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ONCOLOGY ISSUES

This publication is a benefit of membership
Association of Community Cancer Centers

Vol. 37 | No. 2 | 2022

Virtual Reality

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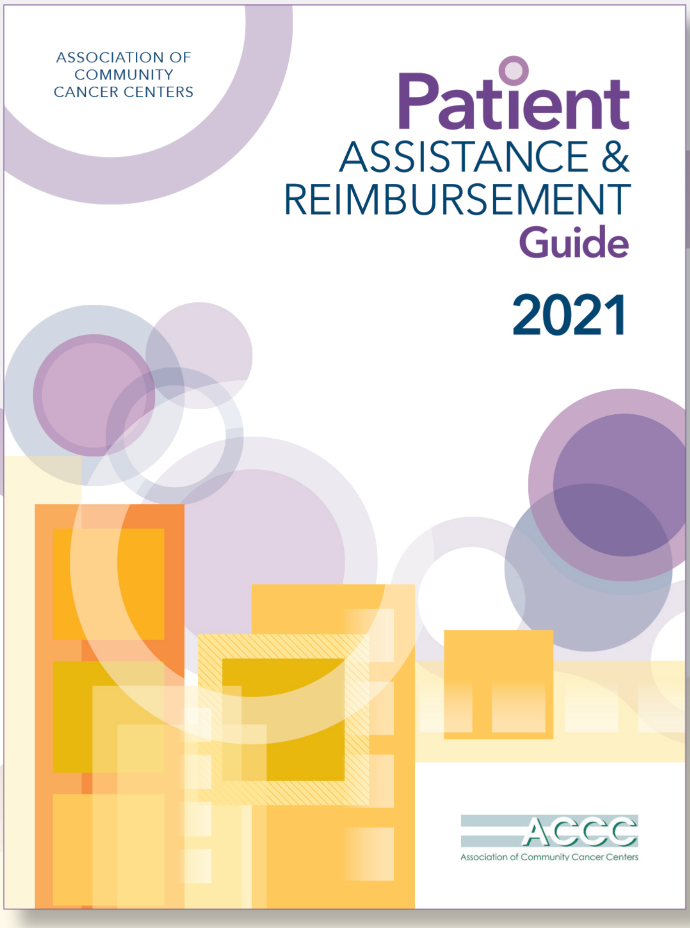

The **Association of Community Cancer Centers (ACCC)** is the leading education and advocacy organization for the cancer care community. Founded in 1974, ACCC is a powerful network of 28,000 multidisciplinary practitioners from 2,100 hospitals and practices nationwide. As advances in cancer screening and diagnosis, treatment options, and care delivery models continue to evolve—so has ACCC—adapting its resources to meet the changing needs of the entire oncology care team. For more information, visit accc-cancer.org or call 301.984.9496. Follow us on Facebook, Twitter, LinkedIn, and Instagram; read our blog, ACCCBuzz; and tune in to our podcast, CANCER BUZZ.

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14 3-D Virtual Reality Takes Patient Education to the Next Level
By Douglas E. Holt

This pilot studied the use of virtual reality in patient education. With this technology, providers show patients the tumor, where it's located in the body, what organs it's near, its size, and how the radiation treatment plan will work, including the size of the radiation beam and where it will target.

DEPARTMENTS

Association of Community Cancer Centers

ONCOLOGY ISSUES

The Official Journal of the
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FROM THE EDITOR

Critical Mass

BY SIBEL BLAU, MD

After nearly two years of battling with the COVID-19 global pandemic, we began 2022 with a new challenge: the Omicron variant. And despite the availability of vaccines, drugs, and monoclonal antibodies, the healthcare field is more challenged than ever.

Though mutations make the Omicron variant well suited for causing breakthrough cases, individuals who receive boosters are protected from severe illness and make up only 1 percent of hospitalizations. The Omicron variant is also less likely to infect the lower respiratory system, resulting more in “cold-like” symptoms. Yet, hospitalizations and daily infection rates are hitting record levels. Despite implementing preventive measures, including vaccine requirements for healthcare workers, Omicron is everywhere.

Our hospitals are in jeopardy. Most surgeries have been canceled, and emergency departments are well beyond capacity. Healthcare staffing shortages caused by COVID-19 mean that only the most ill can be seen in clinics. Hospital and clinic triage systems are overwhelmed with calls from patients about COVID-19 symptoms and there is not enough staff—or testing resources—to care for them. Physicians, nurses, and staff are demoralized and exhausted. Burnout—already a massive problem prior to COVID-19—is now at crisis levels.

Specific to oncology, many long-term patients are now being told to seek evaluation and treatment in urgent care clinics or are being deferred to their primary care providers. At my practice in Washington, on any given day, several staff are testing positive for COVID-19. Most report only mild to moderate symptoms, but they are still taken out of the workforce, resulting in severe operational challenges that jeopardize patients’ access to care.

I believe that we will make it through the Omicron tsunami, but the extremely disheartening absence of a unified response among our fellow citizens regarding vaccinations, coupled with the likely emergence of future variants, means that COVID-19 will remain a part of our lives for a long time to come.

What is also becoming clear is that we need a long-term plan for the health of our hospitals and practices, with a specific focus on the well-being of our staff and physicians.

My practice fared well in the beginning of the COVID-19 pandemic due to a genuine collaborative effort to care for our patients. But staff morale dipped to very low levels this past summer, threatening our ability to care for our patients. In response, practice leadership took several weeks to gain perspective beyond the thousands of daily tasks required to care for patients and listened closely to staff feedback. They shared that staff were overworked and underpaid and experiencing hardships from wearing masks, working in isolation rooms, and caring for ill patients.

Today our practice is more resilient, with systems and processes in place to take into account the opinions of every single staff member, as well as the ability to make changes rapidly to improve staff morale and retention.

Two facts are certain. First, oncology care cannot be provided without physicians, nurses, and other staff. Second, the oncology community has reached critical mass; in other words, a crisis large enough to produce a specific need. And that need is a long-term, congressional-driven strategy that provides additional resources and innovative solutions to a wide range of challenges, including reimbursement cuts, electronic health record issues, burdensome reporting requirements, the abrupt discontinuation of the Oncology Care Model and a lack of clarity on how to move value-based care forward, and critical health equity issues around lack of technology for telehealth, access to care in rural areas, and access to care for diverse patient populations.

Our patients with cancer deserve the best care, and our oncology professionals need to be able to provide it. OI

Health Equity, the Quintuple Aim?

BY KRISTA NELSON, MSW, LCSW, OSW-C, FAOSW

The COVID-19 global pandemic forced practitioners, healthcare leaders, and policymakers to first accept, then understand, and finally begin to grapple with the profound health inequities present in our society. The problem is so pervasive that a recent *JAMA* article made a call to elevate health equity as the fifth aim for healthcare improvement.[1] After reading this article, it's clear that social work expertise and interventions have never been more important to comprehensive cancer care. As a discipline, social workers have addressed the needs of low-income and vulnerable populations—as well as the psychosocial and spiritual domains of care for patients facing a diagnosis—for more than 100 years.

If we address social determinants of health, including access to care, patients will have better outcomes, and our healthcare system will save money delivering care to those patients. The paradox that many healthcare organizations have a hard time accepting—and adopting—is that to save money, they must spend money. Healthcare savings *will* come if we invest in comprehensive cancer care, including social work. In a recently conducted ACCC national survey designed to help explain benchmarking for and barriers to comprehensive cancer care, lack of sufficient reimbursement, staffing, and budget were identified as the top challenges to comprehensive cancer care delivery.

At the end of the day, however, healthcare is a business. And with all businesses, investment requires documentation of return on investment in the form of a business case study or *pro forma*.

To help its member programs and practices demonstrate return on investment in comprehensive cancer care services, ACCC developed a series of business case studies, the latest of which support the hiring of oncology social workers and oncology pharmacists. Access these resources online at accc-cancer.org/business-briefs.

When looking to hire any staff, including social workers, one of the most common questions asked remains, "How many do we need?" ACCC is looking to help there as well. The Association convened an expert group of social workers who designed a survey to get a sense of the current state of oncology social work; for example, number of social workers per new patients or per provider. These data will help inform and drive psychosocial research moving forward. Remember, we need to have basic benchmarking data before we can assess value.

Even after your cancer program or practice has made the commitment to grow its workforce to support the delivery of comprehensive cancer care, you now face the hurdle of hiring. The grim reality is that people are leaving healthcare in droves, and so we must be innovative to entice a new—and diverse—workforce. Now is the time for disciplines, like oncology social work and oncology pharmacy, to recruit and mentor Black, Indigenous, and People of Color into our fields. *Now* is the time for oncology programs and practices to work with human resources to develop creative solutions to recruit and train diverse staff at every level, including senior leadership. Health equity requires that our oncology care teams look like the patients we treat and the communities we live in.

For my last "President's Message," I close with a note of significant gratitude of the incredible honor it is to collaborate with and support a community committed to multidisciplinary cancer care, as well as the opportunity to share my journey with you. Even during a pandemic, I was heartened that so many of you took the time to support each other with simpler concerns, like daily check-ins and mindfulness activities, as well as highly complex issues, such as equity, diversity, and inclusion.

I am so grateful to all the staff, volunteers, and ACCC members who have taught me so much, and I look forward to our continuing growth as an organization under the leadership of ACCC 2022-2023 President David R. Penberthy, MD, MBA.

Reference

1. Nundy S, Cooper LA, Mate KS. The quintuple aim for health care improvement: a new imperative to advance health equity. *JAMA*. 2022;327(6):521-522. doi:10.1001/jama.2021.25181. OI

Coming in Your 2022 *ONCOLOGY ISSUES*

- The Long Road to Recovery: A Snapshot of Cancer Screening in the United States
- Auricular Acupuncture for the Treatment of Cancer-Related Pain
- Cannabis in Cancer Research and Creating a Patient Education Clinic
- A Model for Integrating APPs in a Radiation Oncology Satellite Clinic
- A Day in the Life of a Quality Improvement Officer
- An APP-Physician Model Improves Risk Stratification and Palliative Care
- Remote Monitoring of Patients with Cancer During COVID-19
- Developing a Cancer Care and Community Paramedicine Partnership
- Oncology Capture of ED Patients with Incidental Radiologic Findings
- Practical Application of Geriatric Assessment: Considerations for Your Largest Patient Demographic
- A Comprehensive Oncology Program for Elders (COPE)
- A Model Telehealth Adolescent and Young Adult Oncology Program
- Meeting NCCN Guidelines for Genetic Counseling Referrals Among Cancer Registry Patients: An Ohio Study
- Best Practices for Development of a Successful Cardio-Oncology Program in a Community Hospital

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TOOL

ACCC Patient Assistance & Reimbursement Guide Goes Digital

Find the most up-to-date information on oncology patient assistance and pharmaceutical reimbursement programs by searching for a prescribed product or company name, then streamline your search by applying coverage and assistance-type filters. Access the digital Guide at: accc-cancer.org/patient-assistance-2022.

PUBLICATION

"ACORI Call to Action Summit" Outcomes

The ACCC Community Oncology Research Institute (ACORI) virtual summit convened oncology programs and practices, research team members, patient advocates, trial sponsors, industry representatives, and research networks to identify concrete strategies for engaging patients, caregivers, and their communities to strengthen oncology research across the U.S. Read the Action Items in the ACORI Executive Summary (accc-cancer.org/acori-summit-2021-executive-summary), and see how your clinical trial processes compare.

PODCAST

The Business Case for Hiring Oncology Social Workers

Oncology social workers are integral members of the multidisciplinary cancer care team, but their services are largely unreimbursed by payers, making it challenging to hire additional oncology social work staff. Hear from ACCC 2021-2022 President, Krista Nelson, MSW, LCSW, OSW-C, FAOSW, as she talks about two new resources (a business case study for hiring and a benchmarking survey) coming from ACCC that demonstrate the value oncology social workers play in cancer care. accc-cancer.org/hiring-oncology-sw.

RESOURCE

Overcoming Prostate Cancer Disparities in Care

Research shows that certain patient populations have worse prostate cancer outcomes than others. To address this challenge, ACCC conducted focus groups with four cancer programs. The conversations captured in this on-demand webinar (accc-cancer.org/prostate-cancer-disparities-webinar) feature community engagement strategies, while the publication (accc-cancer.org/prostate-cancer-disparities-publication) reveals practical approaches for providing equitable care that can help improve early detection and care for vulnerable patients.

fast

A Snapshot of Medicare Telemedicine Use

Pre-pandemic, **910,490** Medicare patients filed telemedicine claims—a combination of telehealth, e-visits, and virtual check-ins—between March 2019 and February 2020. During the pandemic, that number swelled to **28,255,180**, representing a majority (**53%**) of Medicare users. Of the total number of Medicare patients who live in a rural area, **44%** used telemedicine services compared to **55%** who live in an urban area. Of the total number of Medicare patients who are Hispanic, **64%** used telemedicine services, compared to **58%** of American Indian/Alaska Native Medicare patients; **57%** of Asian/Pacific Islander Medicare patients; and **57%** of Black/African American Medicare patients.

Source. Medicare Telemedicine Snapshot. Medicare Claims and Encounter Data: March 1, 2020 to February 28, 2021, Received by September 9, 202. cms.gov/files/document/medicare-telemedicine-snapshot.pdf.

Survey Finds Unexpected Effects to Wearing Face Masks

- **95%** of people with hearing loss say face masks and/or coverings have created communication barriers since the pandemic began.
- **89%** report experiencing accessibility issues since the pandemic began, including but not limited to the ability to lipread due to face masks, physical distancing making conversations harder, and not having access to captioning across all technology platforms.
- **70%** are more aware of their hearing loss due to the pandemic; nearly half (**47%**) are more eager to explore hearing loss treatment options.
- **35%** say they have experienced a lack of empathy from others for their hearing loss during the pandemic.

Source. A survey conducted by the Hearing Loss Association of America. hearingloss.org.

facts

30% of hospitals and health systems using revenue cycle automation require 2 or more vendors to manage the process; another 30% have built internal automation teams.

Source. Alpha Health national survey fielded between May 19, 2020 and June 22, 2020 among 587 chief financial officers and revenue cycle leaders at health systems across the United States. alphahealth.com.

5 Key Performance Metrics in Billing

During times of financial uncertainty and to avoid being blindsided by financial dips and unanticipated cash flow bottlenecks, understand your:

1. **Claims denial rate by payer.** Denial rates for each payer should be below **5%** to **10%**. If they're not, take a closer look at your revenue cycle management process.
2. **Net collection rate.** If this rate is below **95%**, keep a closer eye on fee schedules and avoid including inappropriate write-offs.
3. **Days in accounts receivable.** If this number exceeds **50** days, it's time to examine why and take steps to reduce this number, for example, reaching out to payers that are slow to pay.
4. **First-pass acceptance rate.** If the percentage of claims paid after being submitted the first time is low, you may need to work on insurance verification and coding and billing accuracy.
5. **Non-financial key performance indicators.** These include cancellation and no-show rates; patient satisfaction ratings on publicly-available sites; portal enrollment and usage; wait times to book an appointment and/or see a provider once in the clinic; and website traffic.

Source. RxVantage. Billing KPIs for Success in 2021. rxvantage.com/blog/billing-kpis-to-monitor-during-covid-19-and-beyond.

Screening and Prevention Survey Says…

- **2** in **3** Americans are not getting recommended cancer screenings and **32%** are not aware of which screenings they should be getting.
- Minorities are most likely to miss their appointments: African Americans (**41%**) and Hispanics (**40%**) are most likely to have missed, postponed, or cancelled a health appointment. African American and Hispanic women are most likely to miss a mammogram or PAP/HPV test.
- **35%** say they are likely to take a colorectal cancer screening test at home.
- Annual physicals, dentist appointments, mammograms, PAP/HPV tests, and skin checks were the top missed appointments.

Source. The Prevent Cancer Foundation. New Survey Shows Minorities, Children Missing Cancer Screenings and Vaccinations. preventcancer.org.

issues

Health Equity: A Key Theme of Health Care Value Week

BY MATT DEVINO, MPH

From January 24 to 28, ACCC co-sponsored Health Care Value Week—a series of virtual events supporting the advancement of value-based care. By highlighting the success stories of value-based payment models, the event celebrated the progress the healthcare community has made in providing more equitable, accessible, and affordable care in the United States. Programming featured roundtable discussions with prominent industry leaders, as well as participation by top administration officials from the Centers for Medicare & Medicaid Services and the Center for Medicare & Medicaid Innovation (the Innovation Center).

Many conversations throughout the week focused on the Innovation Center's strategy refresh, summarized in a white paper published in October 2021.[1] The strategic refresh identified five objectives for advancing health system transformation during the next decade, including the goal of advancing health equity. In her remarks during Health Care Value Week, the Innovation Center's Chief Medical Officer Dora Hughes, MD, MPH, highlighted the following actions as necessary to achieve this strategic objective:

- Embed health equity in the development of all new and existing Innovation Center models
- Increase safety net provider participation in value-based payment models to ensure these models serve diverse communities
- Evaluate models for their impact on health equity and apply lessons learned to new and current models
- Improve data collection to capture beneficiaries' demographic data, as well as data on their social needs and social determinants of health.

As summarized in the white paper, analyses of several of the Innovation Center's largest alternative payment models have indicated that Medicare beneficiaries aligned to these models are more likely to be White, less likely to be dual eligible for Medicaid, and less likely to live in rural areas compared to the overall Medicare population.[1] To address this disparity, the Innovation Center's goal is to ensure that 100 percent of all new models include safety net providers, such as community health centers and disproportionate share hospitals, to reach underserved and vulnerable populations. This, however, is easier said than done, considering the myriad of obstacles that make it challenging for community providers to participate in alternative payment models.

The Innovation Center is aware of the financial and operational barriers to participating in alternative payment models and is trying to identify strategies to mitigate them. The Innovation Center's Director Elizabeth Fowler, JD, PhD, stated in her opening remarks that the agency is looking closely at opportunities to provide upfront financial and technical support to new program participants, as was done in the Accountable Care Organization Investment Model for providers joining the Medicare Shared Savings Program. Other speakers astutely pointed out that healthcare providers in these underserved communities already lack sufficient resources to support comprehensive care, so financial and technical support is needed throughout the duration of a model, not just up front.

Another challenge: data collection and standardization to appropriately risk stratify and evaluate models while making strides to reduce inequities in care. According to Dr. Hughes, business and information technology specialists within the Innovation Center are already focused on this work, as they seek to create Fast Healthcare Interoperability Resources-based questionnaires that providers can use to collect demographic and social needs information to easily share with the agency. It will also be important that the Innovation Center put appropriate incentives and sufficient reimbursement in place for these models to ensure that the additional reporting burden does not fall on community providers alone.

It is clear now that the Innovation Center has much to do to turn its strategic objectives into actionable tools and programs. As the agency works to implement its health equity initiatives, healthcare providers should take this opportunity to share their experiences with treating disadvantaged patients and their practical concerns about the implementation of new data collection requirements. Interested in contributing your thoughts on this strategy refresh? Submit feedback directly to the Innovation Center at CMMIStrategy@cms.hhs.gov. And share your concerns with ACCC by emailing mdevino@accc-cancer.org.

Matt Devino, MPH, is director of Cancer Care Delivery and Health Policy, Association of Community Cancer Centers, Rockville, Md.

Reference

1. Centers for Medicare & Medicaid Services. Innovation center strategy refresh. Published October 2021. Accessed March 7, 2022. innovation.cms.gov/strategic-direction-whitepaper

ASSOCIATION OF COMMUNITY CANCER CENTERS

Returning to Practice in the Post-COVID-19 Era: Hematology Disease Education

Hematologic malignancy experts in different stages of recovery planning from various regions across the United States discuss the needs that must be considered for this patient population as the pandemic recedes.

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Billing for Split (or Shared) Visits

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

In 2021 the Centers for Medicare & Medicaid Services (CMS) made significant changes to how evaluation and management (E/M) visits are coded and billed in the office and outpatient setting. With the change to total time and medical decision making-based coding criteria, the agency updated a number of its transmittals to include new clarifications about several E/M-related activities. One of the areas for which CMS provided this additional clarification was related to split (or shared) visits.

Defining a Split (or Shared) Visit

The American Medical Association (AMA), within the 2021 Current Procedural Terminology E/M Guidelines, states, *"A split or shared visit is defined as a visit in which a physician and other qualified health care professional(s) jointly provide the face-to-face and non-face-to-face work related to the visit. When time is being used to select the appropriate level of services for which time-based reporting of shared or split visits is allowed, the time personally spent by the physicians and other qualified health care professional(s) assessing and managing the patient on the date of the encounter is summed to define total time. Only distinct time should be summed for split or shared visits (that is, when two or more individuals jointly meet with or discuss the patient, only the time of one individual should be counted)."*[1]

After CMS adopted the AMA's coding updates and guidelines for office and outpatient visits (which went into effect in 2021), the agency updated some of its transmittals to clarify billing items that the AMA does not address in the Current Procedural Terminology manual. Specifically, according to CMS, the guidelines for split (or shared) visits that appeared in the calendar year 2022 Medicare Physician Fee Schedule final rule did not address:

- Who to bill the visit under when the visit is performed by different practitioners.
- Whether a substantive portion must be performed by the billing practitioner.
- Whether practitioners must be in the same medical group.
- The setting where the split (or shared) visits may be furnished in order to be billed.

First, CMS adjusted the definition of a split (or shared) visit to mean an E/M visit performed (split or shared) by both a physician and non-physician practitioner (NPP) who are in the same group in accordance with applicable laws and regulations for new and established patient visits. This updated definition allows split (or shared) visits for new patients; previously these visits were limited to established patients only. In addition, split (or shared) visits can only take place in the facility setting—meaning only settings like hospitals. In other words, the NPP would be part of the physician group working in the hospital setting and not separately employed by the hospital. If the physician and NPP are not part of the same physician group practicing in the hospital, they cannot combine their work and bill for a split (or shared visit). Instead, the physician and NPP would each respectively bill for their services independently based solely on their portion of the visit. If neither provider meets the criteria necessary to support an E/M outpatient service, no services are billed. No partial credit or payment can be made in this scenario and no modifiers are allowed for reduced services.

Next, because this was not specifically defined by the AMA, CMS clarified how to determine who to bill the split (or shared) visit under. Specifically, the agency defines the billing provider as the practitioner who performed the substantive portion of the visit. Per CMS, "substantive portion" is defined as more than half of the total time spent by the physician or NPP. Because changes were only made to E/M services provided in the office and outpatient setting—and not E/M services provided in the inpatient, observation, nursing home, emergency departments, or critical care settings—for 2022, CMS outlined an adjustment for determining the substantive portion. Specifically, in 2022, the agency will allow for the substantive portion to be determined by the practitioner who performed most of the visit related to history, exam, or MDM or the one who provided the services for more than half the total time of the visit. Beginning in 2023, the substantive portion practitioner will solely be based on more than half of the total time.

The documentation for a split (or shared) visit should identify both the physician and the NPP. This documentation must include the names and credentials of both practitioners, although the note only needs to be signed by the practitioner who performed the substantive portion and is billing under their name. Because the substantive portion can be billed by the practitioner who performed the most time related to the visit—with or without direct patient contact—the medical records must identify which practitioner saw the patient face-to-face. CMS also recommends documenting the time spent by both the physician and NPP, because this information will further support the appropriate billing practitioner.

Finally, CMS identified a modifier to identify those visits in the facility setting that are split (or shared):

Modifier -FS (Split (or shared) evaluation and management visit) should be applied to the E/M visit code.

This modifier allows CMS to identify services paid at the full physician rate when the physician did not fully perform the visit. This provides a way for the agency to evaluate services and determine whether adjustments are needed in future rule making.

Finally, CMS outlined a list of services that would and would not count toward the total time for determining the substantive portion. Activities that *would count* include:

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

Items that *would not count* toward time spent in the visit include:

- The performance of other services that are reported separately
- Travel
- Teaching that is general and not limited to discussion that is required for the management of a specific patient.

In summation, split (or shared) visits *do not apply* in the non-facility (office) setting. For visits where the physician and NPP each perform a separate portion of the visit (in accordance with applicable laws and regulations), the visit is billed under incident to guidelines—if criteria are met. This means the physician must still provide the proper supervision of the NPP, but the physician's amount of participation may vary, and the physician would be the billing practitioner.

As the guidelines for E/M services continue to evolve and align with the changing needs of healthcare, it is likely that CMS will release more changes and clarifications to ensure that practitioners are aware of and follow all E/M coding and billing guidelines.

Reference

1. American Medical Association. *Current Procedural Terminology CPT 2021 Professional Edition.* AMA;2020.

Teri Bedard, BA, RT(R)(T), CPC, executive director, Client & Corporate Resources, Revenue Cycle Coding Strategies, Des Moines, Iowa

Cancer Program at Parkland Health, Dallas, Texas

Parkland Health—one of the largest teaching and safety net hospital systems in the country—is home to the Cancer Program at Parkland Health, which offers specialized oncology services in Dallas, Texas. The program's mission is to provide timely access to personalized, high-value care to individuals with, or at risk of, cancer and blood disorders in a safe and patient-centric environment. Parkland Health Cancer Program is accredited by the Commission on Cancer and recognized as High Performing in Cancer Care by *U.S. News & World Report*.[1] "We have a talented team of expert physicians and clinical staff dedicated to the care of our patients, many of whom are uninsured or underinsured and otherwise do not have access to healthcare," said Umber Dickerson, MPH, administrative director at the Cancer Program at Parkland Health.

Expanding the Program

In 2021 the cancer program moved into the new Moody Outpatient Center on Parkland's main campus. This centralized location ensures that patients can be admitted to the hospital without incurring extra travel time and that cancer program staff can oversee patients when they are admitted. This new clinical space allows for multidisciplinary care integration and programmatic growth and was designed to be more inviting and provide a better environment of care for both patients and staff.

The cancer program's outpatient floor comprises 66 exam rooms—shared by medical and surgical oncology staff—and one infusion suite. The 51-chair infusion suite is arranged in a circular format with a combination of shared bays and individual patient bays facing the center. This design increases the privacy of patients and optimizes the workflow of nursing staff by allowing them to safely monitor multiple patients. An infusion-dedicated pharmacy is located within the infusion center where medications are verified and prepared on-site. The pharmacy has a dedicated IV room suite with five biological safety cabinets and two laminar flow rooms (non-hazardous rooms). There are two pharmacy consult rooms where patients receive patient education and ask questions of oncology pharmacists. Medication access specialists are available to help patients find programs and resources to help pay for their medications. Patients can also use the hospital's full-service pharmacy located on the first floor to pick up additional prescriptions.

The Cancer Program at Parkland Health has an Oncology Acute Care Clinic for patients who experience side effects from their cancer treatment and require immediate care. Patients can call in to a nurse triage that assesses symptoms for acuity and schedules same-day appointments with an advanced practice provider, as needed.

The Moody Outpatient Center also houses the Moody Center for Breast Health, which includes breast imaging, breast medical oncology, and breast surgery clinics. The breast imaging department provides a full range of breast screening and diagnostic services in one central location, including mammograms, ultrasound, magnetic resonance imaging, biopsies, stereotactic core biopsy, and the most advanced technology with 3-D mammography. The breast cancer clinic has 18 exam rooms, two procedure rooms, provider workrooms, and a sub-waiting area for gowned patients. The breast health program also includes patient educators and a mobile mammography unit for community outreach.

A Focus on Specialized Care

The Cancer Program at Parkland Health offers comprehensive inpatient and outpatient oncology services. Cancer care at Parkland is supported by clinical experts from the University of Texas (UT) Southwestern Medical Center's Harold C. Simmons Comprehensive Cancer Center faculty. As UT Southwestern's primary teaching hospital, the Cancer Program at Parkland Health incorporates teaching and non-teaching clinics dedicated to specific disease sites. The cancer program has 110 providers (e.g., faculty, fellows, advanced practice providers) in palliative care, medical oncology, surgical oncology, breast surgery, and gynecology oncology at Parkland. The cancer program employs 34 clinical support staff in both inpatient and outpatient settings, 92 nurses, 17 care coordination staff (e.g., nurse navigators and care coordinators), and 30 business support staff. All cancer surgeries are performed in the oncology-dedicated area of Parkland Memorial Hospital or its ambulatory surgical center, depending on the complexity and urgency of a patient's case. Specialized surgical oncology teams treat many cancers, such as breast, esophageal, stomach, liver, bile duct, pancreatic, melanoma, and sarcoma.

In addition to established Parkland patients, the cancer program coordinates referrals from local for-profit institutions and nonprofit organizations. Their navigation and referral coordinators ensure that the transition to Parkland is seamless and timely. Upon receiving a referral, a Parkland referral coordinator reviews patients' cases for financial clearance. If they do not have insurance coverage, the referral coordinator assists in finding and obtaining necessary financial assistance to cover treatment costs. Simultaneously, an assigned nurse navigator schedules patients for their multidisciplinary consultation and completes an orientation to ensure the patients are prepared for their visit and screen for any services the patient may need (e.g., childcare, transportation, and social work support).

Patients who require radiation services are referred to partnering sites to receive therapy. Parkland nurse navigators and care coordinators work closely with external partners to ensure patients' care is coordinated effectively and that they receive their full course of treatment if traveling between multiple locations.

After treatment, patients continue their care at the cancer program's survivorship clinics. During the first survivorship visit, patients will meet with a multidisciplinary team to help them transition into survivorship care. These clinics provide personalized plans for patients by helping identify and address any late or long-term side effects while ensuring proper cancer surveillance.

Addressing COVID-19

Despite the challenges of COVID-19 in 2020 and 2021, the Cancer Program at Parkland Health continued working toward an integrated model of care delivery, while providing high-quality care to patients through the extraordinary efforts of healthcare providers, nurses, and other clinical and support staff. The cancer program was the first of the specialty services at Parkland to provide COVID-19 vaccination during patient visits. For patients in active treatment who have been diagnosed with COVID-19, Parkland's COVID Outpatient Clinic's staff ensures patients continue to receive their cancer treatments following COVID safety protocols.

Supporting Patients and Addressing Health Disparities

Staff are committed to eliminating inequities and disparities in cancer care delivery by identifying and addressing social factors and individual needs that impede patients' ability to engage in their care and adhere to treatment. As the safety net hospital in Dallas County, patients face barriers to care that include lack of access to transportation, cost, limited language and literacy proficiency, and childcare issues. Compared to the national average, Parkland's patients with cancer are younger, travel further distances to receive care, have a lower income and educational attainment, and have a higher rate of being uninsured or underinsured.

Approximately 68 percent of the cancer program's patient population lives about 25 miles from Parkland's main campus. Patients without a vehicle may spend two to three hours navigating public transportation (e.g., train and/or bus) to get to their appointments. When identified, these patients are referred to an oncology-dedicated social worker, who can help patients access bus passes, cab rides, and reimbursed transit fare costs.

Food insecurity has been shown to be higher among patients with cancer, in part due to the financial burden of cancer care on the individual and their families. Parkland's integrated oncology-dedicated dietitians offer personalized nutrition plans for patients based on their disease, food preferences, and food availability, connecting patients to external resources as needed. Additionally, an oncology malnutrition screening tool, created by Parkland staff, is completed during treatment for those who are at high risk for malnutrition (e.g., those with gastrointestinal or head and neck cancers).

In addition to providing dietitians and social workers, Parkland offers patients an array of oncology-dedicated supportive care services, including psychology, psychiatry, mental health counseling, genetic testing and counseling, a medication access program, durable medical equipment support, and financial counseling. Patients have access to free body image, nutrition, and chemotherapy classes in both English and Spanish. Parkland has partnered with the Women's Health Boutique to create a support area where referred patients can access mastectomy bras, wigs, compression garments, and more.

According to Dickerson, "We will implement initiatives and expand our program to address the needs of our community. At Parkland, the cancer program staff seek to inspire hope for our patients, reduce disparities through equitable access to cancer care, foster research and innovation in healthcare delivery, and achieve exemplary outcomes through the delivery of comprehensive, integrated cancer care." OI

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tools

Approved Drugs

- On Dec. 3, 2021, the U.S. Food and Drug Administration (FDA) approved **Keytruda® (pembrolizumab)** (Merck, merck.com) for the adjuvant treatment of adult and pediatric (less than or equal to 12 years of age) patients with Stage IIB or IIC melanoma following complete resection.
- On Jan. 25, 2022, the FDA approved **Kimmtrak® (tebentafusp-tebn)** (Immunocore Limited, immunocore.com) for HLA-A*02:01-positive adult patients with unresectable or metastatic uveal melanoma.
- On Dec. 15, 2021, the FDA approved **Orencia® (abatacept)** (Bristol Myers Squibb, bms.com) for the prophylaxis of acute graft versus host disease **in combination with a calcineurin inhibitor and methotrexate** in adults and pediatric patients two years of age and older undergoing hematopoietic stem cell transplantation from a matched or one allele-mismatched unrelated donor.
- On Dec. 2, 2021, the FDA approved **Rituxan® (rituximab)** (Genentech, Inc., gene.com) **in combination with chemotherapy** for pediatric patients (less than or equal to 6 months old to less than 18 years old) with previously untreated, advanced stage CD20-positive diffuse large B-cell lymphoma, Burkitt's lymphoma, Burkitt's-like lymphoma, or mature B-cell acute leukemia.

Drugs in the News

- Arch Oncology, Inc. (archoncology.com) announced that the FDA granted orphan drug designation to **AO-176** for the treatment of relapsed or refractory multiple myeloma.
- Cullinan Oncology, Inc. (cullinanoncology.com) announced that the FDA has granted breakthrough therapy designation for **CLN-081** for the treatment of patients with locally advanced or metastatic non-small cell lung cancer (NSCLC) harboring EGFR exon 20 insertion mutations who have previously received platinum-based systemic chemotherapy.
- Secura Bio, Inc. (securabio.com) voluntarily withdrew the United States **Copiktra® (duvelisib)** indication for the treatment of patients with relapsed or refractory follicular lymphoma after at least two prior systemic therapies.
- Allarity Therapeutics, Inc. (allarity.com) announced the submission of a new drug application (NDA) to the FDA seeking marketing approval for **dovitinib** for the third-line treatment of patients with renal cell carcinoma.
- Karyopharm Therapeutics Inc. (karyopharm.com) announced that the FDA granted orphan drug designation to **eltanexor** for the treatment of myelodysplastic syndromes.
- AstraZeneca (astrazeneca.com) and Daiichi Sankyo (daiichisankyo.com) announced that its supplemental biologics license application (BLA) for **Enhertu® (trastuzumab deruxtecan)** for the treatment of adult patients with unresectable or metastatic HER2-positive breast cancer who have received a prior anti-HER2-based regimen was granted priority review by the FDA.
- Celcuity Inc. (celcuity.com) announced that the FDA granted fast track designation to **gedatolisib** for the treatment of patients with hormone receptor (HR)+/HER2– metastatic breast cancer after progression on CDK4/6 therapy.
- Immix Biopharma, Inc. (immixbio.com) announced that the FDA granted rare pediatric disease designation to **IMX-110** for the treatment of rhabdomyosarcoma.
- Regeneron Pharmaceuticals, Inc. (regeneron.com) announced that the FDA accepted for review the supplemental BLA for **Libtayo® (cemiplimab-rwlc) in combination with chemotherapy** as first-line treatment in advanced NSCLC.
- Nkarta, Inc. (nkartatx.com) announced that the FDA granted orphan drug designation to **NKX101** for treatment of acute myeloid leukemia.
- Daiichi Sankyo Company, Ltd. (daiichisankyo.com) announced that the FDA granted breakthrough therapy designation to **patritumab deruxtecan (HER3-DXd)** for the treatment of patients with metastatic or locally advanced EGFR-mutated NSCLC with disease progression on or after

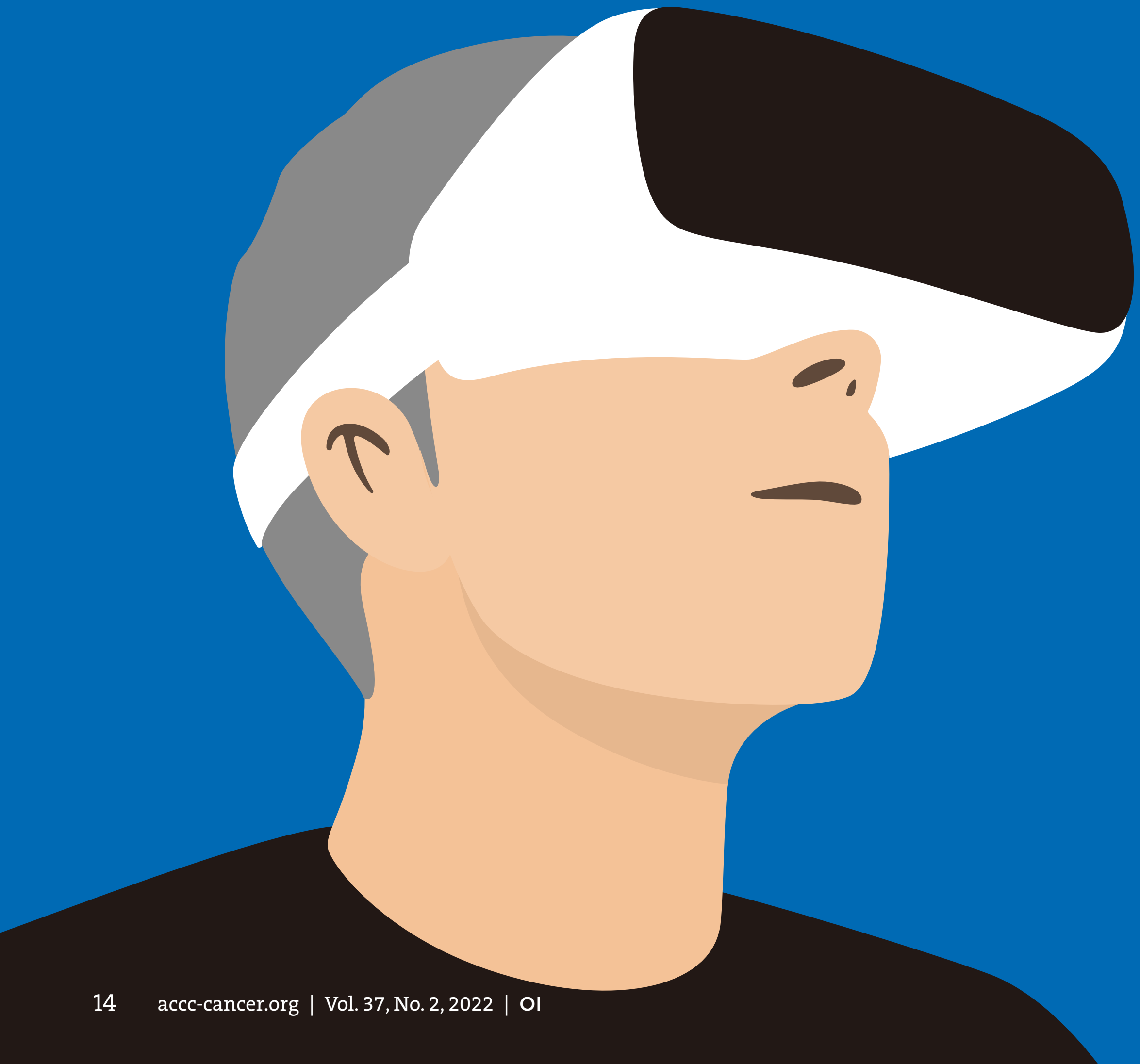
treatment with a third-generation tyrosine kinase inhibitor and platinum-based therapies.

- Senhwa Biosciences, Inc. (senhwabio.com/en) announced that the FDA granted fast track designation to **pidnarulex** for the treatment of patients with breast and ovarian cancers with BRCA1/2, PALB2, or other homologous recombination deficiency (HRD) mutations.
- Spectrum Pharmaceuticals (sppirx.com) announced that it has submitted an NDA for **poziotinib** to the FDA for use in patients with previously treated locally advanced or metastatic NSCLC with HER2 exon 20 insertion mutations.
- Genprex, Inc. (genprex.com) announced that the FDA has granted fast track designation to **Reqorsa™ (quaratusugene ozeplasmid) in combination with Keytruda** (Merck, merck.com) in patients with histologically confirmed unresectable Stage III or IV NSCLC whose disease progressed after treatment with Keytruda.
- Rakuten Medical, Inc. (rakuten-med.com/us) announced that the FDA accepted the investigational NDA to begin clinical studies of **RM-1995** photoimmunotherapy in patients with advanced cutaneous squamous cell carcinoma or with head and neck squamous cell carcinoma.
- Jazz Pharmaceuticals (jazzpharma.com) announced the completed submission of a supplemental BLA to the FDA seeking approval for a Monday/Wednesday/Friday intramuscular dosing schedule for **Rylaze™ (asparaginase erwinia chrysanthemi [recombinant]-rywn)** for use as a component of a multi-agent chemotherapeutic regimen for the treatment of acute lymphoblastic leukemia and lymphoblastic lymphoma in adult and pediatric patients one month and older who have developed hypersensitivity to *Escherichia coli*-derived asparaginase.
- Senhwa Biosciences, Inc. (senhwabio.com/en) announced that the FDA granted orphan drug designation to **silmitasertib** to treat patients with biliary tract cancer.
- The Janssen Biotech, Inc. (janssen.com) announced submission of a BLA to the FDA seeking approval of **teclistamab** for the treatment of patients with relapsed or refractory multiple myeloma.
- AbbVie (abbvie.com) announced that the FDA granted breakthrough therapy designation to investigational **Teliso-V telisotuzumab vedotin** for the treatment of patients with advanced/metastatic EGFR wild type, nonsquamous NSCLC with high levels of c-mesenchymal epithelial transition (MET)< overexpression whose disease has progressed on or after platinum-based therapy.
- Sandoz (sandoz.com) announced the submission of its BLA to the FDA for a proposed biosimilar to trastuzumab (150 mg, for intravenous use) developed by EirGenix, Inc.
- Kite (kitepharma.com) announced the FDA has approved an update to the prescribing information for **Yescarta® (axicabtagene ciloleucel)** to include use of prophylactic corticosteroids across all approved indications.

Devices and Assays in the News

- Blue Note Therapeutics (bluenotetherapeutics.com) announced that the FDA granted breakthrough device designation to **BNT200**, a digital therapeutic to treat anxiety and depressive symptoms in adults with acute myeloid leukemia who are hospitalized for a regimen of high-intensity induction chemotherapy.
- Foundation Medicine, Inc. (foundationmedicine.com) announced that it has received approval from the FDA for **FoundationOne®CDx** to be used as a companion diagnostic for two groups of current and future FDA-approved therapeutics in melanoma, which includes BRAF inhibitor monotherapies targeting BRAFV600E and BRAF/MEK inhibitor combination therapies targeting BRAFV600E or V600K mutations.
- Telix Pharmaceuticals (telixpharma.com) announced that the FDA approved **Illuccix® (TLX591-CDx)**, a kit for the preparation of gallium-68 (68Ga) gozetotide (also known as PSMA-11) injection—a radioactive diagnostic agent indicated for positron emission tomography of prostate-specific membrane antigen-positive lesions in patients with prostate cancer with suspected metastasis who are candidates for initial definitive therapy or suspected recurrence based on elevated serum prostate-specific antigen level.
- The FDA granted premarket approval to Thermo Fisher Scientific's (corporate.thermofisher.com/us/en/index.html) **Oncomine Dx Target Test** as a companion diagnostic to help identify patients with NSCLC whose tumors carry EGFR exon 20 insertion mutations for potential treatment with Rybrevant® (amivantamab-vmjw) (Janssen Biotech, Inc., janssen.com). OI

3-D Virtual Reality Takes Patient Education to the Next Level



BY DOUGLAS E. HOLT, MD

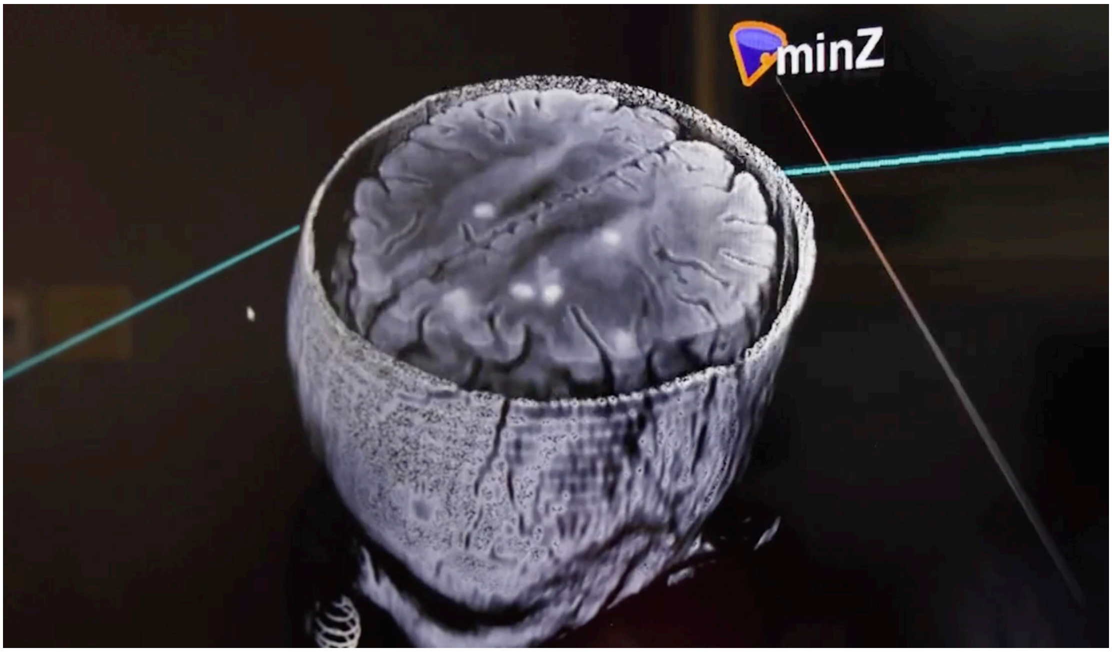
After a cancer diagnosis, patients and their caregivers often struggle to understand what is happening within patients' bodies. These challenges can be around comprehension of their disease, the treatment regimen, and/or specific symptoms or side effects. Studies have demonstrated that patients forget up to 80 percent of the information presented to them almost immediately after their medical consultation.[1-3] Additionally, up to 50 percent of the information patients do retain can be inaccurate.[3,4] These issues are further compounded by highly complex or a large volume of information,[1] poor health literacy,[2] language barriers,[5] and high anxiety or stress.[6] These data should concern healthcare providers because patients are making important and life-altering decisions based on their own limited comprehension of their disease.

Poor Understanding Negatively Impacts Patients

Though patient understanding may not directly impact how well a physician performs a surgery, delivers radiation therapy, or prescribes a systemic regimen, it can have negative consequences for patients and their families. Patients can experience increased anxiety if they do not fully understand their disease and/or recommended treatments.[1,7] Compliance concerns and avoiding recommended treatments can occur with poor patient understanding. Non-compliance can result from patients not knowing what to do or not possessing the rationale of why a certain treatment is important or necessary.[8] Misconceptions or fear of their treatments can also cause patients to avoid recommended therapies.[9]

> Some providers simply overestimate how effectively they teach and incorrectly think that patients understand more than they do.[23-25] This cognitive bias is known as the "curse of knowledge," where persons with more knowledge than those around them are communicating with others, assuming others have the background knowledge to understand.[26]

A lack of or poor understanding can lead to reduced patient satisfaction and lower engagement in their own care.[10] The patient-physician relationship and patients' trust in their providers can also be harmed when patients do not feel that they have good insight into their disease,[10] sometimes resulting in patients seeking medical care elsewhere.[11,12] An important medical concept is shared decision-making. Patients who do not possess a reasonable understanding of their disease, treatment, and related side effects are simply unable to participate in shared medical decision-making.[13,14] Most important, all of these factors are associated with poorer clinical outcomes.[15-18]



A 3-D volumetric rending of a MRI brain depicting multiple intraparenchymal lesions.

Provider Challenges

Providers can make incorrect assumptions that patients and caregivers simply do not wish to be informed about their disease and suggested treatments. A sentinel 1961 study performed in Chicago, Ill., asked physicians whether they would inform their patients of a new cancer diagnosis. Surprisingly, 90 percent of physicians indicated that they would *not* inform their patients about the new diagnosis.[19] Fortunately, much has changed since then with the movement toward patient education and patient-centered care. For many decades, it has been well understood that the vast majority of patients with cancer wish to be thoroughly informed about their disease and treatment.[19-22]

Some providers simply overestimate how effectively they teach and incorrectly think that patients understand more than they do.[23-25] This cognitive bias is known as the "curse of knowledge," where persons with more knowledge than those around them are communicating with others, assuming others have the background knowledge to understand.[26] The problem for medical providers is that they cannot unlearn the knowledge they have, and may no longer remember how difficult it was for them to learn about medicine, cancer, and anti-cancer therapy. A prime example of this phenomenon comes from a study of orthopedic surgeons, where surgeons and patients were asked to evaluate how effective the surgeons were in communicating information to patients on a scale of 0 to 100 (100 = perfect score). The surgeons rated themselves as 75/100 (marking themselves as effective communicators); the patients rated the surgeons 21/100 (rating the surgeons as ineffective communicators).[24]

Providers may also struggle to understand what it is like to have cancer. Even though providers treat hundreds to thousands of patients, they may not be able to fully comprehend the experience of being diagnosed and living with cancer and undergoing treatment. Numerous reports of providers who have developed cancer or a significant illness have found that providers simply did not understand the patient experience until they lived it themselves.[27,28] This means that providers may not be able to relate to what patients with cancer want or need, which may negatively affect the patient experience.

One of the largest hurdles in teaching patients with little to no background in medicine is the subject matter itself. Anatomy, cancer, and cancer treatment are difficult, abstract, and complex. For example, understanding the three-dimensional (3-D) and spatial interface of a tumor and its anatomy is vital for oncologists when staging and making treatment recommendations. But conveying this information to patients is challenging. However, if patients could be given the tools to better grasp this information, it could help them contextualize their disease and treatment, better understand the cause of their symptoms and treatment-related toxicities, and improve shared medical decision-making.

Evolution of Patient Education

Providers are always looking at ways to improve patient education. Below is a synopsis of how teaching has evolved:

- **Verbal discussion or description alone,** which has shown to be the least effective method[29-31] and, unfortunately, the most used strategy.

Provider with patient and caregiver donning virtual reality headsets during a virtual reality 3-D session.

- **Handouts, diagrams, videos, and medical imaging.** These additional methods are helpful[29-31] but likely still inadequate.
- **Two dimensional (2-D) medical imaging to show patients their disease in their body.** Though better, this information is difficult for the lay person to interpret. For example, without training, interpreting 2-D slices from magnetic resonance imaging (MRI) or computed tomography (CT) scan has been equated to reading a Rorschach inkblot. Due to the complexity and abstract nature of anatomy, cancer, and its treatments, these tools are likely insufficient to intuitively convey information in a format that patients and caregivers can understand.
- **3-D printed models show promising results in being able to display the 3-D spatial relationships of a tumor and local anatomy.**[32-34] However, this approach may be limited due to the lack of context of the model within the body, along with logistical issues, such as scaling, cost, and time delay for 3-D printing.
- **Virtual reality.** This next-generation teaching tool displays individual 2-D planar slices of a CT, MRI, or positron emission tomography/CT as a complete 3-D volume. This approach is ideal because it is personalized to patients, enabling them to explore and interact with their own anatomy. This technology also allows patients to see the problem and tumor within their own body, while providing a 3-D framework for added learning and discussion.[35] Finally, presenting information in 3-D versus 2-D can reduce cognitive load, which is important for improved learning.[36]

Several learning theories support the use of virtual reality, including constructivist,[37] embodiment,[38] and situational,[39] for not just hearing or seeing information but experiencing a new realism while interacting with a 3-D object in a new environment. Virtual reality has shown to be very effective in patient education. Though limited, recent studies have noted that the use of virtual reality has led to increased patient satisfaction, higher engagement, and a strong preference for this technology.[40-42] Momentum is building for the use of virtual reality in medicine, with the U.S. Food and Drug Administration now recognizing mixed extended reality.

The University of Colorado Cancer Center Experience

In 2019, at the University of Colorado, Douglas Holt, MD, led the effort to implement and study the use of virtual reality within the clinic for patient education in oncology. The University of Colorado Cancer Center received a 2021 ACCC Innovator Award for this work.

Implementing this technology took time and buy-in. Funded by a grant from the Colorado Cancer Coalition and one from the University of Colorado Cancer Center's radiation oncology department, the virtual reality solution transposed patients' medical images into a 3-D environment. To deploy this tool, the cancer program used state-of-the-art computers and virtual reality headsets that could be moved from room to room via a portable cart. By August 2020, the virtual reality cart was ready to use.

To better engage patients in their cancer treatment, providers used virtual reality to give patients a concrete visualization of what was happening in their bodies by taking the individual 2-D

Patients and caregivers noted virtual reality was a much easier format to learn from, while also providing improved understanding and engagement with their own treatment and providers.[43] Additionally, virtual reality was able to positively change patients' attitudes towards improved compliance.[43]

planar image slices of their medical imaging scans and stacking them on top of one another to form a 3-D image of their bodies and tumors. With virtual reality technology, patients gained a better understanding through a clear visualization of their tumor: where it is located in their body, what organs it is near, and its size.

Patients step into the virtual reality space with their caregiver(s), and the provider visually demonstrates how their radiation treatment plan will work, showing them the size of the radiation beam and where it will be targeted. Going beyond 2-D images and verbal explanations, virtual reality technology gives patients the much-needed intuitive context regarding their disease and treatment.

Measuring the Impact of Virtual Reality on Patients with Cancer

Objectively measuring subjective patient experiences is quite challenging, unlike typical studies of medicine and cancer with hard endpoints of overall survival, disease-free survival, and toxicity. In 2020, working with clinical psychology and a psychometrician, the cancer program used both quantitative and qualitative methods to prospectively evaluate the impact of virtual reality on its patients with cancer and their families. Study abstract results were presented at the 2021 American Society for Radiation Oncology (ASTRO) Annual Meeting.[43] The published ASTRO abstract findings are shared below. Limited findings are shared here. (Manuscript currently in preparation for full results.)

The study included 25 virtual reality sessions with patients and their caregivers in which patients reviewed their 3-D medical imaging scans in consultation with their providers. Patients' ages ranged from 11 years to 95 years old. Patients were asked to rate their understanding of their disease and tumor—once before and then again after their virtual reality patient education consultation—using a 10-point scale (0 = no understanding to 10 = full understanding).[43] Patient understanding of their disease and tumor improved from a mean of 5.6 pre-virtual reality consultation to 9.2 post-virtual reality consultation.[43] When patients were asked about their preferred method for medical imaging review (3-D virtual reality versus a 2-D image on a computer), 97 percent preferred 3-D virtual reality.[43] Virtual reality was the top-ranked educational tool (83 percent over all other current teaching methods, including verbal discussion, self-research, 2-D computer screen imaging review, illustrations, and handouts).[43] Additionally, the vast majority of patients and caregivers (97 percent) agreed that virtual reality should be a standard-of-care teaching tool for patients with cancer.[43]

Qualitatively, patients shared how challenging it had been to learn upfront about their disease and treatment with standard consultation methods.[43] Patients and caregivers noted virtual reality was a much easier format to learn from, while also providing improved understanding and engagement with their own treatment and providers.[43] Additionally, virtual reality was able to positively change patients' attitudes toward improved compliance. [43]

As shared by one patient in testimonial shared outside of study data and included as part of the 2021 ACCC Innovator Award Video (youtube.com/watch?v=NQDfeYMuK9M):

> *I was diagnosed with a squamous cell carcinoma at the base of the tongue. It's [so] difficult to understand where [the tumor's] at, because it's my body right, and I don't know where [or] what's going on inside of it. It is hard to look at a simple picture [of 2-D medical imaging]. When I came here, I got to see my body in front of me and in 3-D, I didn't have to look at some [2-D] images that are sliced through my body. [In virtual reality] you could go in there and zoom in, cut through it and be clear where in the body the tumor is at, and where the problem regions [are that] they have to attack. I could actually see where the [radiation] would be going and that was just really remarkable. It was like comparing a child's drawing to the Mona Lisa. [Virtual reality] did make it more real for me. Because I was able to look at myself in a third person perspective. Everyone should have the opportunity to do this. [Virtual reality] was really helpful.*

Future Directions

With data from this study, Dr. Holt is working to expand use of this technology. He is currently in the process of pursuing additional prospective clinical trials to further investigate and validate its findings. Dr. Holt also will be working with additional institutions to implement and evaluate the use of virtual reality in patient education within the radiation oncology clinic along with other disciplines in oncology and medicine.

Another issue Dr. Holt will address is implementation of virtual reality within the clinical workflow to enable widespread, mainstream use. The ultimate goal is for virtual reality to become the standard-of-care in patient education to help improve the patient-physician relationship and communication by enhancing patient engagement and shared medical decision-making.

Douglas E. Holt, MD, is a radiation oncologist with Gamma West at the Idaho Cancer Center in Idaho Falls, Idaho, and St. Johns Hospital in Jackson, Wyo.

The author reports that there are no competing interests to declare.

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Presentations

This project was awarded the 2021 ACCC Innovator Award and was presented on at the 38th ACCC [Virtual] National Oncology Conference. Additionally, the results of this study were presented at the 2021 ASTRO Annual Meeting in Chicago, Ill. The abstract received the abstract travel award, and the results were also presented at the ASTRO News Briefing.

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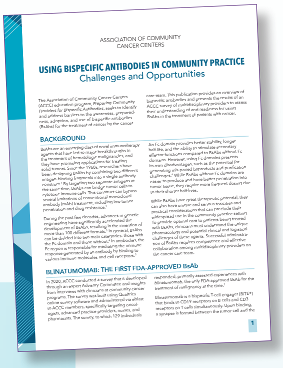
ASSOCIATION OF COMMUNITY
CANCER CENTERS

Preparing Community Providers for Bispecific Antibodies

With more bispecific antibodies (BsAbs) progressing through late-phase trials, providers should be prepared to welcome these agents into the community, as they have great potential to provide value to patients and change the landscape of cancer treatment.



ASSOCIATION OF COMMUNITY
CANCER CENTERS

USING BISPECIFIC ANTIBODIES IN COMMUNITY PRACTICE
Challenges and Opportunities

The Association of Community Cancer Centers (ACCC) education program, *Preparing Community Providers for Bispecific Antibodies*, seeks to identify and address barriers to the awareness, preparedness, adoption, and use of bispecific antibodies (BsAbs) for the treatment of cancer by the cancer care team. This publication provides an overview of bispecific antibodies and presents the results of an ACCC survey of multidisciplinary providers to assess their understanding of and readiness for using BsAbs in the treatment of patients with cancer.

BACKGROUND

BsAbs are an emerging class of novel immunotherapy agents that have led to major breakthroughs in the treatment of hematologic malignancies, and they have promising applications for treating solid tumors. Since the 1960s, researchers have been designing BsAbs by combining two different antigen-binding fragments into a single antibody construct.[1] By targeting two separate antigens at the same time, BsAbs can bridge tumor cells to cytotoxic immune cells. This construct can bypass several limitations of conventional monoclonal antibody (mAb) treatment, including low tumor penetration and drug resistance.[2]

During the past few decades, advances in genetic engineering have significantly accelerated the development of BsAbs, resulting in the invention of more than 100 different formats.[3] In general, BsAbs can be divided into two main categories: those with the Fc domain and those without.[4] In antibodies, the Fc region is responsible for mediating the immune response generated by an antibody by binding to various immune molecules and cell receptors.[5]

An Fc domain provides better stability, longer half-life, and the ability to stimulate secondary effector functions compared to BsAbs without Fc domains. However, using Fc domains presents its own disadvantages, such as the potential for generating mis-paired byproducts and purification challenges.[6] While BsAbs without Fc domains are easier to produce and have better penetration into tumor tissue, they require more frequent dosing due to their shorter half-lives.

While BsAbs have great therapeutic potential, they can also have unique and serious toxicities and practical considerations that can preclude their widespread use in the community practice setting. To provide optimal care to patients being treated with BsAbs, clinicians must understand the unique pharmacology and potential clinical and logistical challenges of these agents. Successful administration of BsAbs requires competence and effective collaboration among multidisciplinary providers on the cancer care team.

BLINATUMOMAB: THE FIRST FDA-APPROVED BsAb

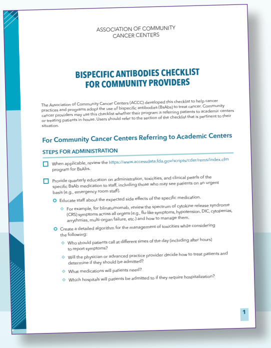
In 2020, ACCC conducted a survey that it developed through an expert Advisory Committee and insights from interviews with clinicians at community cancer programs. The survey was built using Qualtrics online survey software and administered via eblast to ACCC members, specifically targeting oncologists, advanced practice providers, nurses, and pharmacists. The survey, to which 129 individuals responded, primarily assessed experiences with *blinatumomab*, the only FDA-approved BsAb for the treatment of malignancy at the time.[7]

Blinatumomab is a bispecific T-cell engager (BiTE®) that binds to CD19 receptors on B cells and CD3 receptors on T cells simultaneously. Upon binding, a synapse is formed between the tumor cell and the

1

PUBLICATION

Read an overview of bispecific antibodies and the results of a provider survey which assessed an understanding of—and readiness for—using BsAbs in the treatment of patients with cancer.



ASSOCIATION OF COMMUNITY
CANCER CENTERS

BISPECIFIC ANTIBODIES CHECKLIST FOR COMMUNITY PROVIDERS

The Association of Community Cancer Centers (ACCC) developed this checklist to help cancer practices and programs adopt the use of bispecific antibodies (BsAbs) to treat cancer. Community cancer providers may use this checklist whether their program is referring patients to academic centers or treating patients in-house. Users should refer to the section of the checklist that is pertinent to their situation.

For Community Cancer Centers Referring to Academic Centers

STEPS FOR ADMINISTRATION

- ☐ When applicable, review the https://www.accessdata.fda.gov/scripts/cder/rems/index.cfm program for BsAbs.
- ☐ Provide quarterly education on administration, toxicities, and clinical pearls of the specific BsAb medication to staff, including those who may see patients on an urgent basis (e.g., emergency room staff).
  - Educate staff about the expected side effects of the specific medication.
    - For example, for blinatumomab, review the spectrum of cytokine release syndrome (CRS) symptoms across all organs (e.g., flu-like symptoms, hypotension, DIC, cytopenias, arrythmias, multi-organ failure, etc.) and how to manage them.
  - Create a detailed algorithm for the management of toxicities while considering the following:
    - Who should patients call at different times of the day (including after hours) to report symptoms?
    - Will the physician or advanced practice provider decide how to treat patients and determine if they should be admitted?
    - What medications will patients need?
    - Which hospitals will patients be admitted to if they require hospitalization?

1

CHECKLIST FOR COMMUNITY PROVIDERS

Community cancer providers can use this checklist whether their programs are referring patients to academic centers or treating patients in-house.

ON-DEMAND WEBINAR

Learn about the mechanism of bispecific antibodies, discover existing and emerging therapies, and hear about the administration of the first FDA-approved bispecific antibody for the treatment of malignancy.

CANCER BUZZ PODCAST

Hear the latest promising breakthroughs in immunotherapy, challenges facing their widespread use, and what your cancer team needs to know.

DIGITAL RESOURCE LIBRARY

Access tools to support patients who may be eligible for T-cell bispecific antibodies, including information about financial resources.

accc-cancer.org/bispecific-antibodies

In partnership with The Leukemia & Lymphoma Society. Funding & support provided by Amgen.

ACCC
Association of Community Cancer Centers

The Association of Community Cancer Centers (ACCC) is the leading education and advocacy organization for the cancer care community. Founded in 1974, ACCC is a powerful network of 28,000 multidisciplinary practitioners from 2,100 hospitals and practices nationwide. As advances in cancer screening and diagnosis, treatment options, and care delivery models continue to evolve—so has ACCC—adapting its resources to meet the changing needs of the entire oncology care team. For more information, visit accc-cancer.org. Follow us on social media; read our blog, ACCCBuzz; tune in to our podcast, CANCER BUZZ, and view our vodcast channel, CANCER BUZZ TV.

How Do You DISCO?

BY LAUREN M. HAMEL, PHD; DAVID W. DOUGHERTY, MD, MBA;
LORNA MABUNDA, MSI; EYOUAB TADESSE; RAEANN HILL;
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2021 ACCC INNOVATOR AWARD • ASSOCIATION OF COMMUNITY CANCER CENTERS •

Leveraging the Discussions of Cost App to reduce financial toxicity and improve treatment cost communication

The ***Dis***cussions of ***Co***st (DISCO) application (app) is a scalable and individualizable patient-focused intervention designed to prepare patients for their treatment-related costs and help reduce the burden of these costs. Newly introduced at the Karmanos Cancer Institute in Detroit, Mich., the app was built in partnership with cancer survivors and clinicians in response to the mounting evidence that patients with cancer are unprepared when treatment costs arise, resulting in what is termed as "financial toxicity" or the severe burden of treatment-related costs. Up to 50 percent of patients with cancer experience financial toxicity.[1-5] Some of these patients forego treatment due to cost. Many experts argue that treatment cost discussions between oncologists and patients early in their treatment can help mitigate financial toxicity by facilitating patient access to financial assistance and other resources. Unfortunately, research has shown that such discussions are rare, engagement around treatment costs is an unmet patient need, and opportunities to connect patients with support and resources are being routinely missed. In response to these findings, we developed the DISCO App to educate patients with cancer about their potential treatment-related costs and prompt them to discuss these costs with their oncologist(s) using questions tailored to their specific situation.

> Patients with lower incomes are more likely to choose treatments with lower costs even if those treatments have lower survival and higher toxicity.[24] To offset costs, patients may deviate from treatment, including prescriptions for side effects,[3,28,29] and/or forgo treatment altogether.[25]

What is Financial Toxicity?

Financial toxicity—the severe material and psychological burden brought on by the costs of cancer treatment—affects an estimated 30 percent to 50 percent of patients.[1-5] As cancer treatment costs escalate[6] and the cost burden increasingly shifts to patients,[7-10] more patients are experiencing severe economic consequences.

Across cancer types, patients are, on average, responsible for $16,000 in out-of-pocket direct and indirect treatment-related costs annually.[11] People with cancer are 2.6 times as likely as people without cancer to file for bankruptcy.[12,13] Recent studies on survivors of breast cancer found that 24 percent used all of their savings over 6 months to pay for their treatment,[14] and 62 percent of survivors of colorectal cancer incurred debt to pay for treatment, with an average liability of $26,860.[15] Financial toxicity can also result from indirect costs, such as loss of income. Breast cancer survivors reported losing an average of 42 workdays per year, which translated to an average of $8,236 in lost wages.[16] Treatment costs can also have deleterious psychological effects, with almost half of survivors reporting significant, even catastrophic, levels of cost-related distress.[17-19] The consequences of financial toxicity can be both short term (during diagnosis and treatment) and long term (into survivorship).[1,19,20]

Influence on Treatment Adherence and Patient Outcomes

Cancer treatment costs and related material and psychological burden influence treatment recommendations,[21] treatment decisions,[22-25] adherence,[1,3,20,25] and mortality.[26] A majority of oncologists report that anti-cancer drug costs (56 percent) and patient out-of-pocket costs (84 percent) influence their treatment recommendations.[21] Costs also influence patients' treatment decisions,[22-25] including whether to participate in clinical trials.[23,27] Patients with lower incomes are more likely to choose treatments with lower costs even if those treatments have lower survival and higher toxicity.[24] To offset costs, patients may deviate from treatment, including prescriptions for side effects,[3,28,29] and/or forgo treatment altogether.[25] A study of 254 patients being treated with either chemotherapy or hormonal therapy found that 20 percent of patients took less than the prescribed amount of their medication, partially filled, or avoided filling prescriptions due to their out-of-pocket costs.[3] Another study of patients being treated for solid tumors found that 45 percent of patients were non-adherent to treatment due to its costs.[20] A study of 1,556 cancer survivors found that those who reported financial problems were more likely to delay (18.3 percent vs. 7.4 percent) or forgo treatment (13.8 percent vs. 5 percent) compared to respondents without financial problems.[30] In a study of more than 22,000 patients with early-stage breast cancer, higher co-payments were associated with greater non-adherence to treatment by Medicare and non-Medicare patients. Indirect costs (e.g., travel costs and time) also reduce the likelihood of receiving or completing treatment.[31] Severe financial distress resulting from cancer treatment may itself be a mortality risk factor.[26]

Health insurance, whether public or private, does not protect patients against financial toxicity.[1,4] The American Cancer Society conducted a national poll of more than 1,000 adults who reported that they or a member of their household had cancer or a history of cancer.[4] Regardless of insurance, 20 percent of respondents had difficulty paying for basic necessities, 15 percent used up all or most of their savings, and 11 percent incurred thousands of dollars in debt due to treatment expenses. This survey found that 26 percent of respondents who were insured during their cancer diagnosis and treatment experienced problems with their insurance coverage.[4] A study of 10,000 patients with Medicare or private insurance found that higher co-payments were related to prematurely stopping oral chemotherapy.[32]

Inequities in the Burden of Financial Toxicity

The burden of financial toxicity is a health equity issue, disproportionately affecting patients who are of racially and/or ethnically marginalized groups,[15,33-36] have lower incomes,[13,15,18,34] and/or are 65 years of age and older.[13,26,34] Compared to White patients with cancer, Black patients with cancer are twice as likely to deviate from treatment, have utilities turned off, and move out of their homes because they cannot afford to pay for their treatment and living expenses.[33] Black survivors are more likely to report treatment-related debt (15 percent) than White survivors (9 percent). Lower-income Black patients with breast cancer spend a greater proportion of their income (27 percent to 31 percent) on treatment-related expenses compared to lower-income White patients (9 percent to 13 percent).[34] Across all races, survivors of cancer are 1.4 times as likely to be unemployed—often due to extended time off for treatment/recovery—as people without cancer, and survivors from racially or ethnically marginalized groups are twice as likely to be unemployed than White cancer survivors.[37] The disproportionate burden of financial toxicity experienced by historically marginalized groups remains even when controlling for employment status and insurance status at diagnosis.[34,35] Younger patients (less than 65 years old) are also at greater risk for financial toxicity and bankruptcy than older patients, mainly due to insurance status (i.e., Medicare).[26]

Treatment Cost Discussions May Help Reduce Financial Toxicity

Including costs as a topic when patients and oncologists discuss treatment plans could help prepare patients to manage their treatment-related costs. A major contributor to the burden of financial toxicity is that patients are often not aware of the potential costs they may incur during treatment and survivorship and how to manage those costs.[2,38-41] Treatment cost discussions between oncologists and patients could improve patients' knowledge of what costs to anticipate[2,38,40-42] and connect patients with vital financial resources.[43] Most patients want to discuss costs with their physicians.[44-46] However, a rich body of research shows that cost discussions occur infrequently.[47-49] For example, a study of video-recorded treatment discussions (n = 103) found that speaking on costs occurred in only 45 percent of these discussions. When costs were discussed, it was usually initiated by patients (63 percent) and focused more on potential indirect costs (e.g., time off work) than on direct costs (e.g., co-payments).[47]

In an attempt to increase patient awareness and communication about cancer-related costs, the American Society of Clinical Oncology (ASCO) developed tools, including ASCO Answers: Managing the Cost of Cancer Care,[50] the ASCO Value Framework,[2] and Patient-Clinician Communication: ASCO Consensus Guideline.[51] These materials are intended to educate patients on the types of treatment-related costs they may incur, to encourage physicians to discuss patient cost concerns directly, and to refer patients to a social worker or financial navigator if needed. Unfortunately, ASCO's current materials are static and text-heavy and do not provide patients with specific actions they can take to manage their costs. Though these tools encourage discussions, the guidelines are overly general and do not provide patients and physicians with specific strategies to initiate such discussions.

Improving an Effective Clinical Communication Intervention

Question prompt lists are communication tools designed to enhance patients' active participation in interactions with their physicians. These tools list questions that patients might consider asking their healthcare provider during a clinical interaction[52-56] and are shown to improve a patient's:

- Active participation in interactions[57]
- Psychological outcomes (e.g., anxiety)[58]
- Cognitive outcomes (e.g., information recall)[52]
- Report of their role in treatment decisions[53]
- Trust in their oncologist.[52,54,55]

Question prompt lists have also successfully increased patients' active participation, particularly among Black patients with cancer as they discuss treatment with their oncologists.[57] However, most are limited in two ways: 1) question prompt lists do not adequately address treatment-related costs and 2) most are paper-based and static. Although a few question prompt lists and similar interventions are tailorable, these tools have not been used in the context of treatment-related cost communication or financial toxicity.[59] A cost-focused question prompt list in the form of an application or "app" provided to patients in the clinic prior to meeting with their physician may overcome these limitations.

Dr. Hamel brought the idea of an app-based question prompt list to her mentor and collaborator, Dr. Eggly. Drs. Hamel and Eggly are both experts in communication science, with a focus on improving patient-clinician communication to reduce health disparities. Dr. Eggly has led the design and testing of several paper-based question prompt lists in diverse patient populations and clinical settings. Using their expertise, together they sketched out a basic idea and plan for an app-based tool devoted to cancer treatment-related costs.

The study team is based at Wayne State University and the Karmanos Cancer Institute, a National Cancer Institute-designated comprehensive cancer center located in Detroit, Mich. To continue to develop and test the DISCO App, Dr. Hamel leveraged her professional network, institutional funds, and resources. Specifically, Dr. Hamel had established partnerships with:

- Karmanos Cancer Institute's Detroit Healthlink Cancer Action Councils[60]
- Oncologists and social workers from Karmanos Cancer Institute and the Dana-Farber Cancer Institute
- The University of Michigan's Tech Transfer Program
- CrossComm, a mobile application development firm that builds custom apps.

The Cancer Action Councils are racially diverse groups of community members and include many cancer survivors. Several individual council members met one-on-one with Dr. Hamel to go through the wireframe of the DISCO App. This was a critical stage in the app's development because it helped ensure that the tool was acceptable and useful for the people who need it most—patients. Subsequently, Dr. Hamel had several one-on-one meetings with practicing oncologists, social workers, financial navigators, and administrators. This stage helped ensure that the app meet the needs and requirements of the health system in which it would ultimately be implemented. With feedback on content and format from Cancer Action Council members, oncologists, and social workers, Dr. Hamel worked with the University of Michigan's Tech Transfer Program and CrossComm to build the DISCO App.

Preliminary Version of the DISCO App

The first working version of the DISCO App included a treatment-cost focused question prompt list, which provided individually tailored questions to patients. The question prompt list is introduced with the following text, "There is a lot to consider when it comes to treating cancer. One thing many patients don't think about is the cost of treatment and other expenses." The text continues to explain that the DISCO App includes a short survey, which will lead to some cost-related questions the patient can consider asking their oncologist. This section asks patients to enter their demographic information and their financial characteristics. Specifically, patients respond to 17 questions (e.g., How much do you know about your insurance coverage? Are you currently employed? Is there anyone who helps you when you're sick or need help of any kind?). Based on patients' responses, the app then generates an individually tailored question prompt list with up to 18 cost-related questions within 7 categories (Table 1, page 26). For example, patients who indicate they are employed will be prompted to ask, "Can I schedule my treatment around my job?" Patients who indicate transportation concerns will be prompted to ask, "Are services available if I can't find someone to drive me?" Patients who indicate that they are unfamiliar with their insurance coverage will be prompted to ask, "Is there someone I can talk to about my insurance and treatment cost questions?" All patients are provided with four diagnosis questions (e.g., What is my diagnosis?), have the option of adding in any of their own questions, and can then either take the iPad or a printed question list into the meeting with their oncologist.

To test acceptability and readability of this version of the DISCO App, Dr. Hamel recruited an expert panel of 12 members, including cancer survivors, oncologists, and social workers.[61] The majority (n = 10) of panel members found the DISCO App acceptable and likely useful for patients to prompt treatment-related cost discussions between oncologists and patients and for patients to gain important treatment-related information.

However, seven panel members were concerned that oncologists may be unprepared to answer some questions. To address this, a panel member suggested including a tool that would help prepare

Table 1. The DISCO App's Prompted Questions by Question Type

Cost of appointments and treatments

1. How much will I have to pay for my treatment?
2. Is there a less expensive drug, like a generic, that will be equally effective?
3. How many visits will I have? I may have to pay each time I come to the cancer center (co-pay, parking, etc.).
4. What happens if I can't pay for some of my treatment costs?

Help with understanding my treatment costs and what my insurance covers

5. Do I need additional or supplemental insurance coverage?
6. Do I have a co-pay every time I come to the cancer center?
7. Is there someone I can talk to about my questions about my insurance and treatment costs?

Transportation to and parking at the cancer center

8. Does someone need to drive me to treatment appointments?
9. Are services available if I can't find someone to drive me?
10. How much does parking cost?

Living far from the cancer center

11. Is it possible for me to receive my treatment closer to where I live?
12. Are there free or reduced-cost hotels nearby for me and my family?

Working during treatment

13. Can I keep working during treatment? If not, when can I go back to work?
14. Can I schedule my treatment around my job?
15. Do I need to file Family and Medical Leave Act paperwork? If so, how?

Assistance programs

16. Are assistance programs available to help me with treatment costs or other expenses or needs?
17. If I need a wig or other supplies, is there somewhere I can get them free or at a reduced cost?

Family and living responsibilities

18. Can I schedule my treatment around my family's schedule?

General questions about cancer and treatment (all patients will get these)

19. What is my diagnosis and stage?
20. Is it possible to cure my cancer?
21. What is my treatment plan?
22. Are there clinical trials I can participate in? If so, will this cost more or less than standard treatment?

oncologists for such discussions. The resulting tip sheet emphasizes oncologists' role in cost discussions (as encouraged by ASCO) and provides ways to overcome identified barriers to cost discussions.[62-65] The tip sheet acknowledges the complexities of treatment costs by including statements like, "If a patient asks about cost and you do not know the answer, you can simply say, 'I'm glad you brought this up, because it's important for me to know what concerns you have about your treatment. I'm not an expert in this area, but if you have questions about costs, I can arrange for you to meet with a social worker who can help after we're done here.'" The tip sheet is designed as a two-sided, tri-fold document that fits in physicians' white lab coats (Figure 1, page 28).

Clinic-Based Pilot Test

After revising the DISCO App based on feedback from the expert panel, the app was pilot tested for feasibility and preliminary effectiveness in two Karmanos Cancer Institute outpatient clinics. Oncologists (*n* = 3) and patients (*n* = 32) newly diagnosed with breast (94 percent) or lung (6 percent) cancer agreed to participate. Physicians received the tip sheet when they consented to participate in the study. Patients who agreed to participate were invited to use the DISCO App on an iPad and print their question prompt lists while they waited to see their oncologist. Clinic visits were video recorded for later analysis. Patients completed pre- and post-interaction surveys.

Analysis of patient surveys showed significant pre- to post-intervention increases in patients' self-efficacy for managing treatment-related costs ($p = 0.01$) and for interacting with their oncologists ($p = 0.001$). There was also a promising trend toward decreased patient distress. Patients reported that the DISCO App was easy to understand (mean = 4.5 out of 5) and useful as they talked with their doctor (mean = 4); 84 percent of patients reported needing less than 15 minutes to use the DISCO App, and all patients were able to use the DISCO App in the time that they were waiting for their oncologist. On average, patients selected 6.5 out of the 18 possible questions to print.

Most interactions (94 percent) were video recorded; in two cases, technical difficulties prevented recording. Analysis by trained observers showed that all (n = 30, 100 percent) of the video-recorded interactions included a cost discussion, and 23 (77 percent) included multiple cost topics. The most frequently discussed topics were insurance, time off from work, and social work and/or financial navigator referrals, which suggested an immediate and direct benefit of the DISCO App. Taken together, findings from this pilot test suggest that the DISCO App is feasible, acceptable, and effective for improving outcomes.[66,67]

Current Version of the DISCO App

The DISCO App was later revised, based on further feedback from researchers and clinicians (Figure 2, page 29). The current version of the DISCO App includes a brief treatment cost educational video in addition to the original individually tailorable question prompt list. The DISCO App now opens with an introduction screen. Patients watch a 3-minute educational video featuring a communication scientist, medical oncologist, and a patient using the app. The video summarizes the types of treatment costs patients may incur (e.g., co-payments, transportation and/or parking costs, time away from work) and ways to manage those costs (e.g., talk with an oncologist or social worker, contact pharmaceutical companies, seek clarification from insurance providers). The video ends by emphasizing to patients that the best way to start managing treatment-related costs is to discuss them with their oncologist, who can answer their questions or refer them to someone who can assist. After the video, patients are presented with instructions on how to use the question prompt list and are asked to enter their demographic information and their financial characteristics. The DISCO App then uses those responses to produce an individually tailored list of cost-related questions, just as it did in the original version of the app. Thus, the DISCO App provides patients with specific information about the types of out-of-pocket and indirect costs they may incur while undergoing cancer treatment, specific actions they can take to begin addressing those costs, and a list of cost-focused questions they can take with them to their clinic visit to ask their oncologist. This information and individualized prompting are something few patients with cancer currently receive, on any topic.

Ongoing American Cancer Society-Funded Randomized Controlled Trial

In 2020, the DISCO study team was awarded a five-year research scholar grant from the American Cancer Society to test the effectiveness of the DISCO App on short- and long-term patient outcomes, including patient-physician treatment cost discussions, with a diverse patient population (RSG-20-026-01-CPHPS, Hamel, principal investigator).[68] White and Black patients from various ages and income levels diagnosed with a solid tumor at a National Cancer Institute-designated comprehensive cancer center in Detroit, Mich., will be randomized to intervention or usual care study arms. All patients will have up to two interactions with their oncologist video recorded and complete measures at baseline; after the recorded interactions; and at 1, 3, 6, and 12 months after the second interaction. If effective, the DISCO App will improve awareness of and discussions of treatment-related costs and alleviate the burden of financial toxicity. It may be especially helpful to groups disproportionately affected by financial toxicity, including Black patients, younger patients, and patients with lower incomes, thus helping to improve health equity.

We expect the intervention may need reinforcement to influence long-term outcomes (e.g., financial toxicity, treatment adherence, and clinic appointment adherence). Thus, we are testing the use of individually tailored emails with information from the DISCO App. Half of the intervention patients will receive an intervention "booster," comprising an email reminding them of the questions they selected and that treatment costs can be discussed with their oncologist.

Innovation in Action

The DISCO App is innovative because it is among the first of its kind to adapt the question prompt list, an effective paper-based communication intervention, into a digital, individually tailorable, and highly scalable multi-level communication intervention. Designing a communication intervention in a digital format is especially innovative as we aim to enhance scalability to diverse patient populations and begin to integrate into electronic health records (EHRs) and patient portals. Additionally, our study is innovative in its methods, which included evaluation of outcomes using rigorous, systematic analysis of self-reported patient data, and video-recorded interactions of patient-physician treatment discussions. This work is contributing to our understanding of the mechanisms through which treatment-related cost discussions and other aspects of clinical communication improve short- and long-term patient outcomes related to financial toxicity.

Next Steps

The findings from the clinic-based pilot test of the DISCO App's preliminary effectiveness were encouraging, and the current randomized clinical trial is underway. The DISCO App's design, which was based on rigorous testing and strong collaborations among key stakeholders (i.e., behavioral scientists, cancer survivors, advocates, and providers), promises to be effective in the short and long term for a diverse population of patients. However, a multi-level design may increase the effectiveness of the DISCO App. Steps toward this goal include designing an enhanced and

Figure 1. Oncologist Tip Sheet, Front and Back

Reasons to Discuss Treatment Cost with Patients

- Discussing cost concerns, especially early on in treatment, can help patients and oncologists make better treatment decisions and help identify which patients could benefit from referral to a social worker or financial navigator.
- Most patients want to discuss cost with their treating physicians and are comfortable being referred to a social worker or a financial navigator, who are often better equipped and positioned to assist patients with more in-depth financial issues.
- Major oncology professional organizations, including ASCO and NCCN, encourage oncologists to include cost in their treatment discussions with patients.

Barriers and Responses

- **Barrier:** ***Oncologists may not know how to address patients' cost concerns.***

  Response: Oncologists do not need to have all the answers. Many cost-related issues cannot be addressed in a single discussion. The best thing to do is to acknowledge your patients' questions and concerns and then refer them to a social worker or a financial navigator if they need more help.
- **Barrier:** ***Cost discussions take too long during treatment discussions.***

  Response: Karmanos research shows that cost discussions typically last less than a minute. For patients needing more information, a referral to a social worker or a financial navigator can be made. Discussing cost now, may save you time in the future.

DISCO
Discussions of **Co**st
Tip Sheet for Oncologists

Barriers and Responses

- **Barrier:** ***Patients may feel uncomfortable discussing cost.***

  Response: 80% of patients surveyed want to discuss treatment cost, at least initially, with their physician. Then, they are amenable to discussing cost with other providers.
- **Barrier:** ***Patients may be concerned that a less expensive treatment may be less effective.***

  Response: As an oncologist, you are in the unique position to inform patients of the effectiveness of different treatment options and weigh that against toxicity and cost. See the ASCO Value of Cancer Treatment Options Framework for more information.

Communication Tips

- **Patient:** ***"I am worried I can't afford what my insurance won't cover."***

  Response: "I'm glad you brought this up because it's important for me to know what concerns you may have about your treatment. If you have questions about your insurance or other costs, I can refer you to someone who can help after we're done here."
- **Patient:** ***"Will I be able to work during my treatment?"***

  Response: "Many of my patients work during treatment, but some prefer not to. A lot will depend on how you feel once the treatment gets started. Then, we can try to work your treatment schedule around your job."
- **Patient:** ***"Do I need someone to drive me to treatment? Do I need to pay for parking?"***

  Response: "It may be helpful to have someone available to drive you to appointments. If you have concerns about transportation or parking costs, our social work team may be able to provide you with information to help."

As an oncologist, you are your patients' best advocate for all aspects of their treatment, including helping them understand treatment costs.

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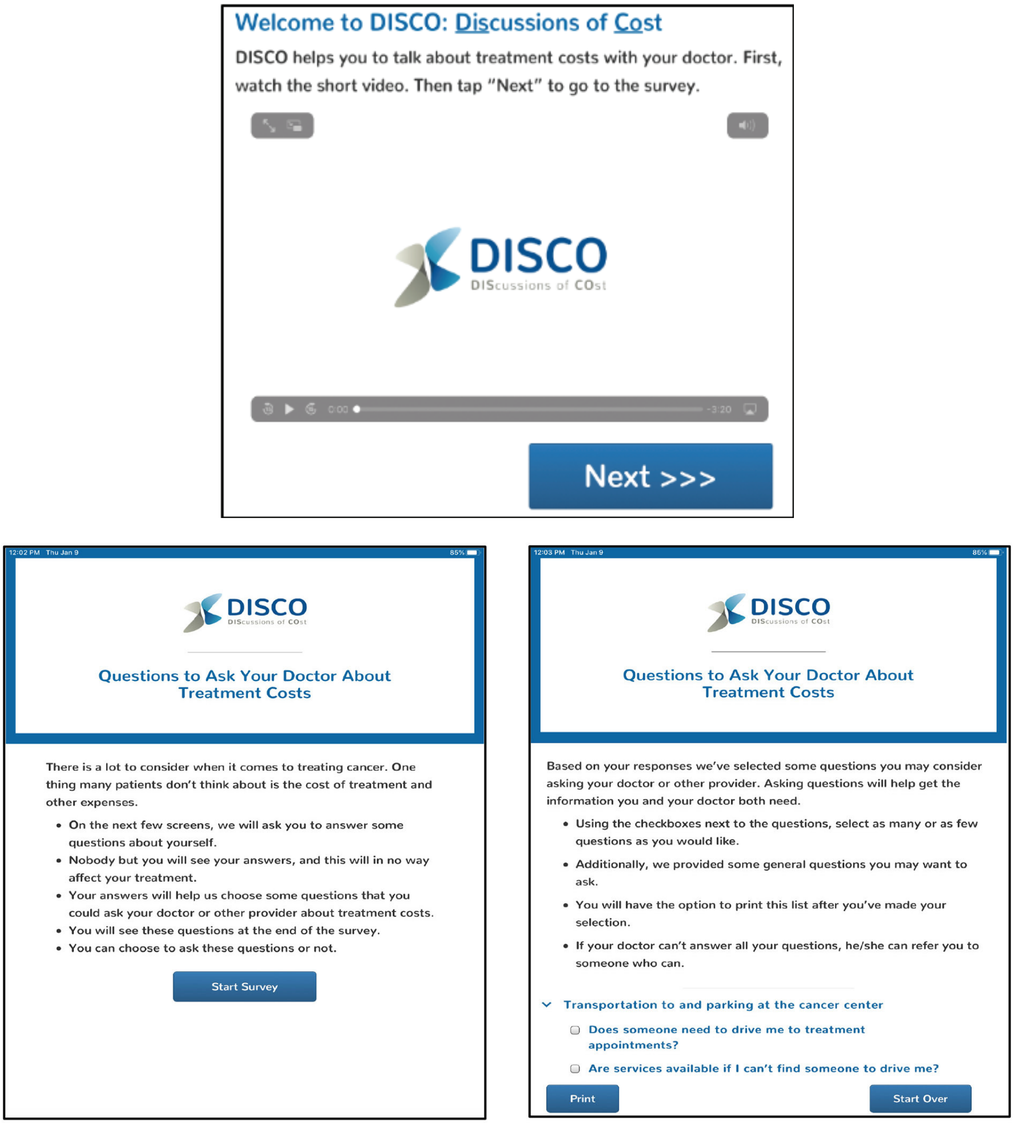
web-based treatment cost discussion training module for clinicians, such as physicians, nurses, social workers, and other advanced practice providers. Although physicians are the primary source of treatment information, nurses, social workers, and advanced practice providers all need to be prepared to discuss costs because they are also important sources of information for patients. Most patients (80 percent) want to start cost discussions with their physicians, but most (74 percent) are also amenable to discussing costs with other providers subsequently.[44,45,65] Optimally, a cost discussion with a physician could prompt a referral to another provider who may be better positioned to assist.[2,41,69,70,43] The physician would be aware of patients' cost concerns, could provide an initial response, and could adapt treatment plans, if possible, while allowing other members of the cancer care team to provide direct assistance. Therefore, this module focuses on preparing the healthcare team to give timely, accurate, and useful information to their patients with cancer.

More improvements include developing the DISCO App for non-English-speaking patients. In Detroit, where the app is being tested, more than 10 percent of the population of the city primarily speaks a language other than English. Thus, it is imperative that we adapt the app for other languages.[71]

Another opportunity lies in the integration of the DISCO App into the EHR. This integration would allow providers to document when they discuss treatment-related cost issues with their patients and perhaps provide a foundation for a real-time method of connecting patients with available resources through the cancer center or other associated organizations or groups. Additionally, EHR integration may help facilitate matching cost topics to specific treatments that patients may receive, because physicians enter specific treatment plans for the patient into the EHR. As patient-reported outcomes become more standardized, the DISCO App could be incorporated directly into this type of reporting for new patients with cancer and also potentially be integrated with individual insurance plans. OI

Figure 2. DISCO App Educational Video and Question Prompt List Introduction Screens



Welcome to DISCO: Discussions of Cost

DISCO helps you to talk about treatment costs with your doctor. First, watch the short video. Then tap "Next" to go to the survey.

Questions to Ask Your Doctor About Treatment Costs

There is a lot to consider when it comes to treating cancer. One thing many patients don't think about is the cost of treatment and other expenses.

- On the next few screens, we will ask you to answer some questions about yourself.
- Nobody but you will see your answers, and this will in no way affect your treatment.
- Your answers will help us choose some questions that you could ask your doctor or other provider about treatment costs.
- You will see these questions at the end of the survey.
- You can choose to ask these questions or not.

Questions to Ask Your Doctor About Treatment Costs

Based on your responses we've selected some questions you may consider asking your doctor or other provider. Asking questions will help get the information you and your doctor both need.

- Using the checkboxes next to the questions, select as many or as few questions as you would like.
- Additionally, we provided some general questions you may want to ask.
- You will have the option to print this list after you've made your selection.
- If your doctor can't answer all your questions, he/she can refer you to someone who can.

Transportation to and parking at the cancer center

☐ Does someone need to drive me to treatment appointments?

☐ Are services available if I can't find someone to drive me?

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Implementing an e-Advisory Council in the COVID-19 Era

BY JULIE BULGER

Winston Churchill famously remarked, "To improve is to change, so to be perfect is to have changed often." If this is true, we all must have evolved into a state of "perfection" over these past two years, right? Though I am not actually suggesting perfection, collectively we all seem to have found new and different ways to adapt to significant, unexpected change.

Let me set the stage. I am manager of Patient and Family-Centered Care at Vanderbilt-Ingram Cancer Center, one of 51 nationally recognized National Cancer Institute-designated Comprehensive Cancer Centers. The cancer center is a leader in the prevention, diagnosis, and treatment of cancer. We have a world-renowned team of experts who provide an integrated, personalized, and patient-centered approach to cancer care, including treatment, research, support, education, and community engagement.

Vanderbilt-Ingram Cancer Center believes in a true partnership with our patients. In early 2019 we set a goal to develop and implement a Vanderbilt-Ingram Cancer Center-specific Patient and Family Advisory Council. The larger Vanderbilt University Medical Center boasts three very successful, engaged, and active Patient and Family Advisory Councils that support Vanderbilt University Adult Hospital (1,162 beds), Monroe Carell Jr. Children's Hospital at Vanderbilt (267 beds), and Vanderbilt Behavioral Health Hospital (106 beds).

Julie Bulger

> Having diverse representation is imperative for the [Patient and Family Advisory] Council to inform the cancer center successfully and fully about the experiences and opinions of its patient populations.

Vanderbilt-Ingram Cancer Center is fortunate to have representation on Vanderbilt's Adult Hospital Patient and Family Advisory Council, especially as it relates to speaking up for the needs of our patients receiving inpatient cancer care. But the world of ambulatory care, in which most oncology patients are treated, is unique. Each day we have approximately 700 scheduled patient appointments, including between 30 to 60 new patient visits. (This number reflects patients seen on our main campus and in eight off-site clinic locations.)

Getting Started

With continued plans for cancer institute growth and expansion, it is imperative to include our patients' and their caregivers' voices, fully and consistently. In 2019, we spent six months developing the cancer center's Patient and Family Advisory Council, including:

- Researching best practices at other academic medical centers
- Identifying and engaging key stakeholders
- Defining the role of the "Advisor"
- Developing onboarding and orientation materials
- Creating a strategic direction, including how to operationalize the meetings
- Collaborating internally to ensure our council aligned with Vanderbilt University Medical Center's mission and other advisory councils.

We wanted to ensure that Vanderbilt-Ingram Cancer Center's newly formed Patient and Family Advisory Council truly reflected the diverse group of patients and families we serve. Having diverse representation is imperative for the Council to inform the cancer center successfully and fully about the experiences and opinions of its patient populations. Thus, we looked at how to include disease-specific diversity, experiences of those receiving different treatment modalities, offsite vs. on-campus care, rural vs. urban care, and patients receiving care via telemedicine, as well as diversity in age, race, sexual preference, education, and socioeconomic status.

We eagerly disseminated our Patient and Family Advisory Council *Call for Nominations* in November 2019. We engaged our faculty for help as they know their patients best. Providers generously responded with nominations for strong candidates; however, unfortunately, the nominees all represented the same demographic and did not offer the diversity needed. All agreed that we needed to re-evaluate and then re-implement a more targeted recruitment strategy. The plan was to launch the new recruitment effort on March 10, 2020.

Going Virtual

Like the rest of the world, when the COVID-19 public health emergency heightened, everyone's priorities shifted. Our March 2020 meeting was postponed, but our team believed strongly that the initiative was too vital to lose momentum. We soon convened and decided that if meeting in person was not possible, we would figure out a way for the Patient and Family Advisory Council to meet "virtually."

Looking back, I am amazed at how quickly we pivoted. By the end of March 2020, we partnered with the Vanderbilt University Medical Center's Director of Patient Engagement, Terrell Smith, MSN, RN. She generously offered us an opportunity to tap into the medical center's enterprise-wide Advise Vanderbilt platform at no cost to the cancer center. Launched in 2016, the online Advise Vanderbilt platform helps Vanderbilt University Medical Center leadership improve patient satisfaction and patient and family engagement in care, while making it easier to participate as patient and/or family advisors through the option of responding to targeted survey questions. Most important, Advise Vanderbilt is popular with patients and families and offers data-driven, dynamic customer insights.

In the first cancer center-specific Advise Vanderbilt outreach, we asked three simple questions:

1. Have you or a loved one received care at the Vanderbilt-Ingram Cancer Center in the past two years? (This was followed by a brief description of the mission and goals of the virtual Patient and Family Advisory Council.)
2. Would you be interested in learning more about this opportunity?
3. If so, would you be comfortable sharing your contact information?

Almost immediately we received more than 700 responses. Interested respondents were sent a more detailed survey that asked about their personal experience and collected demographic information. And by the end of April 2020, the Vanderbilt-Ingram Cancer Center's e-Advisory Council was born!

Fast Forward 18 Months

Vanderbilt-Ingram Cancer Center currently has 274 actively engaged and quite candid e-Advisors. As of October 2020, we have initiated 10 surveys. With all but one survey, we have achieved a 50 percent or higher response rate. Through our e-Advisory Council, we are privy to the thoughts, opinions, and stories of our patients and their families—in real time. To date, we have focused our surveys to specifically contribute to the quality, safety, satisfaction, and experience of our patients and their families and loved ones. And though there are many measures of success, to me the most valuable is the diversity in representation that having a virtual advisory council has brought. Because this is Vanderbilt-Ingram Cancer Center's inaugural Patient and Family

Advisory Council, we cannot "look back" to compare diversity among participants. However, from an initial voluntary set of questions, we were able to track diversity in age, education, gender, LGBTQ identities, type of insurance, languages spoken at home, home ZIP code, and race/ethnicity. It is validating to know we have representation in each of these areas and that, where we are lacking, for example, in representation from Hispanic males, we can work to encourage involvement.

So, what have we learned? First and foremost: Patients and families love to share their opinions! It helps them feel engaged and like a partner in their healthcare decisions. It is vital to share results with Council members so that they can see the impact of their participation. Patients have stopped in our Patient and Family Resource Center and introduced themselves as one of our "Patient Advisors." They are proud to contribute their insights and perspective. Through their participation, advisors are empowered to use their experience with cancer to drive positive change by sharing their thoughts and experiences to help Vanderbilt-Ingram Cancer Center with continuous improvement.

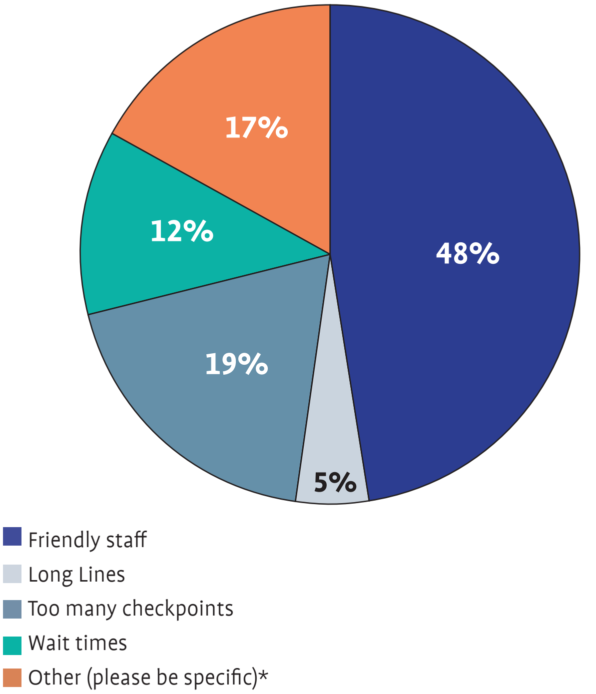
Second, our patients' voices matter. We cannot claim to be "patient-centered" without an avenue in which to engage in active dialogue with those we serve. We always say, no decisions should be made "about me, without me." Vanderbilt-Ingram Cancer Center administration appreciates having data to support the need for change, improved service, or, in our case, a large renovation project. For example, we heard from patients that they would prefer more privacy when they are checking out, along with a place to sit down. In response, we renovated two offices in the clinic specifically to provide patients with a more comfortable place to schedule next appointments, scans, treatments, etc. As our larger renovation projects near, we will both revisit patient suggestions and create a survey with more specific questions related to those plans.

Third, it is critical to find champions throughout the institution, as well as the department, to fully utilize the e-Advisory Council. At Vanderbilt-Ingram Cancer Center, Laura Goff, MD, executive medical director, and Karline Peal, MBA, associate operating officer, approve and support all e-surveys. Results are communicated back, and recommendations are made for additional internal leaders to share. Partnering with champions in operations, outreach, marketing, safety, and clinical leadership is imperative. Peal shares that "the Vanderbilt-Ingram Cancer Center e-Advisory Council has been a great asset to us. During the time we can't bring people together, we have certainly used the direct feedback received via these surveys to drive some very real and positive changes around the cancer center."

So, what have we accomplished?

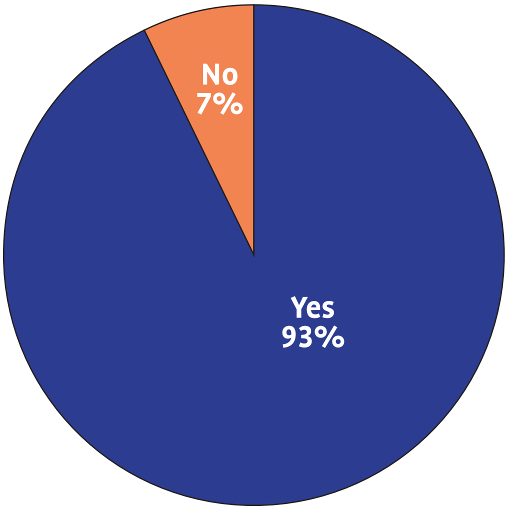
- We improved registration check-in efficiency by removing one entire step. Patients are now greeted and checked-in with a Patient Service Specialist immediately (not stopping and waiting for a greeter), which has eliminated long lines.
- Many patients voiced the registration area felt like a "fishbowl" and disliked the exposed feeling. The glass has now been frosted and allows for a more private waiting experience.

Figure 1. "You've just arrived. What is the one thing that strikes you about our check-in process?"



*Examples: "I always hope I get one of my favorites who knows my name"; "Lab process is not as efficient as other areas"; "Staff always seem very busy but still take time to make me feel like a person"; and "Check-in is always stressful—I equate it with airport security. I can breathe once I'm past it."

Figure 2. If we developed an electronic version or a mobile app to check in at registration, would you utilize it?



- After feedback from the e-Advisory Council, we increased the use of text messaging to notify patients of their appointment time.
- A new lab workflow was developed and implemented to decrease wait times.
- We increased communication to patients and families regarding available support services via an electronic "opt-in" newsletter.
- We piloted digital screens in our waiting rooms. These screens will include cancer-specific content (i.e., resources for support in financial assistance, lodging options, nutrition, mental health, tobacco cessation programs, as well as clinical trial outreach and options).

Our e-Advisory Council is a gift that keeps giving. These engaged members are available to offer real-time feedback to questions like:

- You've just arrived. What is the one thing that strikes you about our check-in process? (Figure 1, page 35).
- If we developed an electronic version or a mobile app to check in at registration, would you utilize it? (Figure 2, page 35).
- In the waiting room, would you prefer these amenities? Select one (Figure 3, below).
- What types of virtual events would you attend? (Figure 4, below).

In the words of Vanderbilt-Ingram Cancer Center e-Advisory Council Member Myra Curry, "The pandemic has brought so much uncertainty and fear into patients' lives. I feel as though offering a meaningful 'seat at the table,' albeit virtually, has given patients an increased sense of empowerment and value." Although Vanderbilt-Ingram Cancer Center looks forward to the return of an in-person Patient and Family Advisory Council, the popularity and success of the e-Advisory Council makes it likely that both formats for listening to the patients' voice are here to stay. OI

Julie Bulger is manager, Patient- and Family-Centered Care, Vanderbilt-Ingram Cancer Center, Nashville, Tenn.

Figure 3. In the waiting room, would you prefer these amenities? Select one.

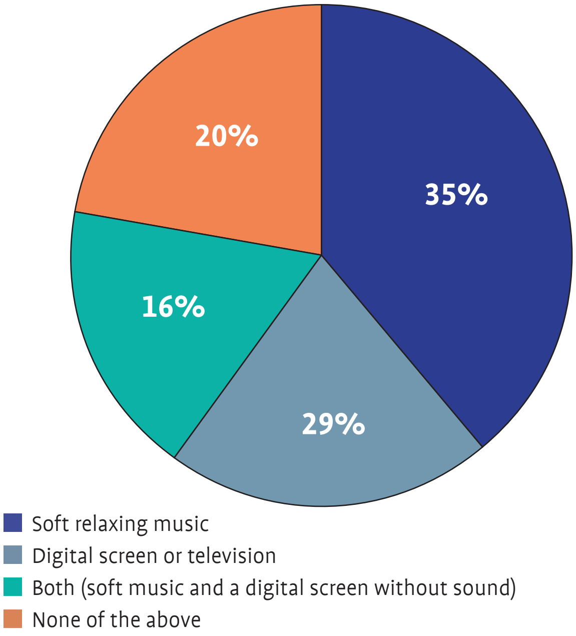
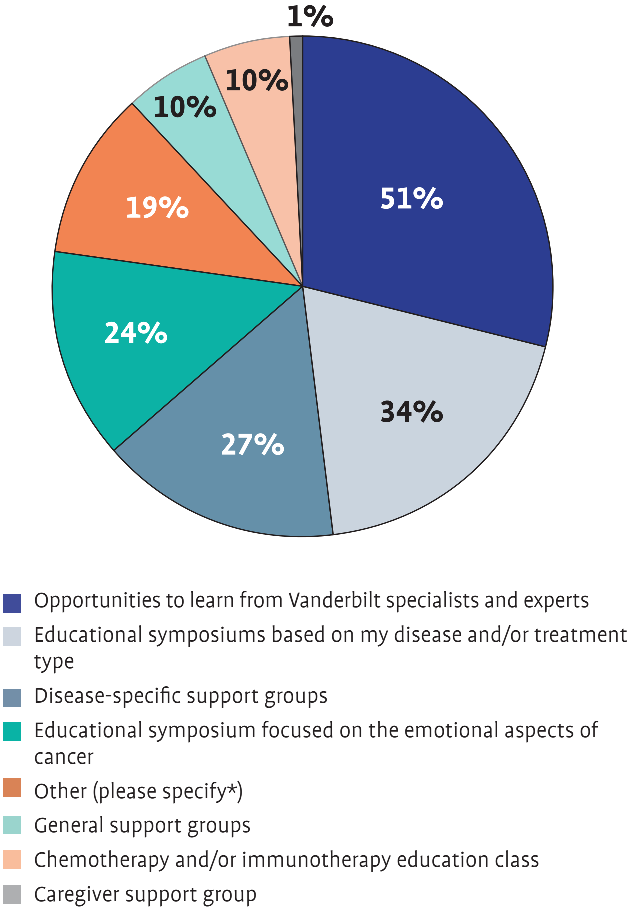


Figure 4. What types of virtual events would you attend?



*Examples: "Long-term effects/survivorship"; "Mental health—how to connect with a therapist who understands being diagnosed with cancer"; and "Advances in cancer research—immunotherapy and oral chemo."

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Funding and support provided by Lilly Oncology.

Development of a Virtual Integrative Oncology Center

BY ALISSA HUSTON, MD

Integrative oncology is defined as "a patient-centered, evidence-informed field of comprehensive cancer care that uses lifestyle modifications, mind-body practice, and natural products from different traditions alongside conventional cancer treatments."[1] It differs from alternative medicine, which the National Cancer Institute (NCI) defines as treatments that are used instead of standard treatments.[2] A 2017 publication by Lopez et al. reported a 30 percent to 60 percent use of at least one integrative oncology-based intervention, such as meditation, yoga, acupuncture, massage, exercise, and nutrition and natural products, among patients with cancer.[3] Despite its growing use, in many instances, patients use complementary health approaches without the guidance or knowledge of their medical providers. This underscores the importance of efforts to make integrative oncology resources more widely accessible to patients, particularly those undergoing cancer treatment, under the supervision of trained providers in a complementary and coordinated approach.

Research surrounding the use of integrative oncology-based modalities for symptom management and quality of life has continued to expand. This has led to the creation of a series of clinical practice guidelines (based upon a systematic review of the literature), as part of a collaborative effort between the Society for Integrative Oncology (SIO) and the American Society of Clinical Oncology (ASCO). One example is the SIO-ASCO Breast Cancer Guideline, published in 2018, which reviews integrative oncology-based modalities and the levels of evidence supporting their recommendation. This ranges from Grade A evidence, such as meditation for reducing anxiety and depression/mood disturbance, to those with limited to no evidence.[4] SIO-ASCO have announced ongoing collaborations for three additional guidelines including: cancer-related pain management, fatigue in cancer survivors, and care of anxiety and depressive symptoms experienced by those with cancer. These guidelines will provide an ongoing evidence-based resource for providers to make informed recommendations on the incorporation of integrative oncology modalities into cancer care.[5]

> Despite this growing evidence and the standardization of integrative oncology recommendations with the more widespread inclusion in guideline recommendations, there remain ongoing barriers to access of integrative oncology resources by cancer patients.

At a national level, there has been significant growth in the area of integrative oncology. A web-based search of the 71 NCI-designated cancer centers identified that at least 22 have current integrative oncology programs. A study from Memorial Sloan Kettering Cancer Center in 2017 cited a 30 percent growth in integrative oncology modalities at NCI-designated cancer centers from 2009 to 2016, and currently 6 out of 12 supportive care National Comprehensive Cancer Network (NCCN) Guidelines® include integrative oncology modalities as part of their recommendations.[6] Additionally, over 60 percent of NCI-designated cancer centers not only offer integrative oncology information and specific services, but provide physician consultation visits in integrative medicine.[7]

Despite this growing evidence and the standardization of integrative oncology recommendations with the more widespread inclusion in guideline recommendations, there remain ongoing barriers to access of integrative oncology resources by patients with cancer. Generally, these services are not reimbursed by payers, leading to financial constraints due to significant out-of-pocket expense thus creating a financial barrier. In regions where integrative oncology-based services are available, there may be additional limitations related to access to providers that have specialized oncology training. Patients living in more remote regions must often travel a significant distance to larger academic institutions offering integrative oncology-based care.

COVID-19 and the Shift to Telehealth

The COVID-19 global pandemic saw a shift in the delivery of healthcare with more widespread adoption of telehealth services. This change was experienced throughout much of the medical community, resulting in the widespread development of virtual services and programs for patients. With this rapid response, academic medical centers determined that high-quality care could be delivered via telehealth. With video consultation appointments, individual assessments could be enhanced by seeing patients as they functioned among family within their own home environment and family. In addition, support persons living outside of a patient's state could now participate in follow-up visits and shared decision making.

With the shift of clinical care to a telemedicine-based format, integrative oncology centers also faced the same hurdle. As the common integrative oncology-based modalities are often dependent on face-to-face or touch interactions between patients and providers, this posed a challenge for most integrative oncology centers. The integrative oncology team at the Leonard P. Zakim Center for Integrative Therapies and Healthy Living at the Dana-Farber Cancer Institute recently published their experience during the COVID-19 pandemic. This experienced team concluded that virtual integrative oncology-based interventions were feasible to deliver to patients and detailed how ongoing research projects were converted into virtual recruitment and delivery formats, resulting in an increase in patient enrollment.[8]

Our Experience

The Pluta Integrative Oncology & Wellness Center is part of the University of Rochester Medical Center, Wilmot Cancer Institute. Our center is the first of its kind in the Western New York Region, with a mission to provide compassionate, evidence-based, and symptom-directed care to patients with cancer—both during and beyond treatment. The center was established in 2018 and focuses on four core pillars: movement, touch, nutrition, and mindfulness. Our leadership team consists of two co-medical directors and a program manager. Services include:

- Acupuncture
- Massage
- Meditation
- Nutrition, such as cooking for wellness classes and chef demonstrations
- Integrative oncology medical consults.

Additionally, we have group classes, like yoga, qi gong, tai chi, ReNEW (Recharge, Revive, Relax, Nutrition, Exercise, and Wellness Program for cancer survivors), art therapy, and an integrative oncology lecture series. All classes are available to patients and their care partners. We are unique in our care delivery in that our providers have received oncology-specific training, providing a level of understanding and care that sets our center and services apart from the local community.

The COVID-19 pandemic initially resulted in a complete suspension of services at the Pluta Integrative Oncology & Wellness Center. However, to minimize patient exposure and risk of possible infection, and to protect those receiving active chemotherapy treatments, telehealth visits—both telephone and video—rapidly became a significant part of how the Wilmot Cancer Institute provided care to patients. Soon our integrative oncology team was assessing how integrative oncology-based services could be delivered via telehealth.

Our Virtual Transition

Within a week of COVID-19 being declared a public health emergency, and the subsequent halt to our integrative oncology program, our leadership team met to strategize ways to continue to support our patients as they navigated their cancer journey. In addition to feeling a lack of control over their cancer diagnosis and treatment, our patients were now dealing with the added stress of COVID-19. Support persons were no longer allowed at follow-up or treatment visits, and patients were feeling alone and isolated without their circle of support. Our initial approach was to create a video library of resources for patients, reflective of our four core modalities. Our integrative oncology providers taped home-based yoga sessions, cooking demonstrations with items one might already have in the home, brief exercise interventions, and meditation exercises. We posted these videos on our website and on social media platforms, including Facebook. At this time, our program manager developed and emailed to patients a series of Pluta Integrative Oncology & Wellness Center newsletters that focused on our integrative oncology pillars (i.e., eating the rainbow, yoga video, etc.). A total of 29 newsletters were sent out during the COVID-19 shut down; these are currently archived on our Virtual Integrative Oncology Center website. (urmc.rochester.edu/cancer-institute/patientscaregivers/wellness/integrative-care/virtual_ioc_covid19.aspx).

After positive response to our online videos, we evaluated each of our core programs as to the feasibility of offering them in a live Zoom session. We ultimately transitioned our entire in-person calendar of events to a fully virtual setting, using the same flow of patients registering in advance for a class and then subsequently receiving a private Zoom link. These virtual sessions included yoga, meditation, and cooking for wellness demonstrations. As telehealth consultations grew, we began offering virtual integrative oncology consultation visits with our program manager and our co-medical directors.

Our ReNEW program, which involves individual exercise assessments, was another area of focus for virtual transition. Our exercise physiologist began performing virtual patient assessments live on Zoom and then developed a home-based exercise intervention plan for patients. When the summer months allowed for outside gatherings in a socially distanced manner, our team began to offer outdoor classes in-person.

Our art therapy program had launched a year prior to the COVID-19 pandemic, and it provided a unique challenge to our team. As we learned more about virtual delivery of services, in early 2021, our art therapist created an online program focused on projects and materials that patients would likely have available to them at home. She created online instructions for projects, including a detailed list of supplies. Throughout the COVID-19 pandemic, our art therapist also provided visual journaling prompts to help patients focus on coping, gratitude, and mindfulness. This was an excellent way for patients to record their personal experiences and feelings with cancer and the global pandemic.

Beyond the conversion of live classes to a virtual, Zoom-based format, our team adapted touch modalities to self-interventions; for example, the use of acupressure in place of acupuncture to target specific symptoms. Acupressure uses the same principles as traditional acupuncture, with administration of pressure by fingers, thumbs, or a device.[9] Our two acupuncturists created acupressure videos for neuropathy related to chemotherapy and for relaxation and stress management.

Table 1, page 42, is an overview of the integrative oncology services developed during our virtual transition. Since initiation of the Virtual Integrative Oncology Center, we have had more than 25,092 total visits on our YouTube video library. In our virtual format, our team was seeing more than 300 patients per month within the core modalities offered. An overview of our video library, as created under each of the four core pillars, is detailed in Figure 1, page 43.

In recognition that health and wellness are important not only for our patients, but also for the staff that tirelessly provides care to patients, our virtual transition provided much-needed support to our staff. All Wilmot Cancer Institute providers have access to our virtual integrative oncology offerings, allowing staff and clinicians to access the tools and resources needed to improve their overall health and wellness. We also created specific tools for staff that our team sent out during the second COVID-19 surge, which aligned with our four core pillars of movement, touch, nutrition, and mindfulness.

Prehabilitation

At the time of their initial diagnosis, many patients with cancer frequently do not meet standard guidelines in the areas of exercise and nutrition as put forth by the American Cancer Society. In response, many cancer programs now offer "prehabilitation" for patients at the time of diagnosis. Prehabilitation is defined as "a process on the continuum of care that occurs between the time of cancer diagnosis and the beginning of acute treatment; it includes physical and psychological assessments that establish a baseline functional level, identifies impairments, and provides targeted interventions that improve a patient's health to reduce the incidence and severity of current and future impairments."[10] This critical time between diagnosis and initiation of surgical treatment creates the opportunity to establish a baseline functional and nutritional status and identify areas of improvement, under the guidance of a nutritionist and exercise physiologist. Because many patients with cancer receive neoadjuvant chemotherapy prior to definitive surgery or have a several-week window of time before surgery is scheduled, prehabilitation can provide potential benefits to this subset of patients. Nutrition and movement (exercise) remain two important pillars at the Pluta Integrative Oncology & Wellness Center. Prehabilitation represents a unique opportunity to intervene with patients at the time of their cancer diagnosis with the goals of decreasing treatment-related morbidity, increasing cancer treatment options, and improving the physical and psychological health outcomes and general quality of life as patients embark on their treatment.

Prior to COVID-19, our center had been building the concept of a prehabilitation program. The pandemic allowed us to reinvent this program in a virtual format, based on our positive experience with our movement and nutrition programs. We transitioned our in-person concept to a virtual prehabilitation program for patients with cancer. Our prehab team started by overhauling our intake forms to best capture a patient's current functional status and nutritional needs. The 90-minute virtual visit is broken down into three 30-minute consultations with one

Pluta Integrative Oncology Team. Team represents all four of the integrative oncology core pillars of movement, touch, nutrition, and mindfulness, along with our art therapist, program manager, and co-medical directors of the center. (Photo taken prior to the COVID-19 pandemic.) *Source:* University of Rochester.

Table 1. Select Components of Our Virtual Integrative Oncology Center

13 Live Zoom classes a week
35 YouTube videos created by staff on the four core pillars: movement, touch, nutrition, and mindfulness
2 virtual cooking/nutrition programs each month • Launched *Nutrition During Chemo* (a two-part series showing how to use food to help manage the symptoms of chemotherapy, which is used at all Wilmot Cancer Institute clinics) • Launched *Virtual Knife Skills for Plant-Based Cooking* • Hosted virtual guest chef experiences—one with a nationally renowned plant-based chef and one with a local executive director of a cancer support organization.
Hosted a virtual *Celebrate the Journey* for 74 patients with cancer, focusing on integrative oncology modalities to improve quality of life.
Limited number of telehealth integrative oncology consultations.

of the integrative oncology co-medical directors, an exercise physiologist, and a nutritionist. This includes a baseline comprehensive assessment administered as part of the initial intake visit with subsequent individualized recommendations and two-week follow-up assessments to measure and track response to the interventions over an eight-week time frame. The initial intake has continued as a virtual option for patient convenience, with in-person exercises and nutrition assessment to follow. The prehabilitation program has been an important component of our virtual integrative oncology platform and has continued in its virtual format and overall growth.

Regional Expansion

Wilmot Cancer Institute encompasses a 27-county region within western and central New York that includes the Finger Lakes, Southern Tier, Central, and Mohawk Valley regions. This catchment area services 3 million people within 27 counties (see Figure 2, page 44). Within this region, 26 counties have a higher poverty level than the U.S. average, and the catchment area, as a whole, has higher rates of cancer than other regions. Specific disparities also exist within our regional clinics, including tobacco use, physical activity, and obesity.

Because integrative oncology providers are often located within larger urban locations and there can be substantial costs associated with the use of specific integrative oncology-based interventions (i.e., acupuncture, massage, exercise, or yoga), there remain significant barriers to accessing these services. Additionally, education about the benefits of integrative oncology-based modalities—including how they can alleviate symptoms during treatment—is important and is not always widely available in more rural communities. The growth of our virtual integrative oncology center has provided an opportunity to expand our services on a broader level throughout our regional cancer clinics, removing barriers by providing virtual access to integrative oncology-based providers and classes. The ability to provide virtual integrative oncology consultation visits and Zoom-based classes also eliminates a financial barrier for patients. Studying regional disparities has highlighted areas, such as physical activity and obesity, for which virtual integrative oncology-based interventions can provide a significant impact. Expanding education through community outreach further helps by improving communication and understanding of how integrative oncology modalities can help patients improve their overall health and wellness and minimize symptoms throughout their cancer treatment.

Future Directions

As with so many in clinical practice, the transition to virtual care during the COVID-19 pandemic brought much uncertainty. How would patients respond to telehealth assessments or group Zoom classes? What would the level of provider and patient engagement be like? What we found: patients not only embraced the pivot to virtual care, but telehealth has allowed our patients more widespread access to integrative oncology modalities.

Future expansion of our virtual program involves a better understanding of the specific needs and barriers of the use of integrative oncology modalities by our patients. We will do so through an ongoing study assessing perceptions of and access to integrative oncology modalities within our regional clinic locations. Data from this study will enhance how we deliver our virtual integrative oncology care. Prior work assessing the use of complementary therapies among rural adults without cancer demonstrated that use is common; although, most patients sought care without the knowledge of their medical provider.[11] A virtual platform provides a mechanism for telehealth consultation visits with an integrative oncology-trained provider to guide and recommend appropriate use of integrative oncology-based modalities.

(Continued on page 45)

Figure 1. Virtual Teaching Video Library by Core Modality

MOVEMENT

Exercise during and after treatment can help manage symptoms of nausea, fatigue, depression, and muscle wasting, and it boosts cognitive function.

YOGA
- Beginning yoga tools using breath and tuning into your body
- Yoga in the outdoors, side stretches, warrior, and pyramid flows
- Outdoor yoga meditation
- Standing poses, arm punches, leg slapping, and mountain pose
- Seated yoga stretches for your neck and back
- Fun yoga moves for the whole family
- Outdoor standing sun salutation
- A message on your at-home integrative practice
- Starting your morning with yoga
- Dealing with a bad day using yoga
- Handout yoga tools

TAI CHI/QI GONG
- Introduction to qi gong, finding your qi, palm qi, and relieving knee stress
- Getting the qi moving and whole-body qi slapping
- Introduction to tai chi moves in small spaces
- Ancient tai chi to expand the lungs
- Cloud hands part 1 for flexible hips and shoulders and to strengthen qi

TOUCH

Therapeutic touch may help decrease symptoms, such as pain, fatigue, and nausea, in patients with cancer.

- Acupressure: stomach 36, dan tian (body power station), and back points
- Acupressure for chemotherapy induced peripheral neuropathy
- Relaxation and stress relief through acupressure in the foot

NUTRITION

Healthy eating habits and support from a registered oncology dietitian can be helpful in alleviating some of the side effects of cancer treatment.

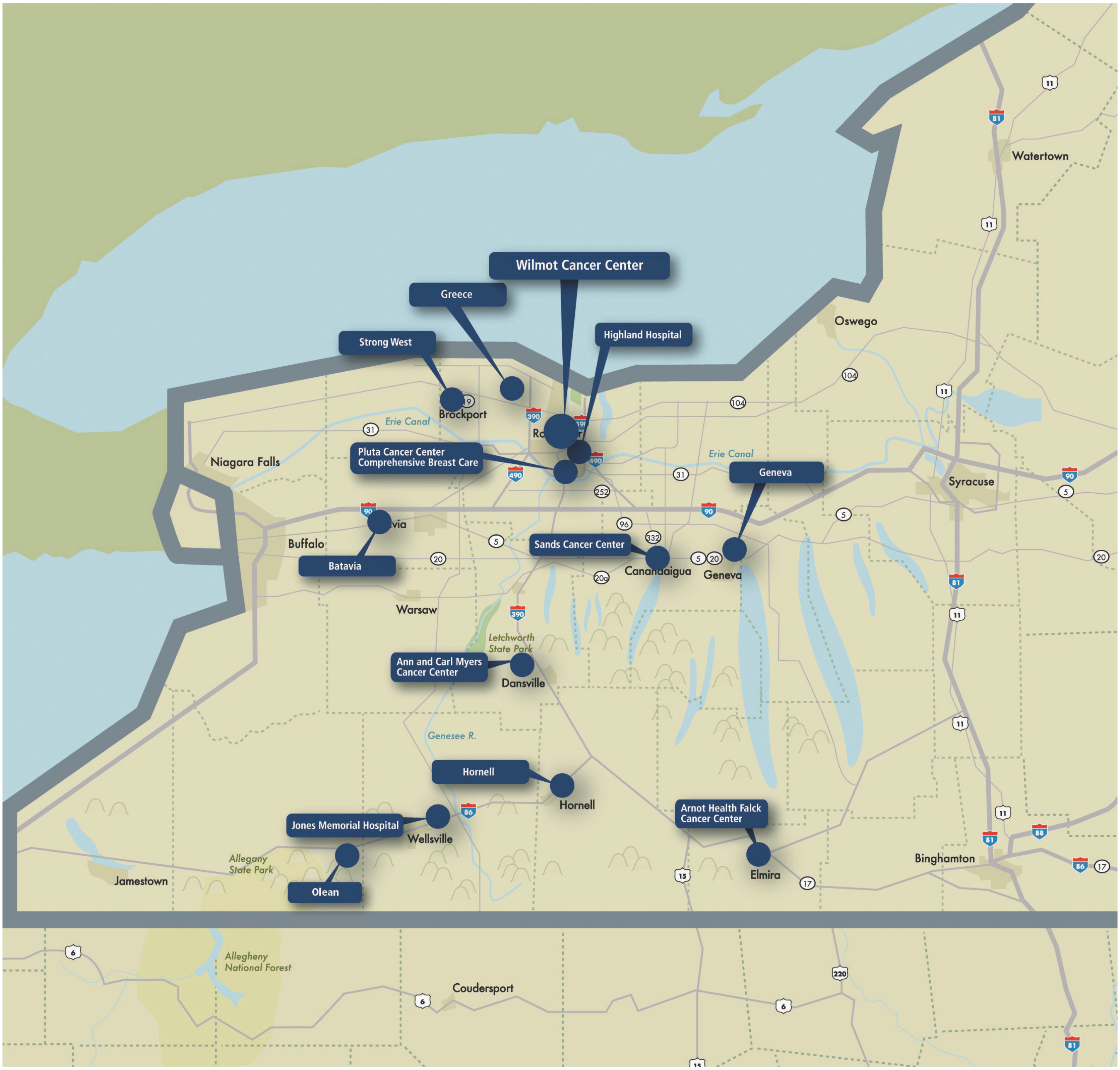
- Chef demo: making homemade granola-like anytime bars
- Chef demo: making sweet potato chili
- Recipe: sweet potato chili
- Chef demo: Mediterranean lentil salad
- Nutrition lecture: nutrition during chemotherapy part 1
- Slide deck handout for nutrition during chemotherapy part 1
- Nutrition lecture: nutrition during chemotherapy part 2
- Slide deck handout for nutrition during chemotherapy part 2
- Video: knife skills for plant-based cooking
- Handout: knife types and cutting techniques
- Find more recipes on our Cooking for Wellness blog
- Handout: smart snacking strategies

MINDFULNESS

Mindfulness refers to being intentionally present in the current moment, without judgment. It involves being aware of where you are and what you are doing.

- Introduction to meditation, five finger meditation, and mantra
- Introduction to mindfulness and focus on the breath
- Alternate nostril breathing meditation to promote calming
- Handout: meditation tools

Figure 2. Wilmot Cancer Institute Regional Clinic Locations



(Continued from page 42)

Other future directions include expansion into a mobile application (app)-based platform, so that patients can navigate the virtual center more easily. An app would also provide real-time use during treatments; for example, using meditation prior to undergoing a re-staging scan or when waiting for a provider in the clinic.

A virtual format also allows the development of research interventions. For example, acupressure is more widely available than acupuncture, because it is a self-based intervention and instruction can be taught virtually. We are developing a trial to understand the impact of an acupressure-based intervention for patients with breast cancer experiencing side effects during treatment. This study has the potential for wider expansion, as the technique is ideal for virtual instruction as it is a self-administered modality. Additionally, we aim to improve education and understanding overall around the benefits of integrative oncology modalities for patients with cancer. Last spring, we hosted a virtual educational seminar for breast cancer survivors focusing on how our four core modalities can help support patients and their overall wellness throughout treatment and beyond. As part of the seminar, a provider from each core modality presented, demonstrating not only the modality itself but also speaking to how that modality could provide ongoing wellness support. We are also developing a virtual training program for staff to learn bedside integrative oncology techniques to use as they care for their patients.

Growing our virtual integrative oncology center will allow us to extend integrative oncology-based modalities to patients with cancer throughout our local community and especially within our regional clinic sites.

Telehealth and the virtual delivery of services represent a huge technological leap forward in the way we support patients with cancer throughout their course of care. The ability to create a fully virtual integrative oncology center allowed us to extend these services at a time when in-person evaluations were limited. A virtual platform has also helped us overcome social and economic barriers facing patients and to increase access to evidence-based, high-quality, and symptom-based interventions under the guidance and direction of trained integrative oncology healthcare providers. This care delivery model remains cost effective in its method of implementation, with the potential to impact more patients over time. OI

Alissa Huston, MD, is an associate professor of medicine and co-medical director at the Pluta Integrative Oncology & Wellness Center, University of Rochester Medical Center, Wilmot Cancer Institute in Rochester, N.Y.

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The Pluta Integrative Oncology & Wellness Center Staff, specifically Judy Zeeman-Golden, LCSW (our first program manager) and Dr. Marilyn Ling (co-medical director), and all of our dedicated staff who provide compassionate care to our patients.

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Leveraging Pharmacy Informatics to Standardize Pharmacists' Review of Oral Oncolytics for Hospitalized Patients

BY MADISON SAXTON, PHARMD; REBECCA KISGEN, PHARMD, BCPS, BCOP; LAURIE LEBOUTILLIER, RPH; AND LISA HYMEL, PHARMD, BCOP, MBA

Over the past decade, advances in oncology practice have led to an increase in the development and U.S. Food and Drug Administration approval of several new, targeted oral oncolytics. Oral oncolytic agents are often thought to be safer than parenteral formulations; however, an error with an oral agent can be equally dangerous as an error with an intravenous agent.[1] In 2012, the Institute for Safe Medication Practices released results from its *Medication Safety Self Assessment for Oncology* survey that focused on the safe management of oral oncolytics.[2] Of the 352 reporting institutions, 311 (88.4 percent) attested to allowing oral oncolytic use at their institution.[2] However, only 153 (43.5 percent) established safety measures for oral oncolytic orders.[2] Lack of safety measures regarding the prescribing, administering, and monitoring of oral oncolytic therapies while patients are hospitalized increases the potential for error and patient harm due to some of the challenges listed in Table 1, page 48. These challenges highlight the need to develop a standardized process to review and monitor the use of oral oncolytics during patient hospitalizations. Unfortunately, there is little literature available to guide the implementation of this process.

> Our teams also used pharmacy informatics to develop a checklist in the form of a structured note in the clinical portion of the EHR to standardize review of a prescribed oral oncolytic medication(s).

Pharmacists as Gatekeepers

In 2018, the Hematology/Oncology Pharmacy Association released its pharmacy practice standards for the management of oral oncolytics.[3] These standards focused on the role of oncology pharmacists on patients' cancer care teams in relation to prescribing, educating, dispensing, distributing, and monitoring oral oncolytics, in addition to conducting follow-ups with patients to improve treatment adherence and side effect management.[3] Literature continues to emerge supporting pharmacist-led oral oncolytic outpatient clinics.[3-5] However, there is minimal literature demonstrating the gatekeeper role that pharmacists can play in ensuring safe medication use during a patient's hospitalization. Hospital-based pharmacists are in an ideal position to collaborate with physicians, nurses, and patients to address the challenges identified in Table 1; ensure order accuracy; and monitor for drug interactions and side effects while patients are admitted.[3]

Table 1. Challenges to Oral Oncolytic Therapy During Hospitalization

Complex regimens	Various dosing schedules, including daily, weekly, and cyclical frequencies
High cost	Non-formulary at most hospitals
Provider unfamiliarity with medications	Prescribing normally limited to oncology providers. Most are not reviewed by hospital medical staff committees as part of formulary review process
Unique side effect profile and monitoring	Each oral oncolytic agent possesses a broad range of unique side effects and specific monitoring parameters
Drug interactions	Pharmacokinetics of these medications lead to a high incidence of potential drug interactions
Transition of care information	Most agents are obtained through a specialty pharmacy, making it difficult to easily obtain a medication history from a local outpatient pharmacy

The Role of Pharmacy Informatics

Sarasota Memorial Hospital, an 839-bed community teaching hospital and Commission on Cancer-accredited institution in Sarasota, Fla., uses a pharmacy specific software module within its electronic health record (EHR) to verify every medication order. This module contains a catalog of medication codes that can be ordered during patients' hospital admissions. These catalog items are built and maintained by the pharmacy informatics team. The pharmacy module then interfaces with the clinical module of the EHR to alert for any potential issues, such as kidney dysfunction or drug-drug interactions. Thus, pharmacy informatics is an important tool that can be leveraged to help clinical inpatient pharmacists ensure the safe use of oral oncolytics during a patient's hospital stay.

Oral Oncolytic Catalog Items

The rate at which oral oncolytics continue to emerge on the market makes it challenging to keep up with the building of all approved medications in the pharmacy system catalog. If a patient is admitted on a medication that does not have a corresponding catalog item, pharmacists must enter the medication via a "free-text" patient's own hazardous medication generic catalog item. Because this is a generic order, the cross-reference to the medication information database in the EHR that provides alerts on drug-drug interactions, contraindications, and duplicate therapy is not available, meaning that a key safety mechanism is bypassed.

In 2019, our pharmacy informatics and oncology pharmacy teams completed a review of approximately 50 patients who were prescribed an oral oncolytic medication during a hospitalization at our institution. We found that most oral oncolytics did not have a corresponding catalog item in the pharmacy system and were, in fact, ordered using the "free-text" patient's own hazardous medication catalog item. After this review, our two teams built all oral oncolytics without a corresponding catalog item into the pharmacy informatics system. To streamline ordering and improve safety, oral oncolytic items were then placed into a specific oral oncolytic order set restricted to pharmacy, which allows an oncology pharmacist to review orders prior to administration to a patient.

Developing a New Workflow

After completing the new catalog items and order sets, our oncology pharmacy and pharmacy informatics teams developed a workflow diagram to standardize the process for oncology pharmacists' review of all oral oncolytics (Figure 1, right). As illustrated in this workflow, once oncologists give the recommendation to continue an oral oncolytic during a hospital admission, an oncology pharmacist is automatically consulted to follow the patient throughout admission.

Oncology Pharmacist Consults

Our teams also used pharmacy informatics to develop a checklist in the form of a structured note in the clinical portion of the EHR to standardize review of a prescribed oral oncolytic medication(s). Oncology pharmacists gather pertinent information, such as a patient's oncology treatment clinic, complete oral oncolytic regimen, side effects, current medications, and laboratory values, as shown in Figure 2, page 50. Pharmacists then complete an assessment based on discussions and communication with the patient, the inpatient attending physician, and the oncologist. If a patient did not have an oncologist consultation during their hospital admission, oncology pharmacists advocated for a medical oncology consult based on patient presentation, drug interactions, and other risk factors that could potentially influence the continuation of the oral oncolytic(s). The completed pharmacy consult structured note is placed in the EHR and contains the information listed above, any pharmacy interventions, and an assessment and plan for the oral oncolytic therapy during the hospitalization. After the initial consult, oncology pharmacists continue to follow the patient daily to review for drug interactions, side effects, and abnormal labs.

Study Design

The next step: evaluation and measurement of the impact of implementing a standardized process for oncology pharmacist review of oral oncolytics ordered during an inpatient admission. Our institutional review board-approved, retrospective, observational study included patients 18 years and older who were admitted to the hospital between January 2020 and May 2020

(Continued on page 51)

Figure 1. Pharmacist Workflow Process for Review of Oral Oncolytics

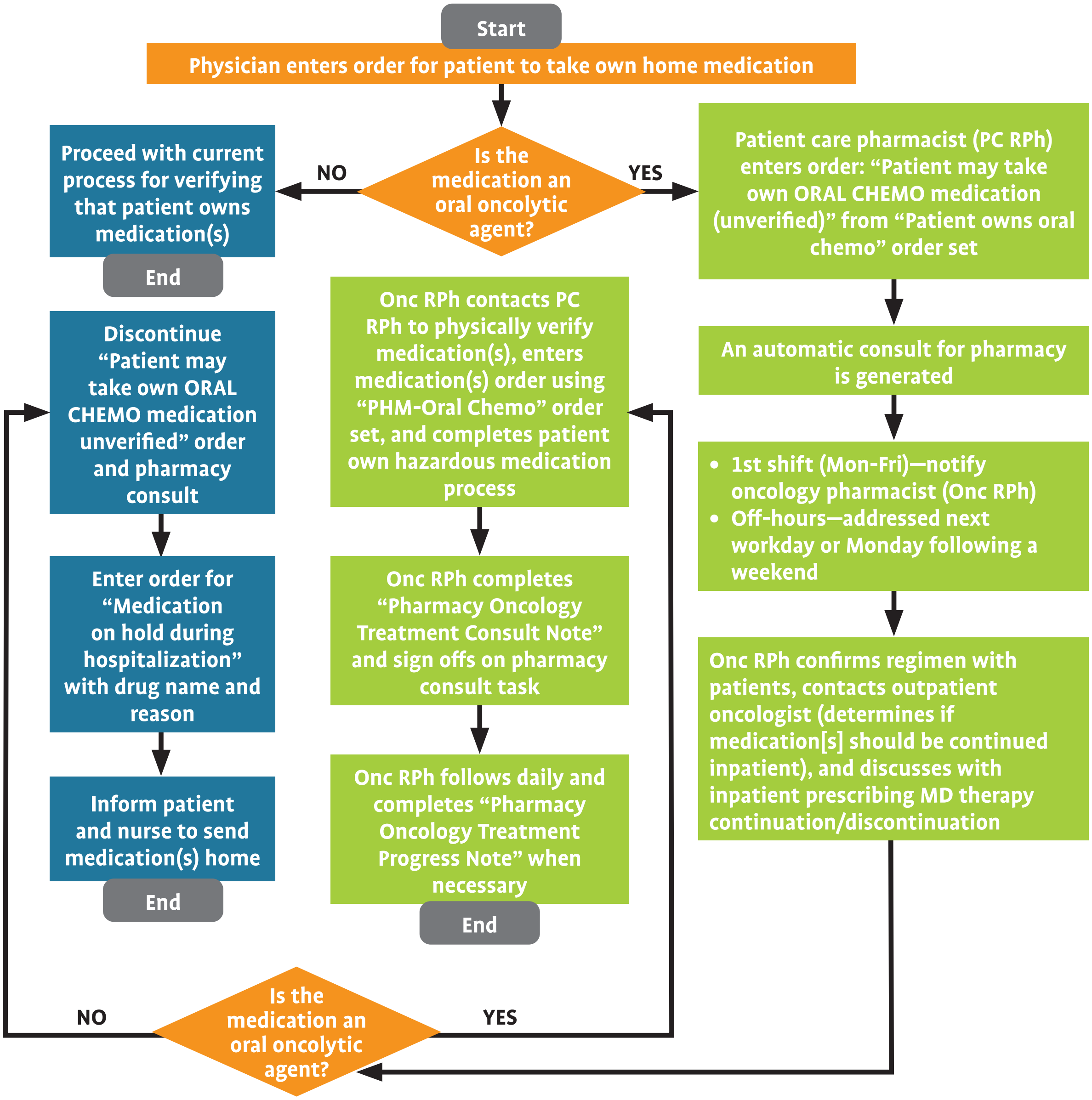
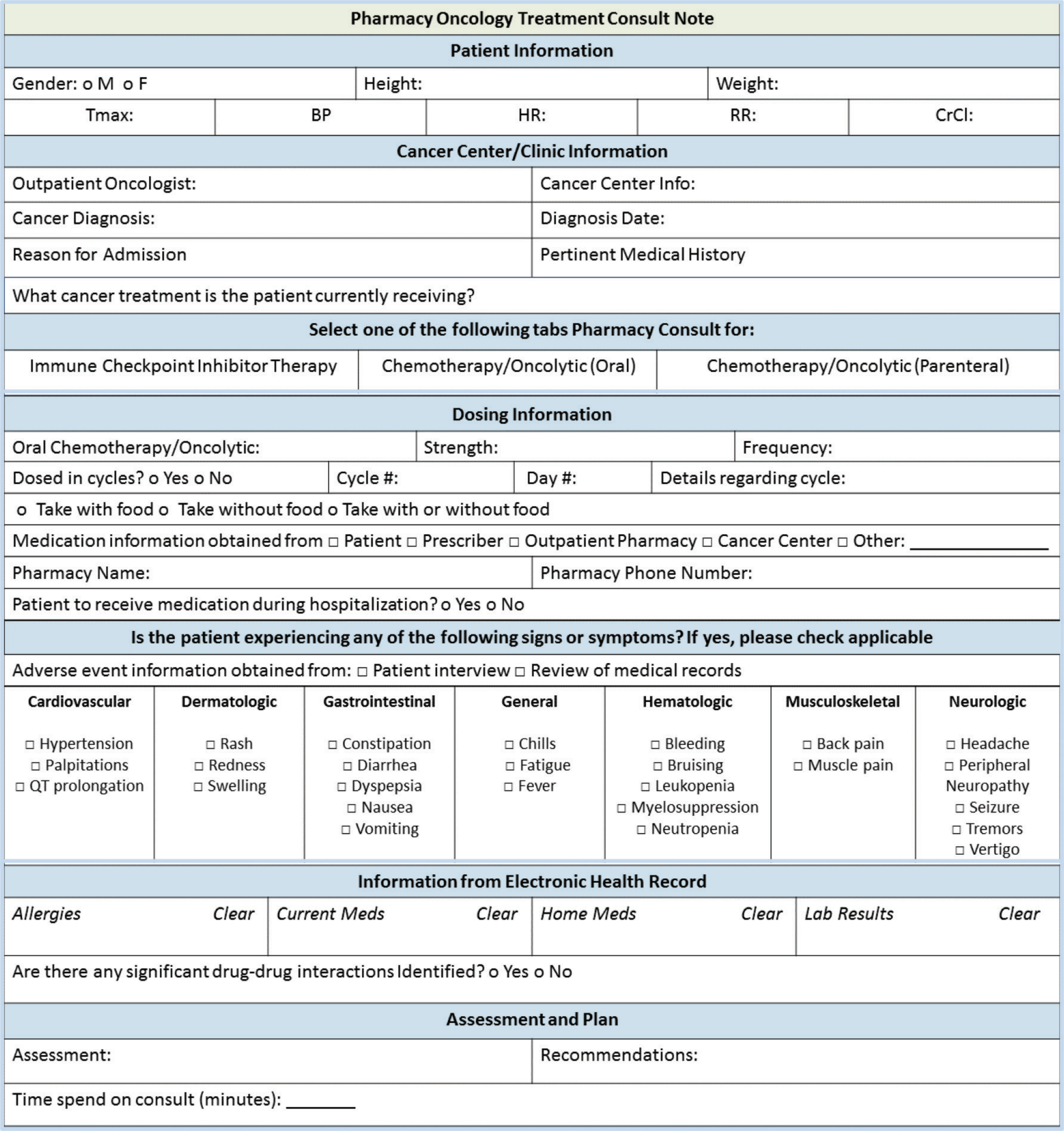


Figure 2. Pharmacy Oncology Treatment Consult Note



Pharmacy Oncology Treatment Consult Note

Patient Information

Gender: ○ M ○ F	Height:	Weight:

Tmax:	BP	HR:	RR:	CrCl:

Cancer Center/Clinic Information

Outpatient Oncologist:	Cancer Center Info:
Cancer Diagnosis:	Diagnosis Date:
Reason for Admission	Pertinent Medical History

What cancer treatment is the patient currently receiving?

Select one of the following tabs Pharmacy Consult for:

Immune Checkpoint Inhibitor Therapy	Chemotherapy/Oncolytic (Oral)	Chemotherapy/Oncolytic (Parenteral)

Dosing Information

Oral Chemotherapy/Oncolytic:	Strength:	Frequency:

Dosed in cycles? ○ Yes ○ No	Cycle #:	Day #:	Details regarding cycle:

○ Take with food ○ Take without food ○ Take with or without food

Medication information obtained from ☐ Patient ☐ Prescriber ☐ Outpatient Pharmacy ☐ Cancer Center ☐ Other: ______________

Pharmacy Name:	Pharmacy Phone Number:

Patient to receive medication during hospitalization? ○ Yes ○ No

Is the patient experiencing any of the following signs or symptoms? If yes, please check applicable

Adverse event information obtained from: ☐ Patient interview ☐ Review of medical records

Cardiovascular	**Dermatologic**	**Gastrointestinal**	**General**	**Hematologic**	**Musculoskeletal**	**Neurologic**
☐ Hypertension ☐ Palpitations ☐ QT prolongation	☐ Rash ☐ Redness ☐ Swelling	☐ Constipation ☐ Diarrhea ☐ Dyspepsia ☐ Nausea ☐ Vomiting	☐ Chills ☐ Fatigue ☐ Fever	☐ Bleeding ☐ Bruising ☐ Leukopenia ☐ Myelosuppression ☐ Neutropenia	☐ Back pain ☐ Muscle pain	☐ Headache ☐ Peripheral Neuropathy ☐ Seizure ☐ Tremors ☐ Vertigo

Information from Electronic Health Record

Allergies *Clear*	*Current Meds* *Clear*	*Home Meds* *Clear*	*Lab Results* *Clear*

Are there any significant drug-drug interactions Identified? ○ Yes ○ No

Assessment and Plan

Assessment:	Recommendations:

Time spend on consult (minutes): _______

Table 2. Types of Pharmacist Interventions

Types of Interventions ($n = 33$)	Percentage of Total Interventions
Therapy held	
Side effects	27.3
Acute illness*	18.1
Patient no longer taking medication	6
Drug interactions	
Major**	9
Minor***	54.5
Clarification of regimen cycle/day	24.2
Obtain oncology consult	15.2

* Examples of acute illness included sepsis, pneumonia, and COVID-19 active infection or rule-out testing.
** Required change in therapy.
*** Required change in monitoring (not recorded as an intervention in primary result).

(Continued from page 48)

nd who had an oral oncolytic order. Patients with oral methotrexate orders were excluded from the study due to the majority of these being used for non-oncology indications; hormone-regulating agents were also excluded. Our primary outcome was the total number of pharmacist interventions that occurred. Our secondary outcomes included the percentage of patients requiring an intervention, the types of interventions performed, the percentage of recommendations accepted, and pharmacists' time spent at an initial consult.

During the study period, 63 patients were admitted to the hospital and there were a total of 66 distinct oral oncolytic orders. Seven of the 66 orders were excluded from analysis because they were not reviewed by a pharmacist due to a patient's discharge or a patient not being able to supply the medication. The final patient population included for analysis consisted of 57 patients and 59 distinct oral oncolytic orders.

Outcomes

The primary endpoint of total pharmacist interventions was 33, with an acceptance rate of 94 percent as a secondary outcome. Fifty-six percent of patients required a pharmacist's intervention and the median time spent in the pharmacy-oncology consult was 45 minutes (±20.4 minutes). The types of interventions that were recommended are included in Table 2, left.

Our study showed that oncology pharmacists made interventions for more than 50 percent of patients with an oral oncolytic order, highlighting the need for identification and close monitoring of these patients. Pharmacists helped bridge the outpatient management of these patients to inpatient by collaborating with the inpatient healthcare team and understanding when to recommend an oncologist consult. Although this process is time-consuming, with a median time of 45 minutes spent on each consult, this patient-centered approach to reviewing every oral oncolytic order proved to be vital during patients' inpatient stays. Seventy-six percent of consults were completed within 24 hours of order entry, even with limited access to oncology pharmacists.

Takeaways

Our study supports the gatekeeper role that pharmacists provide for hospitalized patients, as well as the use of pharmacy informatics to streamline the identification of potential issues for patients on oral oncolytics. Any institution can implement a similar process by using the checklist as a resource when reviewing an oral oncolytic therapy. Implementing a standardized process for the review of oral oncolytics during hospital admissions can lead to improved communication between pharmacists and physicians, patient monitoring, identification of side effects, drug interactions, and clarification of dosing regimens.

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BY VICTORIA R. RENDELL, MD; MELISSA M. RICKER, MD;
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Deconstructing the Meaning of Multidisciplinary Cancer Care

A mixed-method study of patients and providers

Collaborative multidisciplinary cancer care involves multiple specialists who discuss and guide treatment plans together, and this approach is now standard of care for patients with cancer. Whereas initial studies questioned the increased expenses and organizational complexity involved with delivering multidisciplinary cancer care,[1] more recent studies show that effective collaboration of oncology providers impacts treatment recommendations and improves survival for a variety of cancer types.[2-7] Today, cancer programs widely employ the multidisciplinary cancer care process, speaking to the overall positive perception providers have about this model of care.

Though the adoption of multidisciplinary cancer care delivery is high, little is known about which specific structural features most effectively enhance cancer care. Further, the logistics and structure of multidisciplinary cancer care delivery vary significantly by institution and team.[8-10] This variability includes differences in communication models, frequency of interaction, and the nature of decision-making processes, among others.[11]

Although multidisciplinary cancer care is aimed at improving care for patients and families, little is currently known about how this type of care delivery impacts the patient experience. Despite increased focus in recent years on patient satisfaction in healthcare, there remains a significant gap in our understanding of how the multidisciplinary cancer care process impacts patients and families. Few studies have examined patient preferences regarding their initial experiences with multidisciplinary care (i.e., the short time period after receiving a cancer diagnosis).

The Experience at University of Wisconsin Hospitals and Clinics

Over the past few years, the University of Wisconsin Hospitals and Clinics in Madison, Wisc., has been redesigning its clinic structure, including the oncology clinics where multidisciplinary cancer care is provided. As is typical in other institutions, the structure of multidisciplinary teams, the decision-making process employed, and the communication models and processes used vary significantly by cancer type. As part of the conversation regarding the optimal restructuring of these multidisciplinary cancer care clinics, we developed a quality improvement (QI) project focused on understanding how patients view multidisciplinary cancer care. The purpose of our study was to obtain the perspectives—and preferences—of patients and providers on the important structural aspects of multidisciplinary cancer care during the initial phase of care to inform this restructuring. We also looked to uncover any barriers preventing alignment of multidisciplinary cancer care processes with patient preferences. As part of a QI study, an institutional self-certification form was completed, and a formal internal review board analysis was not required. Below we highlight key components of our QI study.

Method: Online Survey

To gain a broad understanding of patients' preferences regarding outpatient cancer care from a national perspective, we surveyed the membership of six virtual national cancer support groups. Survey questions were developed based on the phases of care, including initial diagnosis, first appointment, and follow-up. These questions were formulated from the multidisciplinary discussions that occurred as part of our clinic structure and redesign process and were exploratory in nature. The survey was anonymous, and we solicited voluntary responses. Support group members were asked to specify whether they were a patient with cancer, a survivor, and/or a caregiver, as well as their cancer type. Participants then answered 11 questions regarding their initial cancer diagnosis experience, including the timing of their initial visit(s) with oncology providers, their experience with multidisciplinary teams and nurse navigators, and their preferences. Responses were tabulated and percentages were calculated.

Method: Provider Interviews

To obtain the provider perspective, from June through August 2017, we conducted semi-structured interviews from June through August 2017 with multidisciplinary cancer care providers who had significant experience coordinating the initial care of new patients with cancer at the University of Wisconsin Carbone Cancer Center. We employed the basic principles of qualitative interviewing.[12] Specifically, given that "cancer providers" represent a cultural world within the medical community, we used the lens of ethnographic interviewing for this step. The interview guide was formulated using the question types outlined by Spradley (i.e., descriptive, structural, and contrast questions).[13] We included grand- and mini-tour questions, as well as example and experience questions.[13] The interview topic guide focused on determining provider perceptions of patients' experiences and preferences for multidisciplinary cancer care delivery, as well as understanding providers' experiences with initial multidisciplinary cancer care delivery for new oncology patients.

Method: Patient Focus Group

Our team partnered with a local cancer support organization to obtain the perspectives and experiences of patients with cancer care in our community. After obtaining input from the program director of the cancer support group, we decided that a focus group setting would best allow patients, survivors, and caregivers to discuss their various experiences with the structural aspects of multidisciplinary cancer care. The organization promoted the focus group to its members by posting flyers at their site asking for input to help improve the care of patients with cancer at our institution. The topic guide was designed based on a review of the literature and data previously gathered through the online survey and provider interviews. Our research team reviewed and revised the drafts of the interview guide until a consensus was reached. The focus group topic guide centered on patients' experiences with cancer care, starting at initial diagnosis to after their first multidisciplinary provider visit. A flexible, open-ended, and dually moderated focus group was conducted on-site at the cancer support facility,[14] and no identifying information was collected from participants.

Method: Qualitative Analysis

All interviews and the focus group were audio recorded and transcribed verbatim. Conventional content analysis was used to analyze interview transcripts,[15] and constant comparison analysis was used to analyze the focus group transcript.[16] Two authors (VRR, MMR) coded each transcript independently using line-by-line coding, and an iterative process was used to refine codes. Final agreement was reached by discussion. All study authors sorted and grouped the codes to independently identify central themes and subthemes from the interviews and focus group. Study authors then determined common themes that emerged between both the provider interviews and focus group.

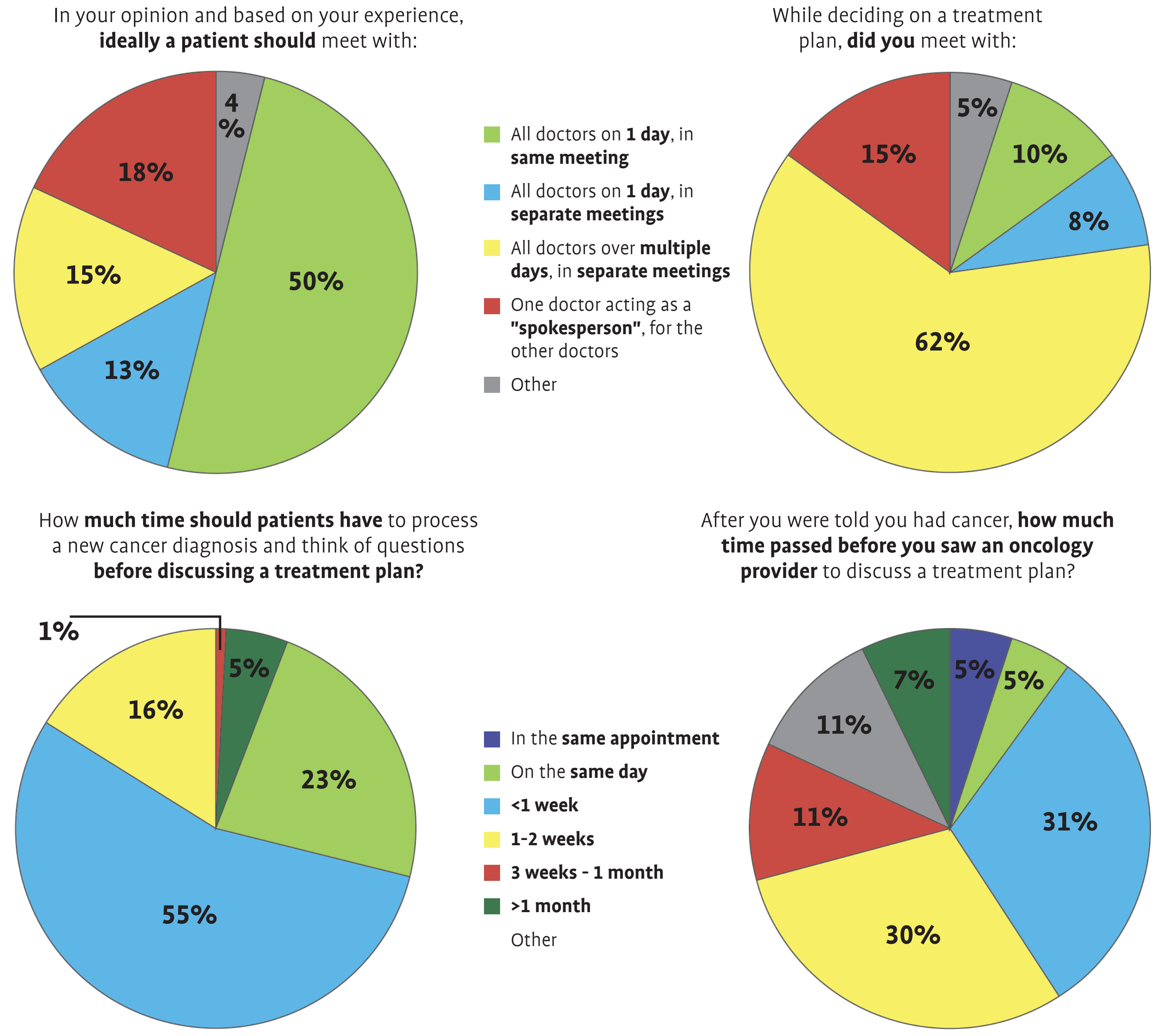
Results: Patient Survey

There were 156 respondents to the online survey. Most respondents reported having colorectal cancer (65 percent), with the remainder having lung cancer (7 percent), pancreatic cancer (6 percent), or other cancer (11 percent) or identifying as a caregiver (11 percent). About 40 percent of respondents received their cancer diagnosis from a doctor or surgeon while they were admitted to a hospital. Fifty-one respondents (33 percent) reported that they were seen by a "multidisciplinary team," but of those who said they were not, 36 (55 percent) reported meeting with multiple specialists (e.g., medical oncologist, radiation oncologist, and/or surgeon) to determine a treatment plan.

After receiving their initial diagnosis, respondents indicated confusion about the next steps—39 percent reported that the next steps were not clear, and 35 percent said they did not know whom to contact with questions. Respondents also reported differences between their preferred structural aspects of initial visits after a cancer diagnosis and what they personally experienced

(Continued on page 56)

Figure 1. Patient Preferences vs. How Care Was Actually Delivered*



*Online support group participants' preferences differ from their own experiences with the structural aspects of cancer care delivery. All support group members (156 people) were asked for their opinions on the ideal timing and contextualization of multidisciplinary cancer care appointments with providers for a patient who had just received a cancer diagnosis. They were also asked to provide information on their own experiences.

(Continued from page 54)

(Figure 1, page 55). For example, although 78 respondents (50 percent) thought a new patient with cancer should ideally meet with all of their treatment physicians in one collective meeting, only 15 (10 percent) had that experience. Of the patients surveyed, 62 percent met with cancer care providers over multiple days in separate meetings. Most patients preferred to meet with a cancer provider within a week of receiving a cancer diagnosis, yet the majority of patients (59 percent) experienced a longer wait time.

Results: Provider Interviews

In total, 10 major themes were identified from the provider interviews (Table 1, right). Comments fell into categories according to the new patient with cancer evaluation timeline that centered on the following time periods:

- Before first appointment
- During first appointment
- After first appointment
- Throughout all time periods.

Before the First Appointment

Four themes were identified that centered around the time between a diagnosis and the first multidisciplinary cancer care appointment.

1. ***Many barriers to streamlining care.*** Providers expressed a desire to streamline the multidisciplinary cancer care process to evaluate new patients, but many barriers often arise, like patients having different preferences, complexities of different cancers and disease staging, desire to be prepared for the first appointment (e.g., obtaining additional diagnostic studies prior to a visit), logistical considerations (e.g., provider availability, facility needs, staffing, etc.), need for experienced triaging, and needed access points that are available to patients.
2. ***Need to get patients "in [and] over the wall."*** Considering the patient experience, providers emphasized the need to connect with patients early. One provider described this as, "You just need to get them in [and] over the wall." Patients perceive that building a connection with the multidisciplinary cancer care team and identifying a contact person early is a substantial challenge for them. One nurse navigator mentioned that connections to a specific and reliable member of the multidisciplinary team within the health system can help overcome this barrier and connect patients quicker. Providers emphasized the importance of nurse navigators in the communication and facilitation of care for patients who are accessing the system.
3. ***Need for early contact.*** Providers noted the benefits of providing information early (as soon as possible after diagnosis) to patients through prior contact rather than waiting until the first appointment. As they discussed early contact with patients, a subtheme emerged: the desire to avoid overwhelming patients while providing this initial information.
4. ***Patient reassurance is important.*** Finally, providers emphasized the importance of reassuring patients during this period of early contact.

During the First Appointment

Three themes focused on the first multidisciplinary cancer care visit.

1. ***Make the most of the patient visit.*** At the time of the first appointment, most providers wanted to "make the most" of a patient's visit by making it a meaningful (i.e., easy, convenient, productive, and informative) experience. Providers expressed the desire to not waste patients' time. This included ensuring all records have been obtained and reviewed prior to the visit. There was general consensus on having all appointments with various providers on the same day and dedicating time for explaining the available supportive care services that can be helpful for patients.
2. ***Provider flexibility is helpful.*** Providers felt that first visits were better when providers were flexible in regard to scheduling last-minute visits or opening time on a non-clinic day. This flexibility was viewed positively by the nurse navigators and cancer center access nurses.
3. ***Desire not to overwhelm patients.*** Providers also acknowledged that the first visit can be overwhelming, and they desired to minimize overwhelming information. However, multiple providers expressed that the overload of information was unavoidable.

After the First Appointment

One theme was consistently identified by all providers regarding the time after the first appointment: ***a need for follow-up contact.*** Providers expressed a goal of not letting new barriers form that prevent patient contact. Nurse navigators, in particular, saw their role as helping explain what was discussed in the first appointment and answer questions. This contact was described as multi-modal and includes the health record messaging system for patients, as well as the 24-hour triage line. Providers also mentioned planning future patient phone calls to continue discussions after the first appointment.

Throughout Treatment

Two identified themes were broadly applicable throughout the multidisciplinary care timeline.

1. Considering the multidisciplinary process as a whole, providers thought ***direct provider-to-provider communication was critical.*** Nurse navigators appreciated the ability to talk with other nurse navigators about a patient's plan. The medical oncology fellows described helpful communication via the chart and phone calls with other providers as well.
2. With many participants included in the multidisciplinary process, providers considered it helpful to have ***one designated provider primarily responsible for each patient.*** This would include any primary communication with patients and coordination with other specialists. The medical oncology fellows thought that there was a good system in place to designate a primary "owner" of a patient case, though others thought this was not always true.

(Continued on page 61)

Table 1. Themes and Subthemes Identified from Analyses of Multidisciplinary Cancer Care Provider Interviews and Patient Focus Group

Timing: Before First Appointment
Provider Interviews
Theme 1: There are many barriers to streamlining care. **Subtheme(s):** 1) Patients have different preferences, 2) complexity of different cancers and disease staging, 3) desire to be prepared for the first appointment, 4) logistical considerations, 5) need for experienced triaging, and 6) many access points to care. **Representative quote(s): “**I’ve heard two different perspectives. Some patients want to be seen right away after their diagnosis; they want all their options, and they want to decide before they leave clinic that day what their treatment plan is. And I’ve had other patients who get their diagnosis, and they want to wait a couple weeks to let it sink in.” (Nurse Navigator) “I think that who they meet first depends on what type of cancer they have and the order that their treatment standard of care needs to be delivered.” (Medical Oncology Fellow) “Record collecting for patients that are not in our system is another big issue. Making sure we have all the records and reviewing the records to see what they have and what they still need—that needs to happen before they [the patient] can be seen, too. If a patient shows up and they haven’t even gotten all their records, then what’s the point of them making the trip all the way here?” (Nurse Navigator) “If we have any questions at all about the urgency, we ask the provider because access is a big problem right now. Most of our providers are booking out at a minimum of two weeks.” (Cancer Access Center Nurse) “I do a tremendous amount of coordinated care so once someone gets into this system, I can call a patient and get a lot of valuable information in order to streamline their care and triage things over the phone, [like] ordering staging workups, tests and labs. I think I know the diseases and the surgeons well enough to reduce travel burden and reduce redundancy in ordering.” (Nurse Navigator) “I think the biggest issue is definitely there are too many access points coming into the same thing.” (Nurse Navigator)
Theme 2: A need to get patients “in [and] over the wall.” **Subtheme(s):** 1) Initiate contact, 2) personal connections are helpful, and 3) nurse navigators are important. **Representative quote(s):** “I give them my direct number just in case they have any type of questions…I’m always available for them to ask.” (Nurse Navigator) “[Other providers] know that they can call me to get someone into the system.” (Nurse Navigator) “I always like to tell people, 'If you have a pancreatic head mass that’s resectable, then you’re going to land on an OR [operating] table whether I’m in the picture or not. I can make that journey much more pleasant.'” (Nurse Navigator)
Theme 3: A need for early contact. **Subtheme(s):** 1) Provide information early and 2) give that information but don’t overwhelm. **Representative quote(s):** “When someone gets diagnosed on the inpatient [side, and you go] in to just tell the patient, ‘Hey, we’re the oncology team. I’m aware of your case. We need x, y, and z done and then we’ll talk more in detail.’ And that seems to be a good kind of in-between discussion. … Meanwhile, we’ll get you into the clinic and get any additional testing we need to give you a better answer to your questions.” (Medical Oncology Fellow) “I honestly think that before that first appointment, if you give them [patients] too much information…it will just completely confuse them. And then the questions they come in to ask will not necessarily have the focus that they might otherwise have had.” (Cancer Access Center Nurse)
Patient Focus Group
Theme 1: Difficulty processing after a diagnosis (“the blur”). **Subtheme(s):** N/A **Representative quote(s):** “I do agree that getting hit with the word cancer—you go into shock. You’re not really listening to what the doctor is telling you right then. My husband was called in with me, and he wasn’t listening any more than I was. We were both in shock. And you just leave the doctor’s office, and you get in your car and you drive home. You’re just gone.” (Focus Group Participant)

Table 1 (continued). Themes and Subthemes Identified from Analyses of Multidisciplinary Cancer Care Provider Interviews and Patient Focus Group

Theme 2: "Somebody there to catch you."

Subtheme(s): Desire for support.

Representative quote(s): "I like this gentleman's idea where you get the news [a cancer diagnosis] in whatever format you get it. And there is somebody there to catch you when you get that news and...say, 'I would really like to call you or have you come in...and make another plan so that we can kind of get beyond the scope that I have cancer and now we need to talk about what we're going to do about this.'" (Focus Group Participant)

Theme 3: A need for early contact.

Subtheme(s): 1) Set expectations and give practical information about first appointment, 2) contact needed before appointment, and 3) desire for streamlined communication.

Representative quote(s): "So maybe, even on the appointment you make—the appointment to speak with the doctor or the surgeon or whoever is going to be the one to tell you that you have this [cancer]—that they would tell you in advance that this appointment is going to take longer. Allow yourself extra time." (Focus Group Participant)

"Call and say, 'I understand you have a diagnosis of cancer,'—maybe it's been identified, maybe it hasn't—'Would you like to set up an appointment? Would you like to talk for a little bit? Do you have some questions?' I mean even...if you're not ready to talk, just say, 'I'm not ready to talk.' And, 'Fine. When would you like me to follow up?'" (Focus Group Participant)

"So we came here, and we had a tour of this place. And then somebody called me and then they were trying to schedule appointments. There was a bunch of calling back and forth, and I turned into a terrible person and hollered, 'This is about my life! Telephone tag is not fun!'" (Focus Group Participant)

Timing: At First Appointment

Provider Interviews

Theme 1: Make the most of a patient's visit.

Subtheme(s): 1) Desire to make first appointment meaningful, 2) all provider visits in one day, and 3) dedicated time for support services.

Representative quote(s): "Getting those pieces and interpreting the information so that they're [patients are] seeing the right disciplines while they're here and making the most of their visit...I think is really important, and I don't know that that's always happening." (Nurse Navigator)

"The ideal thing is to have an answer right away....So usually, if they need different pieces of answers, then definitely the patient would prefer to have it on the same day or at the same time—ideally in one visit." (Medical Oncology Fellow)

"It just pains me when I've had discussions with our patients to only find out after they've completed treatment that they didn't know that there was social work here. They didn't realize they could get a nutritionist consult free of charge." (Cancer Center Access Nurse)

Theme 2: Provider flexibility is helpful.

Subtheme(s): N/A

Representative quote(s): "I think the majority, if not all the providers, are very good at being flexible and helping the patient while they're there [at the cancer center] instead of having them come back." (Nurse Navigator)

Theme 3: A desire not to overwhelm patients.

Subtheme(s): N/A

Representative quote(s): "It really depends on how informed the patient wants to be. There's a surprising number that say, 'Just tell me where to be and when to show up.' Or, you know, 'We'll talk about it.' And it is a lot of information. It's information overload, and that's the fine balance with everything." (Medical Oncology Fellow)

Table 1 (continued). Themes and Subthemes Identified from Analyses of Multidisciplinary Cancer Care Provider Interviews and Patient Focus Group

Timing: At First Appointment
Patient Focus Group
Theme 1: Providers are "in their own bubbles." **Subtheme(s):** 1) No perception of a team, 2) nurses help bridge the gap, and 3) reassurance by protocols. **Representative quote(s):** "I never got the idea [that] there was any team approach. I never had that. I never felt that my oncologist talked to my surgeon. I had the operation, I had the mastectomy, and that's over. Then they'd hand me over to the next person. I never felt…any real communication between the doctors that were supposed to be helping me with the problem. There must've been, but I don't know." (Focus Group Participant) "I found that the nurses, they communicate with each other and other members of the team well. They know each other, and they really helped to collaborate between them [the care team] to schedule a meeting and make sure that everything lined up." (Focus Group Participant) "Despite having several groups, I think there was a standard protocol so that even when they [patients] were passed—start with radiation, followed by surgery, followed by chemo—the protocol is there so they [patients] pretty much know what the protocol is. In that sense, they [patients] could loosely string it [their treatment plan?] together—that's…okay." (Focus Group Participant)
Theme 2: Personalization is preferred. **Subtheme(s):** 1) Having a choice and 2) personalized information. **Representative quote(s):** "I've always met doctors in linear succession. It [a multidisciplinary approach] was never offered." (Focus Group Participant) "I did end up with three books of information. I think that the navigator did want to sit down and say this is your book, and I'll help you." (First Focus Group Participant) "It's customized for your condition." (Second Focus Group Participant) "I think so. That was pretty good." (First Focus Group Participant)
Theme 3: Information issues. **Subtheme(s):** 1) Too much information, 2) not enough information, and 3) information offered at the wrong time. **Representative quote(s):** "Did they hand you a big book?" (Third Focus Group Participant) "Yeah. If we wanted to talk about the big book, I'd have plenty to say about that…" (Second Focus Group Participant) "Somebody plopped this big, three-ring binder into your hands, and no one sits down, I didn't think, and really explains the panoply of services that are available." (First Focus Group Participant) "She [the provider] seemed like she really wanted to let me sit there and settle in and go over the book with me, but my husband kept saying, 'We've got to get out of here.' And that's the kind of guy he is. You go in, you do your thing, you get out, and you're done. And that's hard when one person wants to spend time and the other one doesn't, and you didn't make [prior] arrangements." (Focus Group Participant)
Timing: After First Appointment
Provider Interviews
Theme 1: A need for follow-up contact. **Subtheme(s):** No "new" wall. **Representative quote(s):** "[After the first visit I contact the patient], reiterating what happened during the clinic visit because they're overwhelmed and can't understand anything, interpreting test results, and having these lengthy conversations on the phone." (Nurse Navigator)

Table 1 (continued). Themes and Subthemes Identified from Analyses of Multidisciplinary Cancer Care Provider Interviews and Patient Focus Group

Patient Focus Group

Theme 1: A need for follow-up contact.

Subtheme(s): 1) Phone call and 2) address follow-up at the first appointment.

Representative quote(s): "Even a phone call, I think, would've been nice for checking up, even like a day or so afterward. You don't physically have to go to the doctor's office. I understood what my case was...But all those waits for the next appointment to find out what happened." (Focus Group Participant)

"Even that first day with the oncologist—just to have somebody say that there are other resources and we'll be in touch with you." (Focus Group Participant)

Timing: Throughout Treatment

Provider Interviews

Theme 1: Provider-to-provider communication with multidisciplinary teams is critical ("teams within teams").

Subtheme(s): 1) Processes for provider-provider communication, and 2) it's good to have one contact person.

Representative quote(s): "I would say that there is ongoing communication, like during the handoffs. So before...the chemo is about to end, usually the medical oncologist would be telling the surgeon, 'Hey I'm about to be done. Do you want to meet with the patient to speak about surgery?' And then the surgeon would hand off to the radiation doctor, saying, like, 'I did the surgery. He needs so many weeks of recovery and then you can do radiation.' So, I think this process is well established." (Medical Oncology Fellow)

"It's also good on the back side to have a resource person so that if they [patients] have questions or if they're overwhelmed with all that information, they can just contact that person and sort it out. That's where I feel like my role comes [in]." (Nurse Navigator)

Theme 2: Singular ownership of a patient is valued.

Subtheme(s): N/A

Representative quote(s): "Whoever is mainly managing the patient is the primary, and then we work as a team. But it is obvious that there is someone who has ownership of the patient, and somebody who is just consulting and providing assistance with this patient." (Medical Oncology Fellow)

Patient Focus Group

Theme 1: Provider recognition of personal preferences and differences are valued.

Subtheme(s): 1) Acknowledge preferences and 2) that patients are all different.

Representative quote(s): "I told my doctor, 'Just call me anytime when you get that lab result. I want to know.' And he understands that I'm the kind of person who wants all the facts. Doctors should start understanding how to facilitate and educate their patients as well." (Focus Group Participant)

"Just to say I understand you as an individual...we talked about how different people are, and someone who could understand you and link you to the system because they know the system and they can actually help you navigate it." (Focus Group Participant)

"Patients are so different. There are some patients that just go in and receive a diagnosis and don't ask a question. They do everything the doctor tells them. They don't want a second opinion. They just want to follow along and don't ask, 'Can I have a lumpectomy instead of a mastectomy?' They just go with the flow. And then there are patients, like me, who are asking questions and say, "You know, I read on the Internet..." (Focus Group Participant)

Theme 2: Singular ownership of a patient is valued.

Subtheme(s): N/A

Representative quote(s): "You feel like there's no continuum and that gives patients a sense of being isolated. That no one really cares about you as a person from day one until day whenever, when you go through the process." (Focus Group Participant)

(Continued from page 56)

Results: Patient Focus Group

Seven participants joined the focus group, all of whom had a cancer diagnosis and one individual who was also a caregiver for a family member with cancer. Nine major themes emerged from the focus group (Table 1, pages 59-62).

Before the First Appointment

Three major themes emerged for the period prior to a patient's first visit.

1. ***"The blur."*** Reflecting on their experience at the time of their cancer diagnosis, several participants described a "blur" after learning they had cancer, during which they were not able to hear or comprehend much of what was being told to them.
2. ***Somebody there to catch you.*** One participant said that they needed "somebody to catch" them during this time. This person would provide support and ensure proper follow-up for the patient. Others agreed that early support was needed.
3. ***Need for early contact.*** Patients agreed that early contact is helpful after receiving a cancer diagnosis, including early phone calls to help them feel connected. During this early contact, patients emphasized the need for more practical information about what to expect at the time of their visit (e.g., parking information and appointment length). They also thought it was difficult to find basic information about their cancer ahead of time. One participant expressed frustration about this early contact, which lacked streamlined phone calls and included "phone tag," leading to a negative experience.

During the First Appointment

Three themes focused on the first multidisciplinary cancer care visit.

1. ***Providers are "in their own bubbles."*** Significant frustration arose around participants' perceptions regarding the lack of a coordinated team approach from their providers. Several patients discussed having negative feelings because they thought their various providers were not speaking among one another. The participants said that this lack of communication improved with use of nurses who helped bridge communication gaps and reassure patients that protocols are being followed.
2. ***Information issues: enough information, but not too much information, and information at the right time.*** When discussing the setup and flow of the first visit, participants spent time addressing what the ideal amount of information would be to receive at a first visit. They expressed frustration with both not receiving enough information about the important details of their cancer treatment and available support services available and receiving an overwhelming amount of information that was too difficult to absorb. Several participants also discussed the timing of information delivery at the appointment, describing efforts to provide additional information at a time that was more optimal mentally or for practical reasons (such as not having planned for childcare after a certain time).

> This study found that many patients were initially uncertain of who oversaw their care or of whom they could contact for questions. This confusion improved when patients had a single contact person, which was a main theme identified in our findings.

3. ***Preferring personalization.*** A solution to the issues patients described included offering patients choices about the structure of their visit and giving information customized to their particular disease processes.

After the First Appointment

One theme that emerged was the ***need for follow-up contact.*** Following the first visit with providers, several participants said that they either appreciated or would have a appreciated a follow-up phone call as a check-in to answer any additional questions and to offer more information about the support services that might be helpful for them. Patients also wanted this follow-up to be addressed specifically at the first visit to provide reassurance that follow-up would happen.

Throughout Treatment

When discussing the entire cancer care continuum, participants reiterated multiple times that ***all patients are different.*** They suggested that patients be asked when and how to be given information and how their visits should be structured. One participant specifically mentioned that patients are also different when it comes to their first-visit needs, especially considering how far some need to travel for their first appointment. In emphasizing personalization, several participants described very positive experiences where their provider knew them and tailored information delivery to their preferences.

Participants also discussed a need for ***one identified provider to take responsibility of communicating with patients.*** Others agreed with this idea, stating that their cancer treatment involved many steps with different providers responsible for each step.

Comparing Patient and Providers' Perspectives

Following the individual analyses of the provider interviews and focus group, we compared themes to identify overlapping areas. ***Early contact prior to the initial multidisciplinary cancer care visit*** and ***an established follow-up plan after the first visit*** were important to both patients and providers. Throughout the multidisciplinary cancer care process, patients and providers also viewed ***identification of a provider with singular ownership of the patient*** as important.

Discussion of Survey Findings

In this mixed methods study of provider and patient perspectives on multidisciplinary cancer care, the need for early and consistent contact between provider teams and patients was clear. Foremost, in the vulnerable and overwhelming time after receiving a cancer diagnosis, patients look for reassurance and information that multidisciplinary cancer care teams can provide prior to the first visit, and patients value continued contact and support throughout their care. Secondly, this study identified that patients have a range of preferences regarding the structural aspects of multidisciplinary cancer care, and this can present a challenge to the multidisciplinary cancer care team that is trying to streamline patients' care. However, the ability of providers to acknowledge the preferences of each patient is highly valued by patients.

The need for early and consistent communication expressed by multidisciplinary cancer care providers and patients is consistent with previously identified themes in the literature. In a large study involving interviews and focus groups with 37 patients with cancer and 40 multidisciplinary providers, Admi et al. found that there is confusion and ambiguity regarding the early roles of healthcare providers after a cancer diagnosis.[17] Similar to the providers in our study who described an initial barrier to finding a contact person ("the wall") as frustrating for patients, the providers participating in this study described the need to overcome hospital-community interface barriers with communication and navigation.

Like our online national cancer support group survey, which suggested that a sizeable percentage of oncology patients did not have an identified contact person at the time of their diagnosis and comparable experiences described by our focus group participants, a qualitative study involving phone interviews of 38 patients with cancer in Canada found that good communication is a central consideration for patients early after a cancer diagnosis.[18] This study found that many patients were initially uncertain of who oversaw their care or of whom they could contact for questions. This confusion improved when patients had a single contact person, which was a main theme identified in our findings. Although there are limited studies exploring patient perspectives, most show consistent themes surrounding communication barriers and single points of contact.[19]

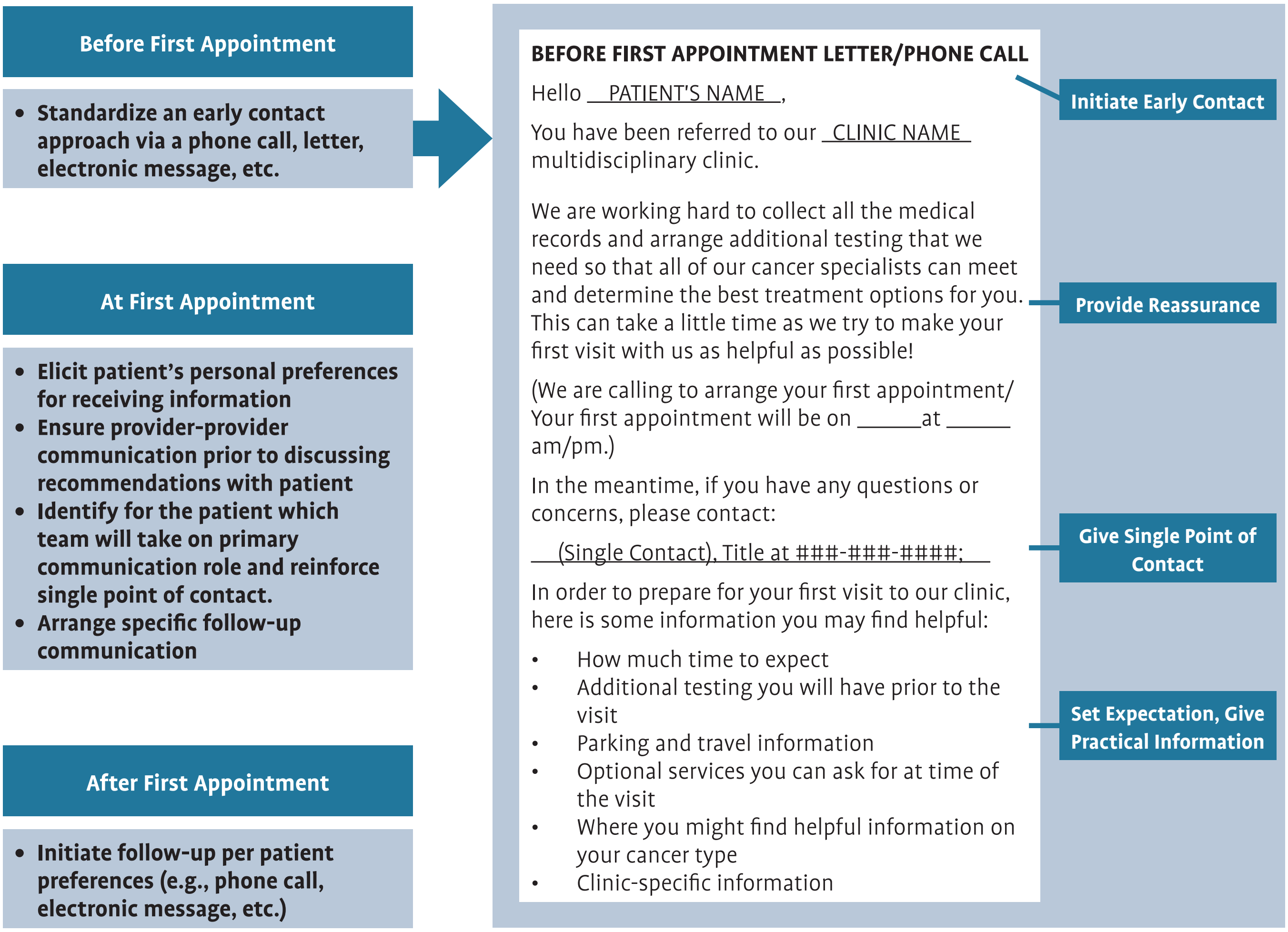
Nurse navigators' roles are uniquely aligned to improve patient-provider communication and break down barriers, which was thoroughly explored in a 2018 National Academies of Sciences, Engineering, and Medicine report on the proceedings of a workshop dedicated to effective patient navigation in oncology.[20] In this report, the role of navigators was emphasized to help reduce communication and healthcare system barriers, as well as to provide emotional support to patients.[20] Patients and providers in several other qualitative studies agreed on the critical role nurse navigators play in communicating with and supporting patients.[21,22]

Overall, studies examining patient preferences regarding the specific structure of multidisciplinary cancer care (i.e., timing of visits, participants involved, etc.) are lacking. Our findings indicate that patients vary in their preferences regarding these structural aspects, and many patient-related factors are likely to play a role. This variation in patient preference, coupled with the complexities inherent to cancer care, is at odds with providers' desire to streamline care, as multiple providers discussed in our interviews. These barriers, such as the time needed to obtain necessary diagnostic information, which limits the ability to see the patient as soon as possible, have been previously acknowledged.[23,24] An excellent effort to incorporate patient preferences into the multidisciplinary cancer care process was conducted at Virginia Mason Medical Center in Seattle, Wash., by Hagensen et al.[25] The group implemented a "Know Me" form at intake to address the differences patients express regarding their interpretation and hope for their cancer prognosis.[25] Our findings support these types of efforts to improve providers' understanding of patients' varying preferences regarding care delivery processes.

The response inconsistencies from the cancer support group participants about what they preferred as their multidisciplinary cancer care structure and what patients actually experienced is concerning. Because standardized approaches are helpful, our findings suggest that incorporating intentional efforts to address patient preferences in a standardized way throughout the multidisciplinary cancer care process are likely to be beneficial. A process to initiate early contact once a patient has been identified as needing multidisciplinary cancer care could follow a template to ensure patients receive helpful information and, most important, have an identified point of contact for any questions (see Figure 2, right). At the first visit, a consistent effort should be made to specifically arrange post-appointment contact, such as a follow-up phone call or health records message (according to patient preferences), to improve communication and eliminate barriers. Finally, patient preferences regarding multidisciplinary cancer care should continue to be investigated to help providers align multidisciplinary care delivery with identified preferences, while considering the variability that exists in patients' preferences and needs.

Although this study contributes new data to the sparse literature in this area, there certainly are some limitations. Admittedly, our study is small in scale, based on its roots as a QI initiative at a single institution. The online survey was a small convenience sample meant to provide an exploratory overview of the perspectives of a broad patient group and therefore did not provide a definitive assessment of all patient perspectives. As such, the perspectives of all patients and providers regarding the issues affecting new patient multidisciplinary cancer care were likely not uncovered through this study. Despite this, the themes presented from our study are consistent with previous studies, and the patient and provider perspectives from our study align in key areas. Further studies with larger, nationwide, and patient and provider samples would help to establish the ideal methods of incorporating patient preferences in multidisciplinary cancer care. Secondly, the role of primary care physicians in communication and coordination processes was not specifically explored because this was beyond the scope of our QI efforts. This is an important area that some have investigated[26] and would be important to consider in future investigations, particularly when resources for navigators are limited.

Figure 2. Template to Standardize Early Contact Methods



Before First Appointment

- Standardize an early contact approach via a phone call, letter, electronic message, etc.

At First Appointment

- Elicit patient's personal preferences for receiving information
- Ensure provider-provider communication prior to discussing recommendations with patient
- Identify for the patient which team will take on primary communication role and reinforce single point of contact.
- Arrange specific follow-up communication

After First Appointment

- Initiate follow-up per patient preferences (e.g., phone call, electronic message, etc.)

BEFORE FIRST APPOINTMENT LETTER/PHONE CALL

Hello PATIENT'S NAME,

You have been referred to our CLINIC NAME multidisciplinary clinic.

We are working hard to collect all the medical records and arrange additional testing that we need so that all of our cancer specialists can meet and determine the best treatment options for you. This can take a little time as we try to make your first visit with us as helpful as possible!

(We are calling to arrange your first appointment/ Your first appointment will be on ______at ______ am/pm.)

In the meantime, if you have any questions or concerns, please contact:

(Single Contact), Title at ###-###-####;

In order to prepare for your first visit to our clinic, here is some information you may find helpful:

- How much time to expect
- Additional testing you will have prior to the visit
- Parking and travel information
- Optional services you can ask for at time of the visit
- Where you might find helpful information on your cancer type
- Clinic-specific information

In conclusion, early contact by multidisciplinary cancer care providers with new oncology patients helps eliminate perceived barriers and provides reassurance during the particularly vulnerable time for patients—the time following a cancer diagnosis. Patient preferences regarding the structural processes of multidisciplinary cancer care are varied, and efforts to improve multidisciplinary cancer care processes by incorporating the patient perspective should ensure early and continued contact, as well as assessments of personal patient preferences to guide interactions and prioritization. OI

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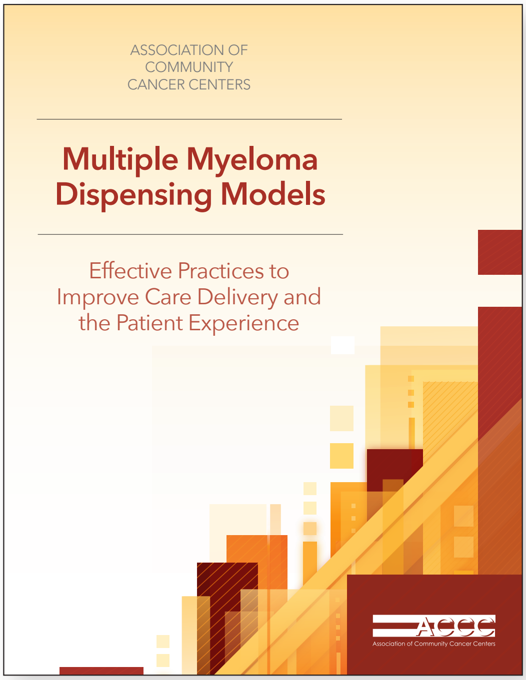

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BRAD COLEMAN, PMP; AND GREG SALINAS, PHD

BIOMARKER TESTING IN PATIENTS WITH NON-SMALL CELL LUNG CANCER

A Mixed-Methods Approach to Understand Clinician Use of Biomarker Testing for Patients with NSCLC

In Brief

While recent advances in precision medicine have substantially changed the management of lung cancer, care must be taken to ensure that these advances do not worsen health disparities. This study included a case component that divided overall respondents into two cohorts to observe how patient characteristics, such as age, socio-economic status, race/ethnicity, and health literacy, affected the likelihood of ordering biomarker testing. Descriptive data analysis and sub-analyses between cohorts captured differences in decision making and attitudes. Two virtual focus groups provided context to these data. The survey found that the main reason clinicians order biomarker testing is to determine treatment decisions, but half also reported using the results to inform patient discussions and determine eligibility for clinical trials. From the clinician's perspective, the least critical factors when ordering biomarker testing were health literacy, caregiver presence, race/ethnicity, and age. Yet, likelihood to order biomarker testing decreases when patients have an unstable housing situation or low health literacy. Based on this study, there is a need for continued clinician education on equity in the ordering of biomarker testing.

Advances in the understanding of cancer genomics and the impact of patient-specific characteristics on optimizing treatment plans has substantially changed oncology practice. In the management of non-small cell lung cancer (NSCLC), the BATTLE and BATTLE-2 trials, among others, showed success when matching patients with targeted therapy based on their biomarker status.[1-3] Use of precision medicine was initially seen as an opportunity to address and eliminate disparities by determining treatment largely on the genetic makeup of a tumor or mutation and an individual's needs for cancer care. Yet, care must be taken to ensure it does not exacerbate existing health disparities.[4]

In 2020, the American Association for Cancer Research released a report[5] focusing on disparities inherent in the management of patients with cancer. One of these sections deals specifically with the "imprecision of precision medicine" due, in part, to the limited understanding of etiology and the genetics of cancer within underserved populations. A precision medicine testing approach requires increased samples from patients in currently underserved populations along with testing access and accuracy in testing interpretation.[6,7] While there are multiple initiatives intended to mitigate these gaps in key population genomic information,[8] other variables may contribute to disparities in biomarker testing, including access to quality healthcare, ability to pay/insurance status, mistrust in the healthcare system, and how patients and clinicians comprehend the importance of biomarker testing with treatment planning. To use precision medicine to reduce disparities of care, all eligible patients with cancer must be offered comprehensive biomarker testing. Yet, recent studies have shown lower biomarker testing rates in patients with cancer from historically marginalized groups[9,10] and specifically for patients with lung cancer.[11-13]

To highlight areas of need for continued clinician education and information, this study explores attitudes of oncology clinicians toward the use of biomarker testing in patients with NSCLC with a focus on understanding factors that contribute to disparities of care in patients of lower socio-economic status. The study attempts to identify inherent barriers to the equitable offering of biomarker testing in patients with NSCLC to recommend specific interventions that can be implemented to optimize care.

Survey Development

A case-based survey was designed to assess oncology clinicians' perceptions on attitudes toward the use of biomarker testing in patients with lung cancer. For the case portion, clinician respondents were randomly split into two slightly modified versions of the case to identify whether patient-specific factors, such as socio-economic status, age, race/ethnicity, and health literacy, affected clinicians' decision to order biomarker testing. The survey used four vignettes that described patients at different lung cancer disease stages with integrated real-world physical and social determinants of health complexities that might influence the ordering of biomarker testing.

Likert-type scales and multiple-choice responses were analyzed to show how clinicians approach biomarker testing use. Questions were asked to understand clinicians' general use of biomarker testing, rationale for testing, barriers, and their demographics.

Study Sample and Data Collection

Clinician survey invitations were distributed by e-mail from June to August 2020 to a random sample of oncology clinicians through ACCC member lists, commercially available lists, and a Sermo social media advertisement. The inclusion criteria specified ACCC-member clinicians that currently see patients with NSCLC who are on Medicaid, are dual Medicare-Medicaid eligible, or are uninsured.

Survey Analysis

Descriptive statistics were conducted on key items of the clinician and patient survey, using Chi-square analysis for categorical variables and T-tests for continuous variables to examine differences between key demographics, including academic versus community and urban versus suburban and rural. Statistical analysis was conducted using SPSS 27 (IBM: Armonk, N.Y.). Values were considered significant when p is less than 0.05.

Post-Survey Focus Groups

Survey results were used to develop a focus group guide, which was used to further probe into key themes identified in the survey. Focus group participants were selected based on their Medicaid population being at least 5 to 10 percent of their total patient population, including two sites with more than 20 percent of their patient population being insured by Medicaid. Two clinician focus groups were conducted via Zoom and recorded, with one focusing on community oncology practices (3 participants) and one on academic cancer centers (3 participants). Focus groups were transcribed verbatim and a thematic analysis was conducted until saturation was reached to identify emergent themes. The study protocol was approved by Advarra internal review board (Columbia, Md.) on April 13, 2020, and the instru-ments (Appendix A: Survey and Appendix B: Focus Group) are available online at accc-cancer. org/eliminating-disparities.

Sample Demographics

Data were collected from 105 oncology clinicians—6 were removed from the final sample due to not meeting the established inclusion criteria. A final sample of 99 clinicians was used for analysis (Table 1, at **accc-cancer.org/eliminating-disparities**). Most of the sample included medical oncologists, radiation oncologists, surgical oncologists, oncology nurses, and pharmacists, who were all involved with a program that treats patients with NSCLC. The sample was evenly split between those practicing in urban (49 percent) versus suburban/rural settings (51 percent), and 68 percent self-identified as working in a community practice setting versus 32 percent who self-identified as academic practitioners. Overall, 20 percent of respondents indicated that their cancer program sees more than 100 patients with NSCLC per month. Academic oncologists reported a higher patient load; 39 percent of academic clinicians see more than 100 patients with NSCLC per month compared to 11 percent of community clinicians. Roughly a third of the clinicians in this study have taken cultural competency and/or cultural humility training. This training most often focused on race/ethnicity and gender/sex competency; only 14 percent had any prior training on competency related to socio-economic status.

Use of and Rationale for Biomarker Testing

Respondents were presented with a patient case consistent with lung cancer (Table 2, at **accc-cancer.org/eliminating-disparities**). At the point of obtaining a biopsy, nearly all respondents were very (34 percent) or extremely likely (44 percent) to order biomarker testing; only 4 percent responded that they were unlikely to do so. When asked generally why they recommend biomarker testing, 86 percent indicated that the results impact their treatment recommendations. Just over half of clinicians indicated that they recommend biomarker testing because results inform discussions with patients about prognosis (57 percent), guidelines recommend testing (56 percent), or results impact clinical trial eligibility (54 percent). Academic clinicians were significantly more likely than community clinicians to have responded that biomarker testing results inform patient discussions about prognosis (73 percent versus 48 percent, (p = 0.021). Only 10 percent responded that they recommend biomarker testing because patients expect it.

Respondents were asked to rate different patient-specific factors related to their approach to discussing biomarker testing with a patient. A 1 to 5 point scale was used, where 1 = not at all significant and 5 = extremely significant. Of the factors provided, respondents rated a patient's level of interest in being involved in decision making as most significant (3.81/5) and patient's health literacy as least significant (3.42/5).

Respondents were then asked about the significance of different clinical and demographic factors in their approach to biomarker testing on the same 1 to 5 point scale. From the clinicians' perspectives, the most critical clinical factors were histology, clinical trial eligibility, and patient preference for biomarker testing; the least significant patient factors were health literacy, caregiver presence, race/ethnicity, and age.

Decision Making for Ordering Biomarker Tests

Respondents were then presented with several patient case scenarios; half of the sample was randomly presented with each version to observe the impact of selected variables on their decision to order biomarker testing (Table 3, at **accc-cancer.org/eliminatingdisparities**). Each case presented a potential disparity: socio-economic status (case 2), age (case 3), race/ethnicity (case 4), and health literacy (case 5). Little difference was seen in clinicians' response to a patient's age or race/ethnicity; respondents indicated high likelihood to order biomarker testing with these cases. But a small difference was seen in how clinicians responded to socio-economic status. Fifty-seven percent indicated they were extremely likely to order biomarker testing in a patient with a stable, executive-level job compared to 32 percent who were extremely likely to order testing for an unemployed, homeless patient. The difference between test ordering was more drastic in case 4: only 32 percent of respondents were highly likely to order biomarker testing for a patient with perceived low health literacy compared to 63 percent for a patient who asks complex questions about their care and are perceived to have high health literacy. Going further, 8 percent of respondents were not at all or only slightly likely to order biomarker testing if the patient was noted to have low health literacy. Additionally, clinicians in an academic setting were significantly less likely than community-based clinicians to order biomarker testing for a patient with perceived low health literacy ($p = 0.016$).

Focus Group Perspectives

The consensus among focus group participants was to offer biomarker testing to all patients with advanced NSCLC early in the clinical decision-making process so that test results were available prior to being seen by a medical oncologist. However, other participants indicated that this strategy is not universally supported and may not be achievable at all cancer programs or practices due to a host of factors.

While training regarding formal health literacy assessment was not evaluated in the survey, no focus group participant knew whether their institution had standard policies for assessing the health literacy of patients with lung cancer. Focus group participants indicated that their patients were unlikely to understand the full implications of testing or ask questions about the implications of their results. Focus group participants identified nurse navigators or lay navigation services as needed resources to guide patients through cancer intake and treatment processes.

Concluding Thoughts

Overall, oncology clinicians indicated they are likely to discuss biomarker testing with a patient with NSCLC at some point along their disease trajectory. There were few differences in clinicians' likelihood to order biomarker testing based on patients' age or race. Decreases in biomarker testing were seen, however, in representative patient cases: those who are unemployed without a stable home and those with a perceived low health literacy. This may indicate that disparities in the use of biomarker testing may arise from both clinicians' perceptions of a patient's employment and/or housing status and their subjective assessment of a patient's ability to follow-up on or understand their results. Yet when asked directly, clinicians did not perceive health literacy to be a very significant factor in their ordering of biomarker testing for patients.

Clinicians did report being more likely to consider patients' preferences for testing, as well as their level of interest in being involved in shared decision-making, when considering whether to order biomarker testing. This would suggest that guideline-concordant biomarker testing is more likely to occur if a patient specifically requests testing. Placing this degree of responsibility on patients—to comprehend the role of biomarker testing at the time of diagnosis and/or disease progression—seems out of sync with most patients' understanding. This is especially true when considering that focus group clinicians do not view most patients with lung cancer as a highly health-literate population.

Based on this study, a patient with an uncertain housing situation or insurance status may be less likely to be offered biomarker testing compared to a more affluent patient. It is uncertain whether this decrease is due to a perceived or real inability to pay for the testing or the stability of their situation. Some clinicians in the panel may be more sensitive to the burdens related to biomarker testing and, therefore, more reluctant to offer testing based on the presumption that a patient cannot follow-up. While there is only a small reduction in the likelihood of ordering biomarker testing in this dyad, it may indicate an educational opportunity for social services training for oncology clinicians, including the need for referral to social workers, patient assessment, and the management of specific challenges faced by this patient population.[14] Additionally, continued resources and tools developed with engagement from communities to increase patient engagement may be needed.

Perception of poor health literacy also appears to be a key driver for ordering biomarker testing, yet it is unclear how well clinicians understand the health literacy of their patients. No focus group participant was aware of any health literacy assessment policies or tools for patients with lung cancer at their institution. Only 32 percent of respondents indicated that their cancer program implemented cultural competency or humility training, and it is likely that formal postgraduate training on health literacy assessment is rarer.

A review of health literacy research[15] found no standard approach to health literacy assessment in the United States, and most assessments focus only on basic functional skills, including ability to read and complete medical forms, not on participating in healthcare discussions or applying health information to one's situation.[16] While tools exist to help understand a patient's health literacy, like the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA), these tools are used primarily for research,[17] require training for administration,[18] and have not definitively been shown to improve patient outcomes.[19] Health literacy assessment results should not be a determinant of whether biomarker testing occurs but insight into the level of patient education that is needed when testing is conducted. Providers need training on patient-directed tools to help patients of all literacy levels understand biomarker testing and their results. Additionally, training in organizational health literacy has been cited by the Centers for Disease Control and Prevention as a critical component of bridging the gap in patient health literacy.[20]

This study has some limitations. While results from clinical assessment research demonstrate that case vignettes, compared with other methods of measuring processes of care (e.g., chart review and standardized patients), are a valid, non-invasive, and cost-effective method of determining clinician practice and intent,[21-24] only a subset of potential scenarios were used. Further, these results represent a small convenience sample of 99 ACCC member clinicians.

In summary, this study shows inherent biases in the ordering of biomarker testing for patients with NSCLC and a need for improved practical training for the cancer care team on the assessment of health literacy. Community-based initiatives may be a promising outlet, as poor health literacy has been shown to be linked to marginalized neighborhoods[25] and health literacy has been determined to be a modifiable risk factor for achieving equity in healthcare.[26] Further, community initiatives related to precision medicine that integrate diverse patients in the design of awareness and educational campaigns are viewed as more trustworthy within ethnically diverse communities.[27] Next, study authors will develop an intervention, based on a validated care sequence tool, to ensure discussions about biomarker testing are easily integrated into care pathways for every patient with NSCLC.

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The full version of this article, including Tables 1-3, can be found online at **accc-cancer.org/eliminating-disparities**.

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A publication from the ACCC education program, "Eliminating Precision Medicine Disparities." Learn more at **accc-cancer.org/eliminating-disparities** or scan this QR code.

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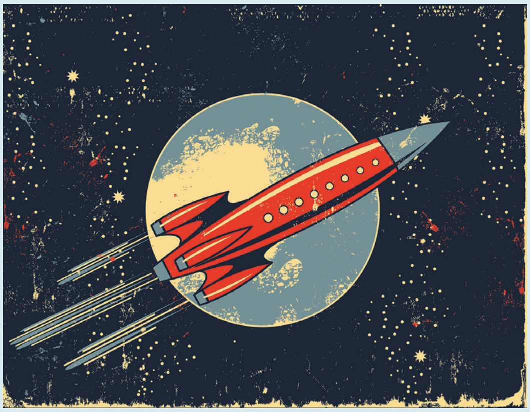
ACCC Supports White House Efforts to Reignite Cancer Moonshot Initiative



On February 2, the White House announced plans to revamp the federal Cancer Moonshot program. To support the relaunch, ACCC made available to the White House resources and tools from its member programs, with a specific focus on cancer prevention for underserved and marginalized patient populations.

That same day, the President's Cancer Panel released the report *Closing Gaps in Cancer Screening: Connecting People, Communities, and Systems to Improve Equity and Access*. The report found that "too many Americans—particularly those in communities of color and socially and economically disadvantaged populations—are presenting with more advanced disease at the time of diagnosis, enduring aggressive treatment, or dying from cancers that could have been detected at earlier, more treatable stages." Download the report in its entirety at prescancerpanel.cancer.gov/report/cancerscreening.

Cancer Screening and Prevention

The report identifies four crucial goals and related recommendations to ensure that the benefits of cancer screening reach all populations. Among these was the recommendation to "facilitate equitable access by providing and increasing funding for community-oriented outreach and support, including robust engagement of community health workers and increasing patient access to self-sampling." This recommendation supports existing efforts at ACCC member programs, such as Yuma Regional Medical Center Cancer Center in Yuma, Ariz., which leverages traditional Hispanic *promotoras*, or community health workers, to reach at-risk and underserved patients. In 2019, Yuma received an ACCC Innovator Award for implementing genetic cancer screening and testing in a medically underserved community.

The report also calls for "strengthening workforce collaborations by empowering all members of the healthcare team to support cancer screening and expand access to genetic testing." Increasing the number of people screened for cancer—especially those most at risk—has long been a priority for ACCC member programs. In 2012, ACCC awarded OhioHealth Grant Medical Center, Grant Cancer Care, in Columbus, Ohio, an ACCC Innovator Award for its ConvenientCare Mammography program, which transports women to cancer screenings from their places of work during their lunch hour. More recently, ACCC recognized the Prevention on the Go Program at Mary Bird Perkins Cancer Center in Baton Rouge, La., which goes one step further and partners with community organizations to bring education and early detection services to where community members live, work, worship, shop, and play. Equity is a pillar at Mary Bird Perkins, and the cancer program won a 2016 ACCC Innovator Award for its work to improve early detection in at-risk and underserved patient populations.

In the next *Oncology Issues*, read more about what ACCC member programs across the country are doing today to improve equitable screening and outreach in "The Long Road to Recovery: A Snapshot of Cancer Screening in the United States."

Genetic Testing and Counseling

Improving equitable access to genetic testing has also been a key focus of ACCC for many years. As early as 2013, ACCC Innovator Award Winner St. Luke's Mountain States Tumor Institute (now St. Luke's Cancer Institute) in Boise, Idaho, addressed two major barriers—access to qualified genetic specialists and patient identification—through a two-pronged approach: telehealth and weekly chart review.

In 2020 ACCC developed the resource Making the Case for Hiring a Certified Genetic Counselor to demonstrate how the provision of these services can improve patient health outcomes and increase patient satisfaction. The resource also discusses how genetic counseling offers a return on investment by helping cancer programs avoid unnecessary costs, decrease liability, and generate downstream revenue. Access this tool online at accc-cancer.org/business-briefs.

In March 2021, ACCC joined other stakeholders in stating its support for H.R. 2144, the Access to Genetic Counselors Services Act of 2021, "to update Medicare law and improve access to genetic counselors for Medicare beneficiaries." Now, ACCC is supporting the Senate version of the bill, S. 1450, which would authorize the Centers for Medicare & Medicaid Services to recognize certified genetic counselors as healthcare providers.

In 2021, the Iowa Oncology Society convened a multidisciplinary consortium to advance genetic counseling in oncology. This year, the Society will release a white paper of its findings with actionable opportunities to improve cancer genetic testing by, for example, referring patients to genetic counselors who can provide clear information about insurance coverage for genetic testing.

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One benefit of ACCC Cancer Program Membership is the opportunity to have your cancer program or practice recognized in our peer-reviewed journal, ***Oncology Issues***. Whether through a feature article or highlighted in our Spotlight column, we want to share your successes—and what it took to get there—with our multidisciplinary readership. ACCC members who recently took advantage of this member benefit include:

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- Helen F. Graham Cancer Center and Research Institute of ChristianaCare: Patients with Cancer, Comorbidities, and No Primary Care Provider
- San Juan Cancer Center: ***Oncology Issues*** Spotlight.

Contact Maddelynne Parker, ACCC content manager, at mparker@accc-cancer.org to learn more.

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ACCC is actively looking for individuals to serve on the ACCC Financial Advocacy Network Committee. Lend your insights and know-how to this committee and help other cancer programs and practices upgrade their financial advocacy services. This is an opportunity to support other professionals who are just starting to revamp (or in the midst of revamping) their current financial advocacy services. There are several ways to get involved, including contributing to ACCC blogs, articles, education resources, town halls, and more! Email cmangir@accc-cancer.org to learn more.

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Supporting Caregivers Through Their Cancer Journey

BY MIKE MCGARRY

Jack's Caregiver Coalition (jackscaregiverco.org) was founded in 2014 by three men who were caring for their wives who had cancer: Kyle Woody, whose wife Sarah was battling colon cancer; Justin Nicolay, whose wife Michelle was in the final stages of melanoma; and Dustin Cesarek, whose wife Kim had metastatic breast cancer.

Caregiving was a lonely place for these men, even when they were surrounded by family and friends. Though their family and friends provided support, this support was directed toward their wives who were receiving treatment for cancer. These men—and new caregivers—found themselves largely in the background, caring for their family and their children often alone, with few people who could relate to their experiences.

Without peers—other men who have been caregivers for their wives with cancer—these men had no one to relate to, no one to share their struggles with, and no one from whom to seek counsel. They found themselves alone in an unknown territory.

This loneliness created a need to find others in similar circumstances. People these men could share their experiences with and talk through struggles. They wanted others with whom they could celebrate successes and those who could offer counsel and solace.

Woody reached out, determined to find someone else who could relate to his experiences. After learning of an acquaintance who had a friend who was caring for his wife who had cancer, Woody did not wait to introduce himself. He asked via email whether the other man would like to talk, get a beer, and whether he could help in any way. Meeting in person, the two men found a common bond: both were caregivers who were trying to do it all. They soon expanded their support-like group by posting online, asking whether there were other men like them who wanted to talk. Cesarek responded to this post, and the core group of Jack's founders started meeting. They found one another and discovered that talking with others about their situations often relieved them of the incredible stress and loneliness they each felt. They shared and learned from each other, and they became better caregivers and better men.

Indoor Sky Diving Jack Event

Born from Struggle

It was through these initial meetings that Jack's Caregiver Coalition was born with a mission of improving the way guys think, feel, and act through every phase of their caregiving journey. Being a caregiver is one of the largest and most important challenges that a man will face in his lifetime. Jack's Caregiver Coalition helps men meet this challenge and bring their boldest and most confident selves to caregiving.

The Coalition helps members recognize the importance of taking care of their own health and well-being while they are caring for their loved ones. If a caregiver isn't taking care of himself, then their whole family can suffer.

Over the years, Jack's Caregiver Coalition has grown through its membership, as well as its offerings for caregivers. Programs and events are created to help caregivers on their journey and to improve their feelings of self-worth. Jack's member programming includes one-of-a-kind event offerings that bring members together to share a unique and often a character building experience.

(Continued on page 76)

(Continued from page 74)

Building a Community of Support

Monthly events bring Coalition members together to share and enjoy activities. These events always end in a meal where members can talk, build relationships, and let their guard down in a supportive and safe environment. Jack's Caregiver Coalition provides these programs to offer members time away—those moments of respite from the challenges of caregiving as well as time to recharge.

Caregiver Klatches are unique, co-ed support groups. The welcoming format encourages caregivers to open up and share their journey with other caregivers. The Klatch discussion group is focused on learning, sharing, and exploring the ways that caregivers think, feel, and act in support of their loved ones. Each group is moderated by a skilled facilitator, who is an experienced caregiver themself and who assists in guiding participants through a structured dialogue around issues that are determined by the group. Each meeting is held at a local establishment where guests are offered food and drink. Klatches are also now offered through Zoom calls, so the Coalition can extend its reach to caregivers outside of Minnesota. Jack's Caregiver Coalition offers two Caregiver Klatches a month. One is titled "Caregiver Klatch," which is intended to discuss general caregiver issues, and the other is titled the "Living with Loss Klatch" and is specifically intended for community members who have experienced loss due to cancer.

Jack's Caregiver Coalition also supports its members through caregiver coaches. New caregivers can team up with experienced caregivers who have "been there and done that." Members meet with these experienced caregivers to discuss their challenges and to discover what they should expect when caring for someone with cancer. This program allows members to share and learn from each other and helps create a community of support for caregivers. Coalition members can also meet with a skilled and experienced healthcare navigator who can help them navigate the complex healthcare paths that exist in oncology care delivery.

Finally, Jack's Caregiver Coalition offers a caregiver crash course, "Help! I'm a Caregiver." This is a unique 101-type course that is intended to quickly break down the important challenges new caregivers will face. This course is led by experienced caregivers who provide a base of knowledge to those new to the role, sharing lessons learned and hard facts with attendees. Because caregivers are busy people, the course is designed to be concise and offer as much help as possible in a short time span. Participants leave with knowledge on the many resources that exist to help make life easier for them and their loved ones. Though caregiving 101 is a one-time class for those new to the role, Jack's Caregiver Coalition also offers a longer-term program called "Jack-to-Jack." Caregivers select from other experienced caregivers who serve as a mentor and friend. Caregivers connect with one another, as those who were once total strangers meet and share their experiences through every phase of their caregiving journey.

"Mike, Meet Jack's Caregiver Coalition. Everyone, This Is Mike."

I have been a member of Jack's Caregiver Coalition since November of 2017, just six months after my wife Tracy was diagnosed with multiple myeloma. This was six months after I had been a caregiver on my own, not asking anyone for help and just blindly moving my family through our day-to-day crises. In October 2017, I was given a brochure for Jack's Caregiver Coalition and quickly signed up to become a member. Within a day, I received a call from Kyle Woody—founder of Jack's Caregiver Coalition—to learn more about my situation and to see how the Coalition could help me. Kyle talked to me about what I was going through and let me know that there are other people out there who are going through the same thing as me. He let me know that I wasn't alone. There were so many others out there who knew what I was going through and who could help me in my caregiving journey.

Kyle became a trusted counsel and friend in my time of need. He encouraged me to reach out to other members who were also caring for their loved ones with cancer. Kyle also encouraged me to attend Coalition events. My first event was a great team building opportunity with other members. We met at a local ax throwing venue in Minneapolis, Minn., where we competed to be the "Bad Axe Champion." It was the first time that I had gone out socially during the first year Tracy was diagnosed with cancer. For me, it was such a relief to be able to step away from the incredible and sometimes debilitating responsibility of being a caregiver. I was able to meet other men who, just like me, were struggling through their own family crises and cancer. I then began attending other Jack's Caregiver Coalition events and was supported along my caregiver journey.

Over the years, I have leaned on the Jack's Caregiver Coalition community when times have gotten tough. They've never let me down. Tracey is now in remission after participating in a clinical trial, and I took over the Coalition's blog (jackscaregiverco.org). I began writing caregiving stories for Jack's in partnership with AARP to shine a light on the trials and challenges of being a caregiver. These insights continue to inspire me as I continue through my own caregiving journey. OI

Mike McGarry is a caregiver for his wife, Tracy, who has multiple myeloma. Mike and Tracy have two boys, Joseph, 16, and Jacob, 14. Mike has been a member of Jack's Caregiver Coalition since 2017.

Tank Driver's Jack Event

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- UCSF Helen Diller Family Comprehensive Cancer Center

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