strategies and Recommendations**
Barriers to timely diagnosis and treatment	Assess gaps of knowledge and issues during diagnosis and treatment among patients with inflammatory breast cancer.
	Develop a strategic plan to address time to diagnosis and appropriate care for rural patients who do not reside near a treatment center. The plan should also include access to an appropriate treatment center.
	Use community-facing patient navigation to address barriers to care, such as lack of social support in juggling childcare, work responsibilities, and difficulty scheduling physician appointments.
	Use treatment navigators to facilitate support resources for patients to address their fear of diagnosis and/or treatment.
	Use of financial navigators to address issues with insurance coverage and financial concerns.
	Create a central source to provide IBC standard of care information to community members and healthcare providers.
	Organizational level, a lack of standard of care, or lack of access to an appropriate treatment center.
Community engagement	Assess knowledge of IBC among local community members.
	Develop a culturally tailored IBC media campaign utilizing social media, television, radio, and print (e.g., newspapers, brochures/pamphlets).
	Create a centralized website for community members to receive IBC information.
	Conduct patient-specific support programs for families and caregivers incorporating testimonials and stories from patient advocates at churches/faith-based organizations, workplaces, schools, and health fairs.
	Incorporate celebrity involvement in community health education outreach initiatives.
Provider education	Assess knowledge and recognition of patient clinical symptoms among healthcare providers.
	Develop educational training opportunities for healthcare providers to address misdiagnoses due to patients not fitting the breast cancer profile. Methods include modules, sessions at academic conferences and meetings, and development of a research agenda with funding agencies and academic/medical institutions.
	Facilitate bidirectional communication between patients and healthcare providers.

diverse stakeholders to develop interventions informed by the engagement process.[30]

Much work has been done to increase breast cancer screening and provide support for survivors, but, as one community partner stated, the focus has primarily been on patients with early-stage breast cancer rather than patients with late-stage or rarer forms of breast cancer.

I think now the next step is to talk about late-stage or more rare forms of breast cancer. One of the challenges I have is how to put out a unique message in a pink-weary world, and inflammatory breast cancer can be a scary message. I always try to wrap everything in hope because I'm here and others have survived much longer than me. I'm seeing women getting a quicker diagnosis because the disease is known, and that gives them a better chance of long-term wellness.

From our interactive session, one strategy that participants repeatedly mentioned for engaging community members was utilizing media—particularly social media, which has evolved into a knowledge exchange. Support groups for breast cancer patients are required for accreditation by the National Accreditation Program for Breast Centers and have proven to help patients by reducing anxiety and improving overall quality of life.[31-36] However, due to issues such as lack of transportation, patients often utilize the Internet and social media platforms—Facebook, Twitter, and blogs—instead of face-to-face meetings for information and support, because online mediums are convenient and affordable. Taken together, improving inflammatory breast cancer patient-centered care and outcomes requires linking local grassroots efforts to build awareness with national breast cancer charitable organizations and the inclusion of various subtypes of breast cancer as part of the conversation.

Need for Provider Education

Feedback from the community engagement session indicated that patients often receive multiple misdiagnoses before finding a physician who correctly recognizes inflammatory breast cancer. Many healthcare providers often mistake inflammatory breast cancer symptoms for mastitis and prescribe antibiotics for a period of time, delaying diagnosis and appropriate treatment, as two patients described:

I woke up, and overnight, my skin had gone from light pink to a quarter of my breast being streaked with purple and dark red circles. … That redness did look like an infection or a cut, that deep red underneath the surface of the skin. I saw the surgeon, who agreed with my self-diagnosis of an infection. He started me on an antibiotic.

A lot of times, the doctors do not know about inflammatory breast cancer; or they think they know about inflammatory breast cancer and if a patient's presentation is different from what they've read in a textbook, they say, "Oh, it couldn't be inflammatory breast cancer." … Doctors send people home with a second round of antibiotics or a third round of antibiotics, a cream, or a "Don't worry about it, dear."

Based on our community engagement session, three major themes emerged related to addressing challenges in inflammatory breast cancer care, including the need for increased support for inflammatory breast cancer patients, greater societal awareness of inflammatory breast cancer, and improved provider education.

Given this misinformation, both the group discussion facilitator and patients recognized that primary care provider and even surgeon/breast specialist education is crucial.

One of the needs that was identified was education of providers—especially primary care providers and dermatologists—about inflammatory breast cancer, its distinguishing characteristics, and the need to treat it quickly.

I think an important thing at our table is making sure that primary care physicians, gynecologists, and local doctors of all sorts are well educated about inflammatory breast cancer and that they know where to refer.

There is a lack of research on the impact of missed or mistaken diagnoses on the experience or outcomes for patients with inflammatory breast cancer.[5,6,37] Notably, women who seek care at local hospitals are the ones at highest risk of receiving care outside of national guidelines across multiple breast cancer subtypes. This highlights the critical need to address a lack of education about inflammatory breast cancer at the primary provider and local hospital levels.[6,38] Primary care providers are often the first point of contact when patients begin experiencing symptoms and can play a key role in early detection.[39] Because inflammatory breast cancer progresses rapidly, it is imperative that these physicians are familiar with the clinical presentation to avoid delaying treatment.

In some countries, physicians have made progress in recognizing the clinical signs of inflammatory breast cancer. In North Africa, primary care providers' knowledge of breast cancer and inflammatory breast cancer was evaluated following a presentation given by an oncologist.[40] Physicians showed a significant improvement in knowledge related to the management, symptoms, and methods of inflammatory breast cancer detection. A similar study was undertaken in Pakistan with primary care providers who were assessed on their knowledge about inflammatory breast cancer and locally advanced breast cancer.[41] Most participants (74 percent) had heard of inflammatory breast cancer, and knowledge regarding not prescribing antibiotics for symptoms lasting

more than one week increased from 49 percent to 86 percent. However, knowledge about inflammatory breast cancer potentially manifesting without a palpable mass improved from 41 percent to only 60 percent. To our knowledge, no studies have been conducted to educate physicians about inflammatory breast cancer in the United States; interestingly, no further efforts have been made to educate physicians in the past 10 years, creating a critical need for further research.

Limitations

Our community engagement session and resulting themes are the first contribution of this type to the inflammatory breast cancer literature. Notably, our interactive session included a wide range of attendees from both the academic and inflammatory breast cancer stakeholder communities, and more detailed perspectives were captured from individual interviews. However, as with any qualitative approach, we recognize that the data may not be generalizable. Because the analyses included responses from all individuals who participated in the session discussions, we could not connect responses to specific individuals. We envision holding future town halls, focus groups, and strategic meetings that will allow us to collect demographics such as race, gender, and ethnicity.

Future Steps

Based on our community engagement session, three major themes emerged related to addressing challenges in inflammatory breast cancer care, including the need for increased support for inflammatory breast cancer patients, greater societal awareness of inflammatory breast cancer, and improved provider education. The inflammatory breast cancer community needs more information about where knowledge gaps exist among providers and how missed diagnoses impact patients in order to design useful interventions. We are currently taking steps to address these issues, which include:

- Assessing knowledge of inflammatory breast cancer among the lay public
- Assessing knowledge and recognition of inflammatory breast cancer clinical symptoms among primary care providers, including physicians, physician assistants, and nurse practitioners
- Surveying patients with inflammatory breast cancer regarding where specific issues arise during diagnosis and treatment

As part of our research plan, data sets from these populations will then allow us to develop appropriate interventions and educational opportunities that will address issues faced by patients with inflammatory breast cancer. As our current research demonstrates, addressing the needs of patients with inflammatory breast cancer requires a multifaceted approach. ◼

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References

1. Matro JM, Li T, Cristofanilli M, al. Inflammatory breast cancer management in the national comprehensive cancer network: the disease, recurrence pattern, and outcome. *Clin Breast Cancer.* 2015;15:1-7.

2. Arora J, Sauer SJ, Tarpley M, et al. Inflammatory breast cancer tumor emboli express high levels of anti-apoptotic proteins: use of a quantitative high content and high-throughput 3D IBC spheroid assay to identify targeting strategies. *Oncotarget.* 2017;8:25848-25863.

3. Evans MK, Brown MC, Geradts J, et al. XIAP regulation by MNK links MAPK and NF B signaling to determine an aggressive breast cancer phenotype. *Cancer Res.* 2018;78:1726-1738.

4. Gradishar WJ, Anderson BO, Balassanian R, et al. Breast cancer, version 4.2017, NCCN clinical practice guidelines in oncology. *J Natl Compr Canc Netw.* 2018;16:310-320.

5. Rueth NM, Lin HY, Bedrosian I, et al. Underuse of trimodality treatment affects survival for patients with inflammatory breast cancer: an analysis of treatment and survival trends from the National Cancer Database. *J Clin Oncol.* 2014;32:2018-2024.

6. Denu RA, Hampton JM, Currey A, et al. Influence of patient, physician, and hospital characteristics on the receipt of guideline-concordant care for inflammatory breast cancer. *Cancer Epidemiol.* 2016;40:7-14.

7. Devi GR, Hough H, Barrett N, et al. Perspectives on inflammatory breast cancer (IBC) research, clinical management and community engagement from the Duke IBC Consortium. *J Cancer.* 2019;10:3344-3351.

8. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol.* 2006;3(2):77-101.

9. Strauss AL, Corbin JM. *Basics of Qualitative Research: Grounded Theory Procedures and Techniques.* 2nd ed. Newbury Park, CA: Sage Publications; 1990.

10. Yeh ED, Jacene HA, Bellon JR, et al. What radiologists need to know about diagnosis and treatment of inflammatory breast cancer: a multidisciplinary approach. *Radiographics*. 2013;33:2003-2017.

11. Smedley BD, Stith AY, Nelson AR, eds. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Washington, DC: National Academies Press; 2003.

12. Hausauer AK, Keegan TH, Chang ET, et al. Recent trends in breast cancer incidence in U.S. white women by county-level urban/rural and poverty status. *BMC Med*. 2009;7:31.

13. Celaya MO, Rees JR, Gibson JJ, Riddle BL, Greenberg ER. Travel distance and season of diagnosis affect treatment choices for women with early-stage breast cancer in a predominantly rural population (United States). *Cancer Causes Control*. 2006;17:851-856.

14. Jacobs LK, Kelley KA, Rosson GD, et al. Disparities in urban and rural mastectomy populations: the effects of patient- and county-level factors on likelihood of receipt of mastectomy. *Ann Surg Oncol*. 2008;15:2644-2652.

15. Punglia RS, Weeks JC, Neville BA, Earle CC. Effect of distance to radiation treatment facility on use of radiation therapy after mastectomy in elderly women. *Int J Radiat Oncol Biol Phys*. 2006;66:56-63.

16. Sammarco A. Perceived social support, uncertainty, and quality of life of younger breast cancer survivors. *Cancer Nurs*. 2001;24:212-219.

17. Sammarco A. Quality of life of breast cancer survivors: a comparative study of age cohorts. *Cancer Nurs*. 2009;32:347-356; quiz 357-358.

18. Arving C, Sjödén PO, Bergh J, et al. Individual psychosocial support for breast cancer patients: a randomized study of nurse versus psychologist interventions and standard care. *Cancer Nurs*. 2007;30(3):E10-E19.

19. Kim SW, Kim SY, Kim JM, et al. Relationship between a hopeful attitude and cellular immunity in patients with breast cancer. *Gen Hosp Psychiatry*. 2011;33:371-376.

20. McGregor BA, Antoni MH, Boyers A, et al. Cognitive-behavioral stress management increases benefit finding and immune function among women with early-stage breast cancer. *J Psychosom Res*. 2004;56:1-8.

21. Von Ah D, Kang DH, Carpenter JS. Stress, optimism, and social support: impact on immune responses in breast cancer. *Res Nurs Health*. 2007;30:72-83.

22. Arora NK, Finney Rutten LJ, Gustafson DH, et al. Perceived helpfulness and impact of social support provided by family, friends, and healthcare providers to women newly diagnosed with breast cancer. *Psychooncology*. 2007;16:474-486.

23. Anderson WF, Schairer C, Chen BE, et al. Epidemiology of inflammatory breast cancer (IBC). *Breast Dis*. 2005;22:9-23.

24. Chang S, Parker SL, Pham T, et al. Inflammatory breast carcinoma incidence and survival: the surveillance, epidemiology, and end results program of the National Cancer Institute, 1975-1992. *Cancer*. 1998;82:2366-2372.

25. Hance KW, Anderson WF, Devesa SS, et al. Trends in inflammatory breast carcinoma incidence and survival: the Surveillance, Epidemiology, and End Results Program at the National Cancer Institute. *J Natl Cancer Inst*. 2005;97:966-975.

26. Fu AZ, Jhaveri M. Healthcare cost attributable to recently diagnosed breast cancer in a privately insured population in the United States. *J Med Econ*. 2012;15:688-694.27. Economic Research Service, United States Department of Agriculture. Unemployment and median household income for the U.S., states, and counties, 2007-17. Available online at: ers.usda.gov/data-products/county-level-data-sets/download-data. Last accessed April 25, 2019.

28. Zafar SY, Peppercorn JM, Schrag D, et al. The financial toxicity of cancer treatment: a pilot study assessing out-of-pocket expenses and the insured cancer patient's experience. *Oncologist*. 2013;18:381-390.

29. Paskett ED, Hiatt RA. Catchment areas and community outreach and engagement: the new mandate for NCI-designated cancer centers. *Cancer Epidemiol Biomarkers Prev*. 2018;27:517-519.

30. Barrett NJ, Hawkins TV, Wilder J, et al. Implementation of a health disparities & equity program at the Duke Cancer Institute. *Oncol Issues*. 2016;31(5):48-57.

31. National Accreditation Program for Breast Centers. *NAPBC Standards Manual: 2014 Edition*. Available online at: facs.org/~/media/files/quality%20programs/napbc/2014%20napbc%20stand ards%20 manual.ashx. Last accessed April 25, 2019.

32. Ashing-Giwa K, Tapp C, Rosales M, et al. Peer-based models of supportive care: the impact of peer support groups in African American breast cancer survivors. *Oncol Nurs Forum*. 2012;39:585-591.

33. Björneklett HG, Lindemalm C, Rosenblad A, et al. A randomised controlled trial of support group intervention after breast cancer treatment: results on anxiety and depression. *Acta Oncol*. 2012;51(2):198-207.

34. Cameron LD, Booth RJ, Schlatter M, et al. Changes in emotion regulation and psychological adjustment following use of a group psychosocial support program for women recently diagnosed with breast cancer. *Psychooncology*. 2007;16(3):171-180.

35. Pinheiro CPO, da Silva RM, Mamede MV, Fernandes AFC. Participating in a support group: experience lived by women with breast cancer. *Rev Lat Am Enfermagem*. 2008;16:733-738.

36. Power S, Hegarty J. Facilitated peer support in breast cancer: a pre- and post-program evaluation of women's expectations and experiences of a facilitated peer support program. *Cancer Nurs*. 2010;33(2):E9-E16.

37. Liauw SL, Benda RK, Morris CG, Mendenhall NP. Inflammatory breast carcinoma: outcomes with trimodality therapy for nonmetastatic disease. *Cancer*. 2004;100:920-928.

38. Wu XC, Lund MJ, Kimmick GG, et al. Influence of race, insurance, socioeconomic status, and hospital type on receipt of guideline-concordant adjuvant systemic therapy for locoregional breast cancers. *J Clin Oncol*. 2012;30(2):142-150.

39. Molckovsky A, Fitzgerald B, Freedman O, et al. Approach to inflammatory breast cancer. *Can Fam Physician*. 2009;55:25-31.

40. Shah NM, Soliman AS, Benerjee M, et al. Knowledge gained after a brief CME module on breast cancer diagnosis. *J Cancer Educ*. 2006;21(3):169-174.

41. Soliman AS, Samadi S, Banerjee M, et al. Brief continuing medical education (CME) module raises knowledge of developing country physicians. *Int Electron J Health Educ*. 2006;9:31-41.

From Invisible Experts to Active Caregivers:

Pathologists Emerge from the Shadows

BY BARBARA A. GABRIEL

A s with many inspired ideas, it started with a tweet.
It wasn't Dr. Lija Joseph's tweet. By her own admission, she knew nothing about Twitter, nor about social media in general. But, as a scientist, she was curious, and she was ready to learn.

The tweet in question came from a woman recently diagnosed with cancer. Lija Joseph, MD—the medical director of the Department of Pathology and Laboratory Medicine at Lowell General Hospital in Massachusetts—learned about this patient in a weekly meeting in which she and her fellow pathologists discuss the latest published literature in their field. One article suggested by a group member featured a story about a patient newly diagnosed with lung cancer. That patient wanted to view her biopsy, so she reached out via Twitter to a pathologist who has a significant online presence. When the pathologist agreed to meet with the patient, he related his account of her traveling from her home in Lowell for a consultation with him in Newton.

It struck Dr. Joseph as wrong that the patient had to travel to simply see her pathology images. "The fact that she had to go so far to meet with a pathologist wasn't right," says Dr. Joseph. "I felt that anyone in Lowell who wanted to view their pathology images should not have to travel to do so." To explore this thought further, Dr. Joseph knew she would have to venture into some unfamiliar territory. She approached social media much as she would a sample in her lab: She observed it closely before coming to any conclusions.

Lija Joseph, MD

A Whole New World

Dr. Joseph began searching various social media outlets, where she discovered a vibrant community of pathologists and patients communicating about their diseases. "There was a lot of this interaction on Facebook and Twitter" says Dr. Joseph. "But I didn't feel very comfortable with it. How would it affect my professional reputation, and what about patient privacy issues?"

For answers, Dr. Joseph invited into her lab radiation oncologist Matt Katz, MD—a big social media proponent. In the beginning of 2017, Dr. Katz gave Dr. Joseph and her colleagues a primer on how to use social media as a medical professional. "He showed us what we were missing," recalls Dr. Joseph. "My colleagues were still hesitant to take the leap, so I decided to be the brave one, and I opened a Twitter account in January 2017."

Those first few months, Dr. Joseph stayed in observation mode, listening to and learning about this new arena. In time, she reached out to the pathologist who had met with the patient with lung cancer whom she and her colleagues had read about. He accepted Dr. Joseph's invitation to meet. Dr. Joseph emerged from that meeting determined to make it possible for interested Lowell General Hospital patients to meet with the pathologists who diagnosed their diseases. Of course, that meant that Dr. Joseph had to be prepared to meet patients herself. "Before this, I had not seen a patient for 18 years—not since my training," she says.

As a pathologist, Dr. Joseph's position was not unusual. Although it is estimated that objective laboratory data influence a significant percentage of clinical decisions, patients are often unaware of the role that pathologists play in their diagnosis. "Many patients believe their surgeon or oncologist diagnosed their malignancy," says Dr. Joseph. "In fact, pathologists are the engines that drive the car, but most of the time patients haven't looked under the hood."

Dr. Joseph says that this perception of pathologists as invisible forces operating behind a curtain can extend beyond the patient care arena. "Even in the medical community," she says, "there is a misconception that pathologists are introverts uninterested in meeting patients."

Dr. Joseph perceives her efforts to open a dialogue between patients and pathologists as not only a patient service but also a benefit to pathologists. A consultation program, she reasons, has the potential to transform pathologists from invisible experts into active participants in patient care and the multidisciplinary care team.

"There is a perception out there that pathologists only do autopsies, and they don't like to talk to patients," Dr. Joseph explains. "I personally think that pathologists are very compassionate and caring physicians. Like most doctors, they chose to go into medicine because they want to help people. But if they are behind the scenes, it takes something away. The patient encounter truly helps maintain a physician's wellness."

A Complete Unknown

Determined to help patients better understand how their diseases affect their bodies, Dr. Joseph began exploring how to create a program at Lowell General Hospital in which patients could meet with pathologists to view their biopsy slides. She reached out to other pathologists she found online who had experience consulting with patients about their diagnoses. Knowing that she would need the full backing of her hospital's leadership, Dr. Joseph met with the hospital's administration, risk management, and marketing departments, as well as its cancer center and professional liability organization. "Everyone was supportive and eager to jump-start the initiative," she recalls, "in part because of our pathology department's excellent reputation."

With her hospital's support, Dr. Joseph established a free oncology consultation program, and she met with her first patient on Mar. 1, 2017. In the early days of the program, Dr. Joseph and the hospital's leadership kept their expectations low. "It was a complete unknown," recalls Dr. Joseph. "Would I have one or 20 patients a year? We had no roadmap and no precedent; we were starting from scratch."

Dr. Joseph and the hospital's oncology department decided to market their new pathology consultation services to patients with breast cancer. "In general, breast cancer patients tend to be very motivated," she explains. "They are young and engaged, and they've done research on their disease."

In Dr. Joseph's first consultation, the patient came prepared, equipped with multiple diagnostic reports and plenty of informed questions. Dr. Joseph shared with the patient slides of her biopsy and invited her to view them through a microscope. She showed the patient a sample of "normal" cells to compare with her cells. "We talked about her diagnosis together," says Dr. Joseph. "It was exciting for me and for her." When their consultation was over, Dr. Joseph gave the woman her card and cell phone number, a practice that she continues today. "No patient has ever abused that information," she says.

Practical Considerations

To date, Dr. Joseph has met with approximately 76 patients, and she continues to see about two to three per month for 30-minute consultations. She sees mostly patients with breast cancer who are referred to her by a breast cancer surgeon who has come to champion Dr. Joseph's program. "Right now, this is an informal referral service," says Dr. Joseph. "Patients find out about it from surgeons who offer the service to them if they want to see their labs before surgery."

Dr. Joseph says she knows that not all patients will seek her out. "This [type of consultation] isn't for everyone," she explains. "The people who come to see me are patients who are curious, who truly want to 'own' their disease and find out everything they can about it."

Dr. Joseph says that for the patients who consult with her, actually seeing the disease they are battling can be empowering. "Often with a cancer diagnosis, there is not much patients can control," she explains, "so to actually see [the cancer] helps them understand it and decrease their panic or anxiety."

In a recent study published by the *Archives of Pathology and Laboratory Medicine*, researchers surveyed 100 patients with cancer to gauge their interest in consulting with a pathologist and viewing a microscopic slide of their tissue. Eighty-five patients indicated that they were either definitely interested or interested, leading the study's authors to theorize that "a patient-pathologist consultation program could provide value by improving information exchange (through enhanced understanding), could help patients manage uncertainty (through demystifying the process of diagnosis and enhanced understanding), and could enable patient self-management (through empowering)."[2]

Although Dr. Joseph is currently the only pathologist at Lowell General Hospital consulting with patients, she says that several of her colleagues have also expressed an interest in doing so. By seeing patients consult with her, says Dr. Joseph, her colleagues have for the first time been able to put faces to the biopsies they work with each day. But she adds that there are skills to meeting with patients that do not always come naturally to physicians who have become accustomed to working in a lab every day.

"Using layman's language that patients will understand has been something I've had to learn myself," explains Dr. Joseph. "Most pathologists have only worked with other doctors in their careers, so they are mostly accustomed to communicating in a scientific terminology that they know their colleagues understand."

Another consideration is the pathologist's time. Currently, patient pathology consults at Lowell General Hospital are complementary. "You are spending a half hour with a patient, and there is no money involved," says Dr. Joseph. "You could be signing out 15 biopsies in that 30 minutes. For some, that could be frustrating."

Patient privacy is also a concern. As the first pathologist in her hospital to consult with patients, Dr. Joseph needed a place to do so that would be both comfortable for the patient and Health Insurance Portability and Accountability Act compliant. For now, that space has been carved out of Dr. Joseph's lab, although she hopes to have a dedicated space in the future.

Finally, says Dr. Joseph, pathologists who consult with patients need to be comfortable when conversations stray beyond the biopsy, and they need to be able to put parameters on their encounter. Dr. Joseph is firm about not going beyond her field of expertise and discussing patients' treatment plans. Patience and compassion are crucial in these cases, she says. "You have to be able to explain your role; you can't just say, 'No, I don't want to hear about that.'"

New Horizons

Dr. Joseph hopes that by nudging her field to be more hands-on with patients, more medical students will be drawn to pathology, a specialty that currently attracts less than 2 percent of medical school graduates. She says she hears stories about pathologists actively dissuading students from choosing pathology because it has traditionally excluded patient interaction. Dr. Joseph hopes that her patient consultations will challenge this attitude.

Dr. Joseph now regularly takes to Twitter with her handle @lijjoseph, #visiblepathologists. There she helps facilitate conversations among pathologists around the world who are also engaging with their patients. Pathologists-in-training are also helping promote patient interactions by offering consultations to them.

At the University of Michigan Medical School, students have produced a YouTube video about a leukemia patient's experience meeting with pathologists who show her the science behind her disease. One pathologist at the University of Michigan has tweeted the results of an online poll of cancer patients in which 75 percent of respondents said they were "definitely interested" in a patient-pathologist consultation program.

Dr. Joseph says she does not want her consultation program at Lowell General Hospital to be confined to her services alone. She says the feedback she's received has reinforced this. "With the explosion of social media, patients are actively seeking to learn more about their disease," says Dr. Joseph. To expand her program, she and her colleagues are exploring the possibility of offering consultations remotely via telemedicine sessions. And to tackle the issue of reimbursement, Dr. Joseph is joining her colleagues at the College of American Pathologists to advocate for reimbursement for pathologists providing patient consults.

To document patient interest in pathology consultations, Dr. Joseph has joined forces with several other institutions that are offering similar services to gauge patient satisfaction via postconsultation surveys. She hopes that this nationwide effort will lend credibility to the usefulness of patient-pathologist interactions. "If the closest patients can get to understanding their own disease is a Google search, that's not good enough," says Dr. Joseph. "If they can see their own biopsies, they will feel like they can better manage their journey to wellness." ◘

Barbara Gabriel is an associate editor for Oncology Issues.

Reference

1. Lapedis C, Horowitz J, Brown L, et al. The Patient-Pathologist Consultation Program: a mixed-methods study of interest and motivations in cancer patients. *Arch Pathol Lab Med*. 2019. Available online at: https://www.archivesofpathology.org/doi/10.5858/arpa.2019-0105-OA.

ACCC Resources

ACCC is partnering with the Association for Molecular Pathology, the American Society for Clinical Pathology, and the College of American Pathologists in a three-phase education program (accc-cancer.org/pathology) to help cancer programs effectively integrate the pathology lab and pathologists into the multidisciplinary cancer care team:

- Phase I—Precision Medicine: Integration of Pathology with the Cancer Care Team, including survey highlights, a landscape analysis, a leadership summit executive summary, and a policy white paper.
- Phase 2—Identification, Demonstration, and Promotion of Effective Practices for Pathology Integration, including a gap assessment tool that cancer programs can use to evaluate the level of pathology integration with the oncology care team. Self-assessments can be used to identify short- and long-term opportunities to improve.
- Phase 3—Ongoing Impact and Measurement (look for new tools and resources coming in 2020).

Geriatric Assessment, Multidisciplinary Model is Focus of FITNESS Study in Older Adults

BY AMY HINDMAN

The Cancer and Aging Resiliency Clinic—or CARE Clinic—at the Ohio State University Comprehensive Cancer Center Arthur G. James Cancer Hospital and Richard J. Solove Research Institute ("The James") is one of only a few hospitals in the nation that provides a unique model of care for older patients with cancer.

The CARE Clinic opened in February 2017 for patients age 65 and older with blood cancer and later expanded to serve patients with solid tumor cancers, such as breast and lung cancers. The clinic is part of the Cancer and Aging Research Group, which joins geriatric oncology researchers in a collaborative effort to design and implement clinical trials to improve the care of older adults with cancer.[1]

The care model at The James pairs patients with a multidisciplinary healthcare team who not only review cancer-specific treatment but also assess patients for balance, cognition, hearing, nutrition, medications, symptom management, emotional health, and social issues such as caregiver and safety concerns and financial constraints—all in one visit.

Novel Aging Research and the Multidisciplinary Healthcare Team

The CARE Clinic incorporates novel aging research with subspecialty evaluations by a nurse, pharmacist, case manager, nutritionist, physical therapist, audiologist, and physician to care for patients. One study, the FITNESS study, aims to obtain a

> Answering the larger question of how to remedy the exclusion of older adults from meaningful cancer research is a crucial aim of the CARE Clinic. Many cancer-related clinical trials have upper age limits or disqualify people for other conditions that older people might have.

better understanding of how seniors age 60 and older tolerate treatments for lung and other cancers and determine which treatments result in worsening disability and functional decline.

"Typically, people arbitrarily pick 65 because that's when you're eligible to enroll in Medicare, but we know that there are some participants who are in their early 60s who chronologically would feel young but physiologically they're much older," Dr. Carolyn Presley, MD, MSH, said. "What is it about the person that can give us an idea of their health status rather than just looking at how old they are?"

Dr. Presley is a thoracic geriatric oncologist board certified in both geriatrics and medical oncology. She and hematologist Ashley Rosko, MD, are co-directors of the FITNESS study, which began accruing patients in September 2018. Dr. Presley leads research and clinical teams for the lung cancer cohort, both of which focus on older adults with lung cancer. Dr. Rosko leads the hematology cohort.

The team at the CARE clinic uses the geriatric assessment tool developed by the late Arti Hurria, MD, a leader in geriatric oncology who advanced the specialty field and was a mentor to both Dr. Presley and Dr. Rosko.[2] The tool is fairly easy to implement into routine oncology care because it is primarily survey based, Dr. Presley said.

Patients in the study fill out a questionnaire about such things as whether they have had any falls, have memory impairment, need help getting dressed, or need help managing their medication. They also do exercises to test their balance and monitor the speed of their gait.

"The study is novel in that it's doing the geriatric assessment at longitudinal time points, or more than one time point, during their treatment," Dr. Presley said. "It's a minimum of at least two times. It could be up to four times, depending on how long they're in the study."

Researchers also will collect blood and stool samples to look at biomarkers of aging and bacteria in the gut microbiome that could be associated with how well treatment is tolerated and how the tumor actually responds to the treatment, Dr. Presley said.

"We really follow them [older patients] more closely for symptoms and side effects and measuring the impact on their daily life more often than we routinely ask about in cancer care," she said. "But we know that living through treatment affects older adults much differently than younger adults, and that's part of what we're trying to understand in this study."

"Most of the study generated in clinical trials that led to the approval of a lot of these newer, super exciting cancer drugs were tested in younger, healthier individuals, and basically everybody now with lung cancer will probably get immunotherapy or targeted treatment, either in place of or in addition to chemotherapy," Dr. Presley said. "But we really don't have a lot of data on how these drugs are tolerated and how the cancer responds to these drugs in older individuals."

Patients have been very open to having a geriatric assessment done. "They want to talk about a lot of these things that we might not necessarily have time to talk about or think that they want to talk about, such as mood, anxiety, depression, mobility, or falls," Dr. Presley said. The study "gives patients the opportunity to talk about those issues."

Doctors are able to ask more questions, which gives them more awareness of what's happening with their patients. "Symptoms are definitely an issue, and balance is another factor that we're able to look at more closely," Dr. Presley said.

Her hope is that the care team "is able to catch side effects earlier and that treatment decisions will be made based on more of the lived experience of getting treatment for lung cancer."

"We've encountered some significant toxicities that have resulted in either ending or changing treatment earlier than we would have otherwise," she said. "We are avoiding the worsening of a side effect or we're trying to prevent an irreversible toxicity from these treatments."

For patients in the study, Dr. Presley said that providers are able to capture data earlier, because they are asking patients questions more tailored to older adults: "It's not, 'Do you have nausea, vomiting, diarrhea?' It's a much more nuanced approach."

Study accrual will end in another year, and some results will be available within the next 18 to 24 months.

Breaking Down the Trial Barrier for Older Adults

Answering the larger question of how to remedy the exclusion of older adults from meaningful cancer research is a crucial aim of the CARE Clinic. Many cancer-related clinical trials have upper age limits or disqualify people for other conditions that older people might have.[3-5]

"There are two problems: Clinical trials are selecting for the healthiest individuals. If you have any issues with a comorbidity, you are much more likely to be ineligible, and they require a lot more work. There are so many hoops to jump through to get into a clinical trial. For most, it's not worth it because it is a significant time and energy burden for people who already do not feel well," Dr. Presley said. "Those are two things that we were purposefully very mindful about in our studies, so that it doesn't require extra visits. It's all pretty much done the same day that they come in for their regular appointment and treatment, and the inclusion criteria are relaxed, meaning you don't have to be, essentially, a marathon runner to be in the study."

"We have to make it easier, not only for older adults but just for people who don't feel well to get onto clinical trials because we don't think about the treatment burden, the work of the patient that it requires to be in a clinical trial," she continued. "Until we actually address that and relax the inclusion criteria, we're going to continue to exclude older adults from clinical trials."

A Continuing Commitment to Improving Care

The James is continually seeking ways to improve care delivery for their older patients with cancer. The healthcare team at the CARE Clinic has recently initiated a simple yet effective measure to help patients manage their medications by distributing pill boxes.

Early in 2019, Dr. Presley sent her nursing staff to a conference specifically focused on geriatric oncology for oncology nurses. The conference is part of an R25, National Cancer Institute-funded grant, in coordination with the Cancer and Aging Research Group. When they came back, nursing staff took the initiative to develop an "older adult" binder specific to lung cancer.

The James is in the process of building a specific onco-geriatrics program. "That's how dedicated we are to cancer and aging research, and cancer and aging clinical care, because this is really the future of cancer care," Dr. Presley said. "Yes, we can develop

all these new, exciting medications and other cancer treatments, but at the end of the day, it's going to be a different story in older adults versus younger adults, and we are very committed to improving the care of older adults with all types of cancer."

"As a healthcare system, just because we treat a lot of patients who are older does not necessarily mean we are good at it. We have a long way to go," she said. "I would really encourage people to try to learn more about the major issues that are affecting older adults. I would say the big issues, at least in cancer, are pain, mood, falls, and polypharmacy, and those are just four main issues, but we have a lot of work to do. We embrace anyone who wants to get involved in that work at Ohio State." OI

Amy Hindman is a freelance writer with over 10 years of experience writing in technology, healthcare, and oncology.
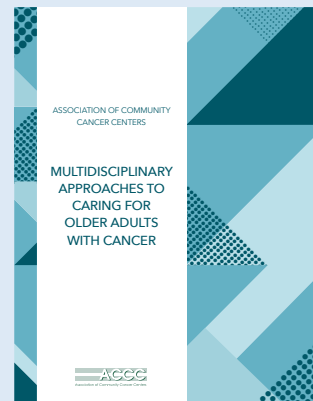
References

1. Cancer & Aging Research Group. Available online at: mycarg.org. Last accessed August 21, 2019.

2. Piana R. Leader in geriatric oncology, Arti Hurria, MD, FASCO, dies at age 48. Available online at: ascopost.com/issues/november-25-2018/leader-in-geriatric-oncology-arti-hurria-dies-at-age-48. Published November 25, 2018. Last accessed September 12, 2019.

3. Span P. The clinical trial is open. The elderly need not apply. Available online at: nytimes.com/2018/04/13/health/elderly-clinical-trials.html. Published April 13, 2018. Last accessed September 12, 2019.

4. Singh H, Kanapuru B, Smith C, et al. FDA analysis of enrollment of older adults in clinical trials for cancer drug registration: a 10-year experience by the U.S. Food and Drug Administration. *J Clin Oncol.* 2017;35:10009-10009.

5. Dale W, Mohile SG, Eldadah BA, et al. Biological, clinical, and psychosocial correlates at the interface of cancer and aging research. *J Natl Cancer Inst.* 2012;104:581-589.

Smitty Proves Age is More Than a Number

Laird "Smitty" Smith is a participant in the FITNESS study at The James under the care of Dr. Presley. After persistent hip pain led him to undergo a battery of tests, he was shocked to learn he had stage 3 lung cancer. The cancer had spread to surrounding lymph nodes and his esophagus.

That was in September 2018. Now he's playing golf up to three times a week with his "buddies," many of whom are cancer survivors themselves and provide a support system for one another.

Smith told Dr. Presley when they first met, "No matter what in life, nothing will ever be as hard as Vietnam." It was during his tour there that Smith was exposed to Agent Orange, a chemical agent that is now a known carcinogen.

Smith attributes his positive attitude and lifestyle to his healing as much as the multidisciplinary cancer care and treatment he receives at The James.

Throughout 5 months of chemotherapy and radiation treatment, he didn't miss a single day of work, walking 9 to 11 miles each day as a manager of 20 buildings in 9 states and 2 countries. He retired on June 14 but said he is busier now than ever.

"I've been busier not going to work than working. I have so much stuff to do, around my house, with doctors' appointments, the VA, The James. I didn't have time before. It's not easy to be retired," Smith said.

He continues to undergo chemotherapy every two weeks and gets a CT scan every two months. On the Thursday and Friday after treatment, he's wiped out, but "then I'm fine," he said. "I can do yard work and play golf. Go to the gym. Everything."

Smith has subsequently changed his diet and lost weight, too. Smith said he eats only organic foods, cut out all meat and dairy, and stopped drinking alcohol, except one glass of red wine on Friday and Saturday nights with dinner.

"You have to keep positive. This thing isn't going to kill me, it's just going to put me down for a while. I'm not too worried about it," Smith said.

An Oncology Symptom Treatment Area Hits the Mark

BY PAULA GOFF, MSN, OCN, BMTCN

Improving care while reducing ER visits and hospital admissions

Oncology patients are a high-risk population with predictable—often severe—side effects that increase the risk of hospital admissions and emergency department (ED) visits. Though side effects from chemotherapy are well managed in the physician practice setting, it can be challenging to meet patient needs outside of traditional office hours. Advocate-Aurora Lutheran General Hospital's physician practices are open 9:00 am-5:00 pm, Monday through Friday. This meant that patients who experienced side effects from chemotherapy after hours would often wait at home through the night and call the provider the next business day, hoping to be seen. Unfortunately, physician practices often have full schedules and are sometimes unable to accommodate such patients, leaving them no choice but to go to the ED.

From both the patient and provider perspectives this scenario is not optimal. Research has shown that nearly 60 percent of patients with cancer who visited EDs were admitted to the hospital with an average length of stay of three days.[1] To better meet the needs of patients and as part of efforts to reduce healthcare costs, Advocate-Aurora Lutheran General Hospital partnered with two private practices to increase patient access to much-needed services when physician practices were closed. Here's our story.

> Because the OCNs staffing the oncology symptom management treatment area would have access to patient records, sick patients could avoid unnecessary paperwork and the burden of having to repeat their history to non-oncology providers.

Getting Started

Lacking access to a 24-hour clinic, where could Advocate-Aurora Lutheran General Hospital direct its patients? In 2015 the hospital formed a planning team to answer this question, led by myself and Jon Richards, MD, president of Community Hematology Oncology Management Services. Other team members included Ashley Acuna, BSN, RN, OCN, BMTCN, Clinician IV, and Jane

Kosirog-Glowacki Pharm-D, both from the hospital's Oncology-Stem Cell Transplant Unit.

Our team's main objective was to research the feasibility of treating patients in an unused space on the hospital's inpatient oncology unit. We envisioned using this space to implement an oncology symptom management treatment area where oncology certified inpatient nurses (OCNs) would assess, treat, and then discharge patients with cancer who needed to be seen outside of traditional office hours, avoiding the need to send these patients to the ED. Our team identified numerous benefits to an oncology symptom management treatment area, including the following:

- *Improved care coordination.* For patients who needed to be admitted to the hospital, the oncology symptom management treatment area would help ensure a smooth transition.
- *Reduced patient wait times.*
- *Streamlined processes.* Because the OCNs staffing the oncology symptom management treatment area would have access to patient records, sick patients could avoid unnecessary paperwork and the burden of having to repeat their history to non-oncology providers.
- *Improved care of immunocompromised patients.* These patients could avoid exposure to infectious risk that is often associated with the ED.
- *Fewer ED visits and hospital admissions.*
- *Fewer unnecessary or duplicate labs and texts.* Highly skilled OCNs could manage patients with cancer and their symptoms more efficiently than ED providers.

With a plan in place, our team engaged other key stakeholders, such as billing, finance, coding, bed coordination, the ED manager, registration, the IT department, and construction to bring the oncology symptom management treatment area to life.

Planning Phase

The next step was minor modifications to the unused space that our team had identified as the home for the oncology symptom management treatment area; for example, installing three additional patient call lights and wiring them to the central call lights. Necessary equipment purchases included a desk for the OCN, three patient recliners, portable privacy dividers, three intravenous pumps, and a vitals sign machine. We converted a medication cart for supplies with a lock for security. After a fresh coat of paint and the addition of artwork to brighten up the space, the oncology symptom management treatment area was ready for use. (Because the space had once been used as a patient gym, a TV was already available to help patients and families pass the time more comfortably.)

Next, our team had to identify which patients would be treated in the oncology symptom management treatment area. It was decided that patients who experienced any of the following six symptoms could be treated in the oncology symptom management treatment area: nausea, dehydration, constipation, fever, pain, and diarrhea.

Our team developed order sets that gave the OCNs autonomy and standardization for patient safety. Dr. Richards created the order sets and presented them at the hematology oncology division meeting for approval and adoption. Ashley Acuna, the lead nurse who worked on this project, was critical to obtaining staff buy-in. She served as the conduit between staff and physicians during development of the order sets. Staff input was invaluable and their buy-in was key to ensuring a successful and safe implementation of the oncology symptom management treatment area. This quality improvement initiative was an excellent opportunity for a staff nurse to gain leadership experience without leaving the bedside. In fact, Ashley presented this project to the Clinical Career Advancement Board and achieved a nurse clinician IV status, which is considered "expert" status per the Patricia Benner nursing theory.[2]

In March 2015 our team mapped out workflow processes for the oncology symptom management treatment area. Figure 1, right, illustrates the patient care flow model implemented.
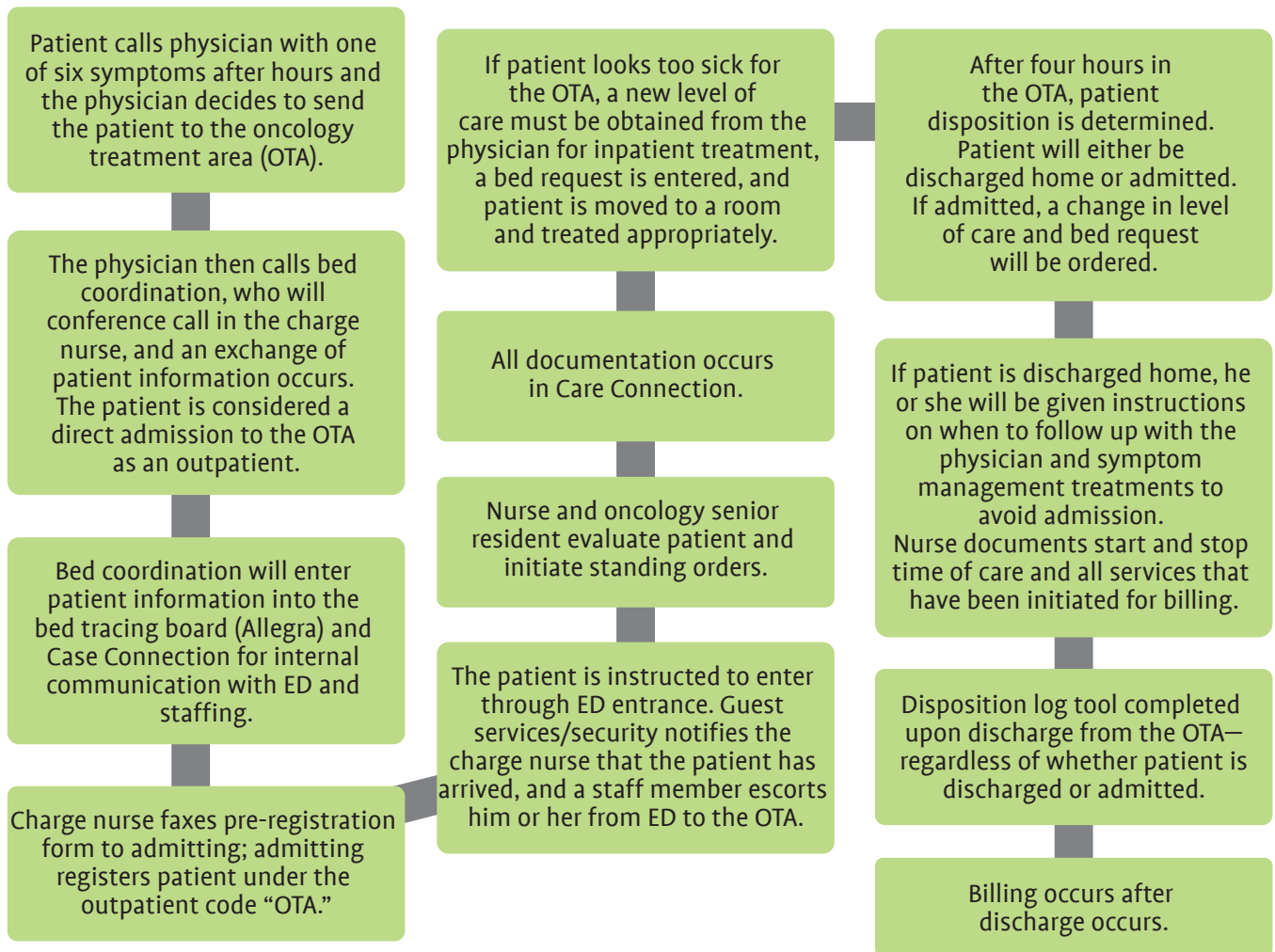
Next, we developed a communication plan to ensure that all hospital staff—from admitting to ED to physicians—understood the appropriate patients to send to the oncology symptom management treatment area and how to navigate these patients to the dedicated space within the inpatient unit.

Our team educated the billing department that patients seen at the oncology symptom management treatment area were considered and should be billed as outpatients—even though the oncology symptom management treatment area was physically located on the inpatient unit. A specific billing code was developed for the oncology symptom management treatment area so that we could easily track patients treated. We also used these data to ensure that the appropriate patients were being triaged, and not just for convenience, and that the oncology symptom management treatment area did not become a catch-all for blood transfusions or antibiotic infusions.

Our team developed documentation standards so that OCNs did not have to perform a full history on patients seen at the oncology symptom management treatment area, ensuring OCNs easy access to medical records in the physician practices. These standardized order sets streamlined care so that OCNs were able to quickly triage patients as soon as they entered the oncology symptom management treatment area. To ensure continuous quality improvement, our team developed an evaluation tool that OCNs completed for all patients.

With these processes in place, the oncology symptom management treatment area went live in July 2015.

Figure 1. Patient Care Flow Model

Patient calls physician with one of six symptoms after hours and the physician decides to send the patient to the oncology treatment area (OTA).

↓

The physician then calls bed coordination, who will conference call in the charge nurse, and an exchange of patient information occurs. The patient is considered a direct admission to the OTA as an outpatient.

↓

Bed coordination will enter patient information into the bed tracing board (Allegra) and Case Connection for internal communication with ED and staffing.

↓

Charge nurse faxes pre-registration form to admitting; admitting registers patient under the outpatient code "OTA."

If patient looks too sick for the OTA, a new level of care must be obtained from the physician for inpatient treatment, a bed request is entered, and patient is moved to a room and treated appropriately.

↑

All documentation occurs in Care Connection.

↑

Nurse and oncology senior resident evaluate patient and initiate standing orders.

↑

The patient is instructed to enter through ED entrance. Guest services/security notifies the charge nurse that the patient has arrived, and a staff member escorts him or her from ED to the OTA.

After four hours in the OTA, patient disposition is determined. Patient will either be discharged home or admitted. If admitted, a change in level of care and bed request will be ordered.

↓

If patient is discharged home, he or she will be given instructions on when to follow up with the physician and symptom management treatments to avoid admission. Nurse documents start and stop time of care and all services that have been initiated for billing.

↓

Disposition log tool completed upon discharge from the OTA—regardless of whether patient is discharged or admitted.

↓

Billing occurs after discharge occurs.

The Oncology Symptom Management Treatment Area at Work

Once patients arrive to the oncology symptom management treatment area, the OCN initiates standing orders under the physician's direction. Complete assessments are performed—not only by the OCN but also by the physician who is identified as the medical officer on duty assigned to oncology. Care coordination between the OCN, the medical officer on duty, and the attending physician makes patient care seamless. After four hours, a determination must be made as to the disposition of the patient. Patients who feel better are discharged home. Patients who require additional observation will be put on observation status. In the case of patients who need to be admitted to the hospital, the OCN will notify the admitting physician and care is resumed on the inpatient unit. In three years of operation, a patient has never stayed longer than four hours in the oncology symptom management treatment area; this time frame is a hard stop.

One of the most common questions our team is asked is how we were able to make the OCN a budget-neutral staffing position on the inpatient unit. Our answer is simple: we assigned these duties to a charge nurse (an OCN) who had formerly been free of patient care duties. We have found that the OCN is able to perform her charge nurse duties and provide care to patients in the oncology symptom management treatment area. Note: Though three patients are the maximum number who can be seen at any one time in the oncology symptom management treatment area, this rarely, if ever, happens. In the unlikely event that the charge nurse needs to assign patients to another nurse, patients are

assigned to a nurse in close physical proximity to the oncology symptom management treatment area and counted into that nurse's patient assignments without exceeding that assignment. Patient volume at the oncology symptom management treatment area has been approximately 17 to 30 patients per month, a very manageable volume. Rather than feeling burdened by these new duties, our charge nurse has shared that she feels empowered about caring for these patients.

Figure 2, below, tracks our hospital's admissions vs. discharges since the oncology symptom management treatment area went live in July 2015.

Barriers and Growing Pains

During the first two years of operation, our oncology symptom management treatment area faced some barriers and growing pains. For example, our team had to re-educate nurses and physicians. We performed this education at our local physician practices. In addition, a graduate nursing student worked collaboratively with hospital staff to develop a poster about the oncology symptom management treatment area, which was displayed in both physician offices and the hospital. This poster fulfilled many purposes, including:

- Serving as an ongoing reminder to physicians and staff about these services
- Communicating how the oncology symptom management treatment area could help reduce healthcare costs
- Educating patients and families about these services
- Communicating how the oncology symptom management treatment area could help ensure patients immediate access to care, as well as avoid long wait times and exposure to infections often found in the ED

Another way we increased awareness of the oncology symptom management treatment area was the creation of rubber bracelets that were given out to patients at physician offices at the start of chemotherapy treatment and at the hospital upon discharge. The information printed on these bracelets served as a helpful reminder for patients to call their physicians first, avoid the ED, and reduce their medical costs. Phone numbers for the physician office and the oncology symptom management treatment area are located on the outside of the bracelet; the inside of the bracelet identifies the six symptoms treated at the oncology symptom management treatment area.

Key Successes

- After implementation of the oncology symptom management treatment area, our hospital admission rate is about 20 percent, compared to our hospital's ED admission rate of 54 percent and the national average admission rate of almost 60 percent.[1]
- OCNs have been the key to the success of the oncology symptom management treatment area. These staff members are experts in cancer care, symptom management, and bone marrow transplant. They are the driving force behind the

Figure 2. 2015-2018 Data on Hospital Admissions vs. Discharges

Oncology Treatment Area
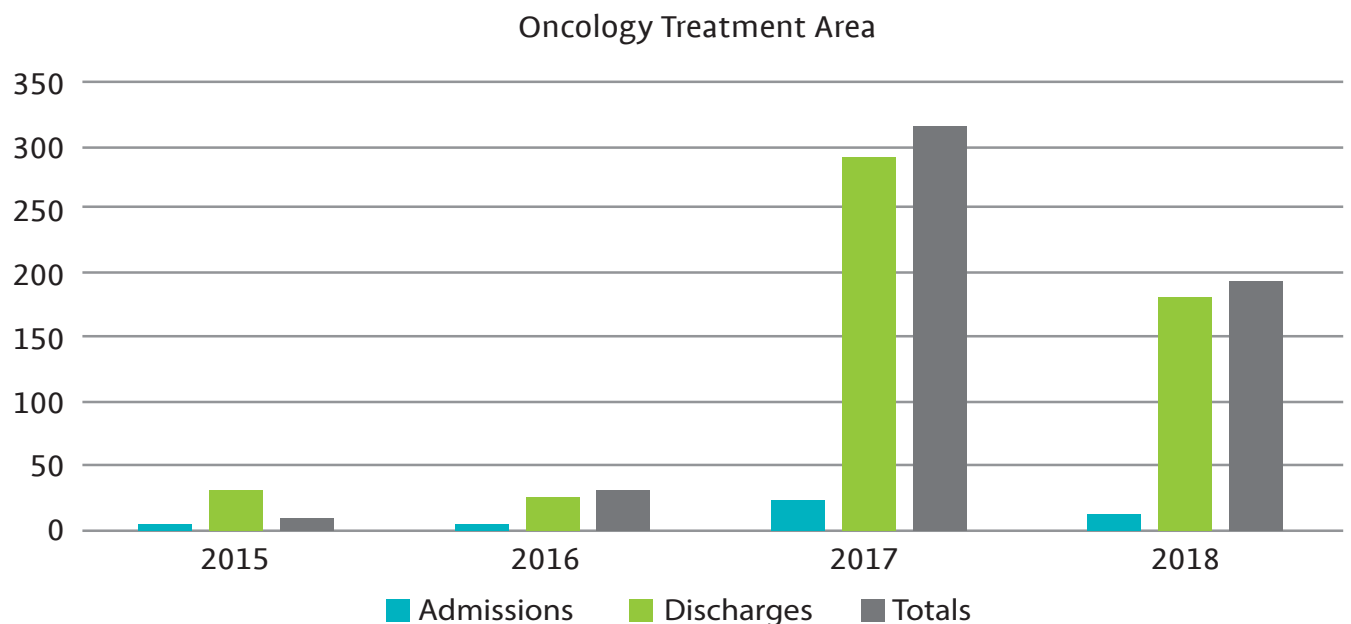
successful operationalization of our oncology symptom management treatment area.

- Patient satisfaction scores are much higher in the oncology symptom management treatment area compared to the ED. We attribute most of this to the fact that patients are seen immediately and treated by OCNs they know and often physicians they are familiar with as well.
- Case mix index for the oncology symptom management treatment area on average is 1.44 versus the ED average of 1.24. OCNs were more successful in treating and managing the patients in the oncology symptom management treatment area and discharging patients home compared to the ED.

A Manager's Reflection

To me, the idea of an oncology symptom management treatment area made sense; I believed it was the right thing to do for patients and families. As managers, we understand how census and productivity are calculated and how heads in beds are counted. I did sometimes worry about staffing for unpredictable volume and how that might impact patient care. I also had initial concerns about staff reactions. Would staff view the oncology symptom management treatment area as "extra work"? However, these concerns were allayed quickly when my staff readily embraced the quality improvement project. OCNs were and continue to be empowered and proud to care for patients in the oncology symptom management treatment area. Patients were very appreciative, and staff saw the difference in our outcomes data. The charge nurses enjoyed the direct patient care, as well as the opportunity to meet to debrief issues and develop action plans.

When I became the manager of the outpatient infusion center, we expanded hours, and some patient volume did shift back to the infusion center. However, the oncology symptom management treatment area remains open when physician offices and the infusion center are closed—ensuring 24-hour access to our patients. More, over the last four years, the oncology symptom management treatment area has proven to be a cost-effective quality improve initiative for the hospital and may soon become a system-wide initiative throughout our healthcare organization. ◗◗

Paula Goff, MSN, OCN, BMTCN, is manager of Oncology/ Stem Cell Unit Outpatient Infusion Center and Apheresis Center, Advocate-Aurora Lutheran General Hospital, Park Ridge, Ill.

References
1. Rivera DR, Gallicchio L, Brown J, et al. Trends in adult cancer-related emergency department utilization: an analysis of data from the nationwide emergency department sample. *JAMA*. 2017;3:e172450.

2. Benner P. *From Novice to Expert: Excellence and Power in Clinical Nursing Practice*. Upper Saddle River, NJ: Prentice Hall Health; 2001.

action

ACCC Welcomes Its Newest Members

Buffalo Hospital
Allina Health Oncology System
Buffalo, Minn.
Delegate Rep: Stacy Mattila, RN, MS, OCN
Website: buffalohospital.org

Cambridge Medical Center
Allina Health Oncology System
Cambridge, Minn.
Delegate Rep: Pamela Whitehead, RN, BSN, MA
Website: allinahealth.org/Cambridge-Medical-Center

District One Hospital
Allina Health Oncology System
Faribault, Minn.
Delegate Rep: Erin Ferris
Website: allinahealth.org/District-One-Hospital

Mercy Hospital
Allina Health Oncology System
Coon Rapids, Minn.
Delegate Rep: Eric Drake
Website: allinahealth.org/Mercy-Hospital

New Ulm Medical Center
Allina Health Oncology System
New Ulm, Minn.
Delegate Rep: Lorna Holmberg, RN, BSN, OCN
Website: allinahealth.org/New-Ulm-Medical-Center

Regina Hospital
Allina Health Oncology System
Hastings, Minn.
Delegate Rep: Cristine Kramer, RN, BSN, CNOR
Website: allinahealth.org/regina-hospital

River Falls Area Hospital
Allina Health Oncology System
River Falls, Wis.
Delegate Rep: Heather Simpson, CoC
Website: allinahealth.org/river-falls-area-hospital

WestHealth
Allina Health Oncology System
Plymouth, Minn.
Delegate Rep: Lisa Entleutner, RN, MSN
Website: allinahealth.org/abbott-northwestern-westhealth

UAB Medicine: Russell Medical Cancer Center
O'Neal Comprehensive Cancer Center at UAB
Alexander City, Ala.
Delegate Rep: Ellen Abernathy
Website: uabmedrussellcancer.com

Green Bay Oncology
Green Bay, Wis.
Delegate Rep: Lori Schneider
Website: gboncology.com

Conway Medical Center, CMC Cancer Center
Conway, S.C.
Delegate Rep: Kim Hunsucker, MSN, FNP-C
Website: conwaymedicalcenter.com

Piedmont Fayette Hospital Cancer Center
Fayetteville, Ga.
Delegate Rep: Catherine Hoffman, RT(R)(T)
Website: piedmontfayette.org/littlec

System Membership
Allina Health Oncology System
Minneapolis, Minn.
Delegate Rep: Melissa Wall, RN, BSN, MBA
Website: allinahealth.org/Virginia-Piper-Cancer-Institute/about-us

WellSpan Health System
York, Pa.
Delegate Rep: Shelli Laux, MBA, RHIA, CTR, CCRP
Website: wellspan.org

ACCC Holds Metastatic Breast Cancer Summit in Washington, D.C.

On Oct. 7 ACCC brought together a variety of stakeholders in the cancer care community to identify practical action items that cancer practices large and small can implement now to expand holistic care of their metastatic breast cancer patients. Members of the multidisciplinary cancer care team that participated in the summit included social workers, program managers, nurse practitioners, chaplains, financial navigators, and patient advocates. As a continuation of ACCC's Metastatic Breast Cancer Project, the summit centered around the recognition that there are significant disparities in the resources available to patients with metastatic disease. A full executive summary of the summit's main findings will soon be available online, and a more in-depth summary is available at accc-cancer.org/acccbuzz.

Shine a Spotlight on Your Cancer Program or Practice

In every *Oncology Issues* our editorial team interviews a member program or practice for the journal's "Spotlight" column. We are currently looking for members to feature in 2020. Being profiled in ACCC's peer-reviewed journal offers your cancer program or practice many benefits. For example, the two-page article is a great tool to market your services to your local community, including potential patients and referring physicians. All it requires is a 30- to 60-minute phone interview and submission of high-resolution photos to include with the article. Our editorial staff will do the writing and editing for you! Don't miss out on this member benefit: email Maddelynne Parker, mparker@accc-cancer.org, to schedule an interview to have your program or practice featured in *Oncology Issues*.

An Oncology Podcast for Your Ears

ACCC's podcast, CANCER BUZZ, features fresh perspectives on hot topics in oncology care delivery. CANCER BUZZ is conversation that unpacks the issues and sparks insight. It is where stakeholders from the front lines of care to the C-suite, from research to the registry, from chairside to benchside, talk about top-of-mind questions and real-world impact. In its most recent episode, Montana State Oncology Society's President Jack Hensold, MD, of Bozeman Health Cancer Center addresses the unique challenges rural cancer care providers face, including workforce shortages, travel distance, clinical trial access, and more. All episodes can be found on Apple Podcasts, Spotify, or wherever you get your podcasts. Listen today and be a part of these important conversations!

views

Musings on State Oncology Society Membership

BY W. CHARLES PENLEY, MD

Like many of today's young oncologists, in the early 1990s I was focused on building my practice, raising young children, and becoming a member of a community outside of medicine. At that point, I had not yet focused on organized medicine at all. It seemed distant and separate from my work—something that other doctors engaged in when confronted by larger issues in society and healthcare.

But about that same time, oncologists in Tennessee were faced with a Medicare carrier policy that would severely limit reimbursement for in-office-administered chemotherapeutic agents. This policy threatened the viability of our practices and our ability to care for our patients in outpatient or office settings.

At the time, Tennessee did not have an organized state oncology society. Seeing the need for a unified response to the new Medicare policy, oncology practices from around the state convened a meeting in Nashville, and the Tennessee Oncology Practice Society (TOPS) was born.

I was very fortunate to be able to represent our small practice at that meeting. TOPS's founders learned many lessons in those early years, but I believe the most important one was that we were stronger when we joined forces and spoke with one voice. On a personal level, I learned that when confronted with important tasks, oncologists should not rely on others to do the heavy lifting—we must roll up our own sleeves and get involved. I remain a proud member of TOPS today.

For nearly 30 years, TOPS has served oncologists and patients in Tennessee. The organization has focused primarily on issues related to the delivery of the highest quality cancer care, while also working to deter threats to the viability of the community practice model.

I found my work at the state level to be quite gratifying, and TOPS had early successes. Drug reimbursement and so-called off-label coverage occupied much of our time. For example, our Medicare carrier had proposed requiring oncologists to submit invoices with their billing documents. Due to the efforts of TOPS's leadership and members, this proposal never came to fruition. But we quickly realized that most Medicare policies, though administered at the state level, have their origins in Washington, D.C.

As an affiliate of the American Society of Clinical Oncology (ASCO), TOPS members have access to the advocacy efforts of a much larger organization with more funding, a larger staff, and a seat at the table during legislative discussions with members of Congress and regulatory discussions with organizations like the Centers for Medicare & Medicaid Services. State oncology society presidents are invited to become members of the ASCO Clinical Practice Committee, where issues of common interest are discussed. Though the details of policy implementation vary from state to state, overarching issues are the same.

Other organizations, such as ACCC and the Community Oncology Alliance, are likewise engaged and involved participants in our discussions about issues that affect the entire oncology community.

My participation in advocacy efforts at the state level led directly to personal opportunities to serve on the national level. While serving as TOPS's president in the late 1990s, I was appointed to the ASCO Clinical Practice Committee, ultimately serving as the committee's chair from 2008 to 2009. While on the Clinical Practice Committee, I was fortunate to be able to represent ASCO to the American Medical Association's Common Procedural Codes Editorial Panel. It was a critical time, because the Medicare Modernization Act had required the American Medical Association to rewrite the entire series of drug infusion codes. ASCO's Drug Infusion Workgroup spent many hours restructuring these codes, culminating with the Relative Value Update (RVU) Committee assigning new RVU values to this series of codes.

From 2012 to 2013, Sandra Swain, MD, invited me to chair the ASCO Government Relations Committee during her presidency. My term on this committee gave me a front-row seat to the advocacy work carried out by ASCO and other cancer care organizations on behalf of oncologists and patients. Around that time, it became clear to me that I had become one of those "other doctors" who were doing the work of organized medicine. It also became clear that policy and advocacy work is incremental, much like cancer research. There aren't too many "Eureka!" moments, but incremental steps forward represent progress over time.

My consistent observation in my advocacy work has been that when the oncology community speaks with one voice, although our political leaders do listen, political pragmatism most often wins the day. Changing policy is less challenging than changing law, and maybe that is a good thing.

I've been fortunate to be able to serve ASCO and ACCC in many capacities, and I fully believe that none of these opportunities would have been possible if I had not chosen to involve myself with TOPS. Choosing to get involved was one of the best decisions I've made, and I strongly encourage others to do the same.

W. Charles Penley, MD, is a medical oncologist with Tennessee Oncology.

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References: 1. ClinicalTrials.gov. Bethesda (MD): U.S. National Library of Medicine. Effect of TTFields (150 kHz) in non-small cell lung cancer (NSCLC) patients with 1-10 brain metastases following radiosurgery (METIS). NCT02831959. https://clinicaltrials.gov/ct2/show/NCT02831959. Updated January 15, 2019. Accessed January 23, 2019. **2.** Gutin PH, Wong ET. Noninvasive application of alternating electric fields in glioblastoma: a fourth cancer treatment modality. *Am Soc Clin Oncol Educ Book.* 2012:126-131. **3.** Kirson ED, Dbaly V, Tovarys F, et al. Alternating electric fields arrest cell proliferation in animal tumor models and human brain tumors. *Proc Natl Acad Sci USA.* 2007:104(24):10152-10157. **4.** Gera N, Yang A, Holtzman TS, Lee SX, Wong ET, Swanson KD. Tumor treating fields perturb the localization of septins and cause aberrant mitotic exit. *PLOS ONE.* 2015.10(5):e0125269. doi:10.1371/journal. pone.0125269. **5.** Novocure Data on File. NovocureTrial.com. METIS. 2018.