# SPRING 2023

# PERSONALIZING Sepatient Experience

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Two case studies on facilities in Denmark and Australia designed to make patients feel welcome. Page 23



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ASTRO news

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### **EDITOR'Snotes**

### The Patient's Perspective

#### IT'S SOMETHING WE AS RADIATION ONCOLOGISTS

come to terms with over time — delivering bad news to a patient with cancer. It's never easy. But what's it like for the patient? Fear, shock, devastation ... there's no way of knowing how a person will respond emotionally. And that's just the start of their treatment journey. How can we help them navigate this dynamic process, involving various interactions, events and transitions? We have a collection of excellent articles in this quarter's magazine exploring facets of this question.

One piece starts with a personal experience of the author being informed about her diagnosis and how she responded in the immediate aftermath. Another tells of a patient who initially declined treatment because he thought undergoing treatment would result in his wife being left without any money.

How can we make the difficult experience better for patients? Anesa Ahamad, MD, FRCR, DABR, points out that reliable communication is essential and explores the cost of brevity (page 10). Abigail T. Berman, MD, MSCE, looks at shared decision making (SDM), which includes the patient in the discussion on treatment (page 12). Julianne Pollard-Larkin, PhD, writes about physicists coming out from behind the machines and interacting with patients (page 14). Shearwood McClelland III, MD, and Ursula Burnette, MA, discuss clinical and logistical obstacles (page 16), and the importance of patient navigators. Matt Manning, MD, FASTRO, and Christina Yongue, MPH, MCHES, write about socioeconomic barriers and also shed light on institutional racism (page 18). Kiran Devisetty, MD, looks at financial and insurance challenges (page 20) as do Alexandra Baez and Fumiko Chino, MD (page 21), who also cover the difficulties with prior authorization. Architecture and building design play a role as well - the Danish Centre for Particle Therapy in Aarhus, Denmark, being a case in point (page 23). By creating a culturally sensitive environment, the Alan Walker Cancer Care Centre in Darwin, Australia, more than doubled the utilization of cancer treatments among indigenous patients (page 25).

BY NAJEEB MOHIDEEN, MD, FASTRO SENIOR EDITOR, *ASTRONEWS* 

Assessing patient experience seems to lag behind similar evaluations in other industries. In a digital world, service quality is being redefined by how quickly and intelligently frontline teams can act — at any point during live patient journeys. Software can directly impact areas such as the pre-visit experience, intake, during-visit experience, patient safety alerts, patient comfort and the post-visit experience, but that's the low-hanging fruit.

Can we empower patients to play a more active role in their care? Patients now have ready access to notes and investigations. In practice, this means that doctors and patients often receive results simultaneously — and some patients are seeing them before doctors can review them. Initial reports on radiation oncology patients show a strong interest and meaningful benefits in open access to physician notes.<sup>1</sup> Most oncologists would have no objection to this. However, immediate patient access to biopsy and imaging results, patients learning about lifealtering developments through online portals and left to process the information on their own without medical context — that's concerning for oncologists.<sup>2</sup>

More work needs to be done to educate physicians and patients on SDM. Beyond a trusting partnership, digital empowerment and patient-driven platforms may eventually allow patients to engage their care providers in open discussions and make this more likely. But as care shifts to increasingly rely on digital tools, digital inclusion will become critical to promoting health care equity. Delivering equitable care to underserved patients requires an inclusive system that ensures access to affordable broadband, internet-enabled devices, digital-literacy supports and appropriately designed platforms.

Given the theme, it's fitting that we end with Joe Barthold, MD, FASTRO, who passed away this February. Joe served on the *ASTROnews* Editorial Board for many years. We will miss his outgoing personality, kindness and many contributions to articles. He would often say, at the end of the day you have to take a more holistic perspective of the well-being of patients.

The theme of this issue couldn't have been better expressed.  $\square$ 



View references for this article on ) page 30.

### CHAIR'Supdate

GERALDINE JACOBSON, MD, MPH, MBA, FASTRO, CHAIR, BOARD OF DIRECTORS



**SPRING IS A TIME FOR NEW BEGINNINGS**, for planting seeds that will bear fruit in the future. A common thread that links the goals of ASTRO's strategic plan is a focus on investing in the future of our specialty. The goals of our current strategic plan, approved in July 2022, include the following: cultivating fuller engagement with the radiation oncology community, fostering a diverse workforce, improving access to equitable care, driving high quality care, leading policy advocacy, enhancing research and innovation in the field, showcasing the patient benefits of radiation therapy, and ensuring access to innovative education. Pursuing these goals requires ongoing planning, focused activities and continual reassessment.

ASTRO's grants, fellowships and training awards promote many of our strategic goals, including fuller engagement with the radiation oncology community, fostering a diverse workforce and enhancing research and innovation in the field. Our research awards include seed grants for trainees, an emerging investigator award to build a diverse scientific workforce and career development awards. ASTRO has partnered with NRG to provide a fellowship in Health Equity and has supported industry research training fellowships in collaboration with corporate partners. Through collaboration with other societies and industry, ASTRO has increased the breadth of research topics and the level and duration of funding. Preliminary data indicate that ASTRO grant awardees have a high rate of follow-up funding, and we continue to evaluate the impact of these awards.

The Workforce Diversity Committee of the newly formed Council on Health Equity, Diversity and Inclusion is working with our programs to increase the diversity of our trainees and promote diversity in ASTRO leadership. The ASTRO Medical Student Fellowship Award introduces medical students underrepresented in medicine to the field of radiation oncology and supports an eight-week training program and travel expenses for the Annual Meeting. The Leadership Pathway Program provides awardees with a two-year career development program that includes leadership training, mentoring and networking opportunities. We are already seeing the impact of these programs in expanding interest in the field of radiation oncology and the diversity of our

future leaders.

As oncologists, our clinical and research activities have traditionally been directed to local control, cure, palliation and minimizing treatment effects. These are important components to providing safe and effective care. But our patients have their own stories to tell about their experience with the diagnosis and treatment of their cancer. These stories shape their perception of the care they receive and may affect their outcome.

As Maya Angelou, an American author and poet, noted: "I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel."

A systematic review of cancer patients' experiences from three English speaking countries showed that being from an ethnic minority, being diagnosed with poor prognosis cancers and having delayed treatment was associated with a poorer cancer experience. Being diagnosed with earlier stage disease, perception of effective communication, positive patient-provider relationships and receiving treatment with respect were associated with better cancer care experiences.<sup>1</sup> This information supports our promotion of screening and early diagnosis, fostering health equity and removing barriers to timely treatment. In addition, it reaffirms that thoughtful communication and respectful interactions with our patients contribute to a positive cancer care experience and emphasizes the value of our personal interaction with our patients.

The patient experience is emerging as a guide to quality improvement in cancer care as well as an important field of research. This issue of *ASTROnews* explores multiple aspects of the patient experience from communication to facility design. I'm looking forward to learning about innovative and practical approaches to improving the cancer treatment experience for our patients.

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# SOCIETY NEWS

### RO-ILS 2022 Safety Honor Roll

### PATIENT SAFETY IS INHERENTLY

INTERTWINED with patient experience. Patients expect clear communication and timely, highquality care without any medical errors or harm. An ASTRO 2021 Annual Meeting session\* focused specifically on this topic and highlighted how the RO-ILS: Radiation Oncology Incident Learning System<sup>®</sup> can be leveraged to improve patient treatment and experience. Suzanne Evans, MD, MPH, FASTRO, shared how she has a conversation with each patient early in their journey about the importance of speaking up. "We welcome questions [from you as the patient]. If there is something that doesn't meet your expectations, please let us know. We'd be happy to explain to you what is going on."

Promoting open dialogue from the start helps engage the patient in their care. Patients can be an

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untapped safety advocate who could help identify or stop an error. More than 75 events have been reported to RO-ILS in which the patient discovered the error.

### ROILS

RO-ILS participants have access to a readyto-use data collection tool with analysis features to aggregate and learn from their errors in a secure and protected environment. To benefit the broader community, publicly available RO-ILS education shares de-identified events, trends and lessons learned.

Thanks to generous contributions from the sponsors and supporters listed below, RO-ILS is free to users. This benefits the field of radiation oncology so together we are improving safety and the patient experience.

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"RO-ILS has created an opportunity for shared learning to take place that will help patient safety across our community. We applaud this effort and are honored to be part of supporting the community."

> - Chris Toth, President and CEO, Varian, a Siemens Healthineers company

"RO-ILS reinforces that the field of radiation oncology must remain committed to collaboration, communication, as well as independent oversight of the complex processes involved in the delivery of care."

— Erin Schesny, Vice President of Integrated Marketing, Sun Nuclear Corporate

\*RO-ILS and APEx participants can access a free recording of the Annual Meeting session as a part of their exclusive benefits in ASTRO's Quality Improvement Newsletter.

# SOCIETY NEWS

### What's New in ASTRO Member Benefits

### THE MOST POPULAR BENEFITS OF ASTRO

membership include free or discounted rates for access to our journals, the weekly ASTROgram and significant discounts to the Annual Meeting and other educational offerings. ASTRO membership is also a gateway to making important connections. The RO*hub* is a private online community where you can have discussions on field-specific topics and access the member directory. The RO*hub* also provides the forum to participate in Mentor Match and Peer-to-Peer to review cases with colleagues.

ASTRO membership is the stepping stone to having a wider impact in the field, such as participating in the Society's advocacy initiatives, or eligibility for leadership positions. Members can see job postings on the ASTRO Career Center three days in advance and employers can post new opportunities using their member discount. New in 2023, **ASTRO members receive complimentary access to the Science Highlights** sessions presented at the 2022 Annual Meeting. At the end of each month, a new session is released, highlighting key findings in a particular track while featuring cutting edge research. Central Nervous System and Lung Cancer/Thoracic Malignancies are already available and may be accessed in the ASTRO Academy. Head and Neck Cancer will be available at the end of April and Genitourinary Cancer in May.

**Need CME?** Another free member benefit is the availability of the latest Red Journal, *PRO* and *Advances* journal activities in the ASTRO Academy, offering registrants access to the latest peer-reviewed science and helping practitioners provide the best care for their patients while earning CME. Find these and the Science Highlights at academy.astro.org.



# SOCIETY NEWS

### ASTRO's Legislative Priorities in the 118th Congress: Navigating Gridlock for Our Patients

BY GOPAL BAJAJ, MD, MBA, FASTRO, CHAIR, AND CASEY CHOLLET-LIPSCOMB, MD, VICE-CHAIR, GOVERNMENT RELATIONS COUNCIL

"Even in a time of divided government and tribal politics, legislation will advance, and deals will have to be made in order to ensure government can meet its basic obligations to the people."

– John Boehner, Former Speaker of the U.S. House of Representatives

#### FORMER SPEAKER OF THE HOUSE

John Boehner said this recently in describing the current political environment, where Republicans have a narrow majority in the House, Democrats a narrow majority in the Senate, and Democratic President Joseph Biden controls the White House, with 2024 elections already front and center. The Republican from Ohio would know, having presided, and then resigned as Speaker in 2015 amid divided government and party polarization.

While the contentious 15 votes needed to elect new Speaker Kevin McCarthy (R-CA) clearly previewed congressional gridlock, ASTRO must heed the wise words of former Speaker Boehner and find ways around, over and through the logjam to advance the policy priorities critical to radiation oncology, and most importantly, our patients.

On January 20, the ASTRO Board of Directors approved legislative priorities for 2023, as recommended by the diverse perspectives of volunteers on ASTRO's Congressional Relations subcommittee and the Government Relations Committee. The legislative priorities are designed to address the most pressing needs facing radiation oncologists and patients, per ASTRO's membership survey and new strategic plan, and do so in a manner that can appeal to lawmakers from across the political spectrum.

The priorities are as follows:

- Enhancing care quality and value for patients by reforming radiation oncology payment.
- Ensuring patients and radiation oncologists make all treatment decisions.
- Increasing cancer research funding that leads to cancer cures and improves outcomes.

Critical issues like stabilizing Medicare physician payment for radiation therapy services, fixing prior authorization, improving funding for cancer research at the National Institutes of Health and National Cancer Institute, among others, all fall neatly under these priority areas.

ASTRO communicated these priorities to bipartisan, bicameral congressional leaders and Capitol Hill in a January 26 letter, which was shared with the membership in the following week's ASTROgram and is available on ASTRO's website. These priorities will guide ASTRO's lobbying team in their day-to-day efforts to convince legislators from both parties to preserve and expand the high-value nature of radiation oncology for patients.

ASTRO's legislative priorities will also be featured during the premier radiation oncology advocacy event, ASTRO Advocacy Day, May 22-23, in Washington, DC, when radiation oncology advocates from across the country will meet directly with their senators and representatives to advance radiation oncology's policy goals. Registration is open at ASTRO.org for this educational, fun and important event.

While it is likely that far fewer pieces of legislation will make their way to President Biden's desk this year, there is precedent for major legislation or bipartisan priorities to pass, even in a Congress as bitterly divided as this one. Join us at Advocacy Day, invite your members of Congress to tour your clinic, volunteer for a Government Relations Committee, or work directly with Advocacy staff to ensure your voice is heard in the 118th Congress.

Gridlock is no excuse to back away from actively participating in the legislative process, and ASTRO will not let down our fight for what radiation oncology patients and professionals need most.



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## THE PATIENT EXPERIENCE

### INFORMED AND ENGAGED PATIENTS HAVE BETTER HEALTH OUTCOMES. THAT'S OUR TOP GOAL.

An AARP study from December of 2012 has shown a positive link between patient engagement and health outcomes. When patients are well-informed, engaged and satisfied they are more likely to follow health recommendations from their providers and consequently have improved outcomes.<sup>1</sup>

Beyond the health outcomes, health care is literally financially invested in patient satisfaction due to the Centers for Medicare and Medicaid Services (CMS) monitoring of publicly shared patient experience surveys, which impacts reimbursement. Coincidentally, great patient experiences are linked to reductions in malpractice claims and retention of patients.<sup>2</sup> Finally, improving patient satisfaction is just the right thing to do for our patients. Every clinical visit should be maximized for our patients' benefits. For these reasons, all of health care is invested in patient satisfaction and radiation oncology is no exception.

( )

### Patient Satisfaction is Our Top Priority

BY JULIANNE POLLARD-LARKIN, PHD

In this issue, we will discuss how in radiation oncology we are steadily improving our patients' experiences by breaking down communication barriers and building bridges with our patients through transparency and novel physicist-patient communication consultation visits. We also have greatly improved resources for coordination of care and are providing improved financial literacy for our patients. Even the very design of our radiation oncology facilities is being augmented with the sole purpose to create more inclusive and welcoming environments for our patients from a diverse array of backgrounds. By all accounts, radiation oncology is helping lead the way in patient satisfaction.

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# Communicating Realistic Expectations with Patients

BY ANESA AHAMAD, MD, FRCR, DABR

#### IT WAS THE NINETIES IN A BUSY MORNING CLINIC,

and as a junior resident, I was bursting with the usual eagerness to learn everything oncology from my revered attending physician. After all, he knew everything: spinal cord tolerance in 1, 8, 10, 15 and 20 fractions! I presented my patient to him having already explained to her a course of radiation therapy treatment for an unresectable glioblastoma multiforme. Clutching the paper chart, my attending shook her hand and said: "So, we will get going with the treatment that Doctor A just explained to you." Our patient adjusted her wig over the scar on her scalp, looked up at him and said: "So, what's the chance that I will see my 3-year-old grow up?" I felt relieved to be the resident as I watched him form a response. Within a second, my esteemed mentor, with his hand in the pocket of his white coat, calmly said to the 37-year-old anxious patient: "Let's say 50/50. If you have any questions let us know. I'll see you in two weeks."

Great answer: "50/50." It condensed a five- to 10-minute conversation into a few seconds so we could get on with the clinic and spared her the bad news that she was unlikely to survive to see her child grow up. His brief standardized answer is understandable when we consider that our work is often valued and rewarded according to the number of patients that we treat or articles that we publish. Even payment for the communication portion of physician consultations in the United States does not require patient-centered exchange. Rather, it is according to time spent on counseling and/or coordination of care.

But what is the cost of this brevity? It robs us of the gains of effective communication, and leads to lower compliance with treatment,<sup>1</sup> quality of life and satisfaction,<sup>2</sup> psychological functioning of patients,<sup>3</sup> more anxiety, lower recall and understanding,<sup>4</sup> and less valid and ethical informed consent for patients contemplating radiation therapy treatment.<sup>5</sup> Further, it increases the malpractice claims rate,<sup>6</sup> clinician stress and emotional burnout, and decreases job satisfaction.<sup>7</sup>

Perhaps less studied is the effect on our own happiness and health. It turns out that according to the longest in-depth longitudinal study on human life ever done, the Harvard Study of Adult Development (Robert Waldinger and Marc Schulz), neither money, station nor rank make people happy. Rather, good relationships lead to health and happiness. Each encounter with a new patient is an opportunity to forge a relationship and perhaps an opportunity to improve our own well-being.

Like other complex techniques that we perform routinely in radiation therapy, high-quality, effective discussion about realistic expectations is not difficult but requires similar precision and planning. The American Society of Clinical Oncology consensus guidelines on patient-clinician communication<sup>8</sup> summarize the optimal elements:

- · that diagnostic and prognostic information is tailored to the patient's needs and provides hope and reassurance without misleading.
- that patient's goals, priorities and desire for information should be reassessed when considering a significant change in the patient's care.
- that the information is conveyed in simple and direct terms.
- that in the event of bad news, we should take additional steps to address the needs and responses of patients.

There is emphasis on patients' needs, goals, priorities and desire for information. We cannot know these needs unless we take time out to elicit them. This is not the same as telling patients to let us know if they have any questions as we prepare to leave the room. Why not stop and take time out to elicit questions? Are we afraid that we do not have sufficient time? How about the familiar excuse: "it's-the-system-so-much-stuff-to-dowe-do-not-have-time-to-chat." Here is some good news: research shows that when patients attending radiation therapy consultation were deliberately invited by their radiation oncologist to ask all their questions and concerns exhaustively, the mean and median number of questions that they asked was only six.9

While institutions adjust their staffing and infrastructure to increase cultural competence, the act of eliciting patients' questions and concerns offers a shortcut to better understand their culture, personality, comprehension and preferences. As these are revealed, we can tailor our communication style and content to the patients' preferences instead of ours. It also enables customization of their treatment plan accordingly.

Whether we are talking about prognosis, toxicity, delays in treatment that are outside of our control or giving good news, highly personalized communication style and content is a valuable investment that yields better outcomes for institutions and patients and personal fulfillment for clinicians.



Illustration credit: Anesa Ahamad, MD, FRCR, DABR

Anesa Ahamad, MD, FRCR, DABR, is a radiation oncologist with GenesisCare USA and practices in Florida. She has published on effective communication with patients undergoing radiation therapy and is Faculty Alumna of the MD Anderson Cancer Center in Houston and served on the ASTRO Communications Committee.

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### IMPROVING THE PATIENT EXPERIENCE

with Shared Decision Making in Radiation Oncology:



ELEMENTS TO SUCCESS

BY ABIGAIL T. BERMAN, MD, MSCE

SHARED DECISION MAKING (SDM) in radiation oncology is the formalized process by which patients and their care team exchange medical knowledge and patient preferences to determine the best treatment for that specific patient at that given time. SDM has been recognized as a critical effort by providers, patients and legislators. For example, the Centers for Medicare and Medicaid Services (CMS) has mandated SDM using decision aids (DAs) for three conditions (lung cancer screening, atrial fibrillation and implantable defibrillators).<sup>1</sup> Although CMS does not require SDM for oncologic treatment decisions, it has been well recognized as a critical part of a positive patient experience.

The goal of SDM in cancer care is to improve the patient experience upfront and to decrease decisional regret beyond treatment. In radiation oncology, key shared decisions can include radiation versus surgery and/or systemic therapy, radiation modality and fraction number. SDM has critical structural components, including communication training for care teams and DAs for patients, yet this has not translated to increased shared (versus physician-controlled) decisions.<sup>2</sup> An SDM program requires careful planning and customization for a given type of cancer.

#### Use principles of implementation science

Three primary considerations ensure that an SDM program translates to increased patient satisfaction.

First, evidence suggests that SDM requires components beyond decision aids. For example, in prostate cancer, DAs alone have not been shown to improve decisional outcomes.<sup>3,4</sup> One approach to augmenting DAs has been to use the principles of implementation science. The fundamental tenets of implementation science are detailed by the National Cancer Institute and the Consolidated Framework for Implementation Research,<sup>5</sup> among other constructs. Still, the unifying concept is that the intervention can be quickly disseminated and sustained. Although no precise data show that cancer SDM using implementation science is more effective,<sup>1</sup> a thoughtful approach to the intervention, recipients, infrastructure and external environment are critical facets of any SDM program.

#### Involve the entire care team

Second, education and deliberation can and should involve the entire care team to maximize the patient experience. Although physicians are central figures in patient education, nurses, advanced practice providers and social workers have an increasingly vital role in the radiation oncology clinic. Provider-level interventions should be customized to all critical functions of the care team beyond the physician. One unrecognized pillar of the care team for SDM is the patient navigator. The patient navigator plays a crucial role, mainly when the shared choice is interdepartmental such as surgery versus radiation. The patient navigator is not always centered in one department but rather interdisciplinary; therefore, special attention should be paid to SDM training and the involvement of the patient navigator.<sup>6</sup> (Read more about patient navigators on page 16.)

### Consider race/ethnicity disease prevalence and severity

Third, race/ethnicity and broader social determinants of health are required when the patient experience is at the core of a robust SDM program. For example, many cancers, such as prostate cancer, disproportionately affect Black or African American men and other minorities, with more aggressive disease and mortality in these populations. Despite this, many studies on decisional conflict and DAs in prostate cancer have included sufficient numbers of minority men, however it has been hypothesized that the mixed results are partly due to the lack of customizing DAs to minority populations. A multicenter cluster randomized controlled trial tested a DA in prostate cancer where minority men were oversampled; despite this participant enrichment, minority men did not confer measurable gains in prostate cancer knowledge.7 Therefore, a gap remains in how to customize SDM for race/ethnicity impact on cancer prevalence and severity.

In SDM, the patient remains at center stage when the program design considers implementation science principles, an inclusive care team education and race/ ethnicity disease prevalence and severity. As outcomes after radiation improve and patients live longer, careful SDM will gain importance to enhance the longitudinal patient experience, particularly decisional outcomes.

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View references for this article at www.astro.org/Spring23News.

### PATIENT EDUCATION TOOLS

ASTRO and the ROI have many tools available for providers to help patients and their caregivers better understand their diagnosis and radiation therapy treatment options. This list is not exhaustive of all the resources available.

#### **RTAnswers.org**

ASTRO's patient website, is a resource for patients and their caregivers to find detailed information about radiation therapy, including what to expect before, during and after treatment, questions for patients to ask their providers about radiation safety, and a dictionary to help patients with common terms. Videos and brochures are available by disease site and written at a sixth to eight grade reading level. This site is maintained



by the ASTRO Communications Committee and is continuously updated. ASTRO members can embed the patient videos onto their facilities' website and download the brochures for free and customize with your facility name or purchase brochures in bulk to provide to patients and their caregivers. More information can be found at www.astro.org/ProviderResources.

### Ask a Radiation Oncologist

www.RTAnswers.org/AaRO

This series brings together a panel of radiation oncologists to answer patients'

most frequently asked questions. Each session centers around a specific disease site and serves as a valuable tool for patients and their caregivers by covering treatment options, side effects, what to expect during treatment and much more.

### Communicating the External Beam Radiotherapy Experience (CEBRE) Guides

www.roecsg.org/cebre | www.roecsg.org/cogbe

Dan Golden, MD, MHPE, and his team from the University of Chicago developed narrative guides for patients using illustrations to provide visual cues while the provider explains the radiation therapy process. With funding from the Radiation Oncology Institute and the Bucksbaum Institute for Clinical Excellence, these guides explain external beam radiation therapy and include disease-site specific guides for lung, breast, prostate, H&N, CNS and GI. In addition to the





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CEBRE guides, the team developed a patient guide for gynecologic brachytherapy. All illustrated guides are available for download free of charge and customizable.

### PHYSICISTS CAN IMPROVE PATIENT SATISFACTION TOO!



JULIANNE POLLARD-LARKIN, PHD

LONG GONE ARE THE DAYS of medical physicists hiding behind their equipment and calculations. Today, given the increase in specialized, hypofractionated treatments, medical physicists are front and center alongside their radiation therapist colleagues in treatment vaults directly interacting with patients. This role may be new to some physicists as well as radiation oncologists, but to many progressive physicists, it's about time.

Cancer patients have been documented with having radiation therapy anxiety rates of nearly 40%.<sup>1</sup> The complexity of cancer care plans which can include surgery, chemotherapy, immunotherapy and then a multistep radiation therapy process can be overwhelming for a large portion of radiation therapy patients. It is incumbent upon our specialty to identify tools to combat fear, anxiety and anything that would reduce the likelihood of a patient following through with their cancer treatment. A fearful patient is dissatisfied and more likely to be noncompliant.

The National Cancer Institute has recommended several psychosocial techniques to reduce fear, stress and anxiety in cancer patients such as relaxation training, counseling, support groups and cancer education sessions.<sup>2</sup> Most radiation oncology centers employ some if not all of these practices to care for their patients in a more holistic way. However, it wasn't until 2018 when medical physicist Todd Atwood, PhD, helped lead a team to provide radiation therapy patient education and counseling using a new representative from the radiation oncology treatment team.

Dr. Atwood's team's "Establishing a New Clinical Role for Medical Physicists: A Prospective Phase II Trial" was unexpected, well-needed and disruptive in the best way.<sup>3</sup> Since the first use of radiation to treat or image disease in a patient, medical physicists have used their skills to ensure accuracy, precision and safety of the treatment or procedure. However, never had we been considered to be a mouthpiece for direct interaction with the patient. This study changed that irrevocably.

Members of the American Association of Physicists in Medicine debated the merits of this work repeatedly at their annual meetings and in social media posts. For traditional medical physicists already overwhelmed with their roles as radiation safety officers, special procedure overseers, educators, researchers and quality assurance specialists for all radiation equipment and procedures, they had no interest in adding one more role to their overfilled list. For other physicists seeking to improve the quality of their patient's 4-D CT scans, breath hold compliance and overall treatment outcome, this idea from the University of California San Diego (UCSD) team could not have come sooner.

Admittedly, I am biased and in the latter aforementioned group. Anything that increases the fidelity of a patient treatment is worth the treatment team's effort. And putting the needs of the patient first is the hallmark of health care. The phase II study was simple and provided each of the patients two consults with their physicist, once prior to CT simulation and the second meeting prior to their first fraction of radiation therapy. The physicist-patient consult meetings were for just 20 minutes for the pre-simulation meeting and 40 minutes for the prefirst fraction meeting. This allowed for the patient to learn a more thorough overview of the process they were undergoing for simulation and treatment delivery and also, allowed the patient multiple opportunities to have questions answered regarding their plan. In order to prepare for patient interaction, the physicists on the study were trained for eight hours on how to communicate with patients. This training has now been standardized and is being used routinely for physicists across the country. The results of the phase II study indicated that for their 30 patients investigated, they were able to reduce anxiety with their physicist consults in a statistically significant fashion (p<.0001).<sup>3</sup>

In the group's phase III trial, they studied the impact of their physicist-patient interactions on a group of 66 randomized patients. And the results from their phase II study was further supported by the phase III cohort who showed statistically significant decreases in anxiety and increases in technical satisfaction in the arm of patients who received the physicist consultations.<sup>4</sup> While the patient anxiety level between the cohort of phase III patients with physicist consultations did not decrease statistically significantly until the last treatment, physicist communication definitely had an immediate impact on technical satisfaction from simulation and throughout the end of treatment. Physicists clearly are able to articulate to patients the complexities involved with their radiation treatment plan and procedures. Therefore, if a patient's anxiety level is related to not technically understanding the process of radiation therapy, having an effective communications physicist is a top priority for any radiation therapy center.

Physicist consults for potentially anxious patients and those who must comply to a special procedure whether it be breath hold, 4-D CT, surface guidance or even having to use the immobilization devices that we employ in our centers, can ultimately improve a patient's understanding of why their compliance is necessary. The consults may empower the patient to perform better than otherwise and have a resultant improved treatment outcome. All of this is possible with little to no extra cost other than a small time investment.

As a highly involved, in-the-vault with the patient everyday medical physicist, I am thrilled at the expansion in expectations for those physicists willing to learn and hone a new communication skill. Admittedly, for a program like this to be successful, patients should be stratified based on anxiety level and then the clinic should provide the resources to train their team. I look forward to larger studies showing the impact of physicists educating and showing compassion to our patients that link to dosimetric parameters that will convince a broader audience as to why all of us should be better communicators.

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## LOGISTICS OF CLINICAL CARE AND RELATION TO PATIENT SATISFACTION FOLLOWING RADIATION THERAPY



BY SHEARWOOD MCCLELLAND III MD, AND URSULA BURNETTE, MA

View references for this article on page 30.

"Hearing the words, "You have cancer," is one of the most devastating times in a person's *life.* You hear nothing else the physician may be saying at that moment. Your mind begins to race with a million questions and thoughts, such as, "How long do I have to live? What am I going to tell family and friends? How am *I going to get through this?*" And so forth. To benefit a patient most upon diagnosis would be to have a physician say "A team will come to discuss some of the thoughts that are running through your mind." *Having a patient navigator work* with the doctors and specialists creates a "united front" where everyone is looking out for the best interests of their patients.

Once I received my diagnosis, I could have benefited from a navigator to discuss a plan from the origination of the diagnosis to any treatments and/or surgeries that would be needed, plus mental and emotional support services, and daily living with cancer support services. I do not think many oncology physicians *are aware that the accessibility* of a patient navigator can greatly impact a cancer patient's perspective of their diagnosis and offer a glimpse of hope from something so devastating." - Ursula Burnette, MA

The diagnosis of cancer is one of the most life-altering experiences conceivable for patients and their loved ones. Not only is the diagnosis itself jarring, but it comes with a simultaneous insult to injury: the clock is ticking, with every second of delay in optimal treatment potentially decreasing the risk of survival. Furthermore, the precise knowledge of what optimal treatment entails is often shrouded in confusing verbiage that can hinder patients from decisively and expediently seeking the care they need from the right provider at the right place and at the right time.

As radiation oncologists, we are often unaware of the reality of these difficulties cancer patients face unless they directly impact our treatment plans to kill their cancer. Such impacts include insurance denials, missed clinic visits, missed treatment fractions, inability to complete radiation therapy as planned, and missed follow-up post-treatment. If we are to truly optimize the care of our patients, we must be proactive in addressing often well before these patients reach our clinic.

An evidence-based proven methodology of optimizing oncologic patient care from diagnosis to treatment involves integrating the use of a patient navigator. Navigation is a community-based intervention designed to optimize access to timely diagnosis and treatment by eliminating barriers to care, serving as a patient-centric health care service delivery model.<sup>1</sup> Ideally instituted at the time of cancer diagnosis, navigators work with patients to guide them through the maze of visits, laboratory tests and imaging comprising optimal care in a timely and cost-efficient manner.

Founded by Harold Freeman, MD, the importance of navigation (and its integration into the health care team) has increased over time commensurate with the increasing complexity of cancer care requiring coordination between the three arms of cancer treatment: surgical, medical and radiation.

As patient satisfaction has increasingly become a greater influence on reimbursement, it has become not only the right thing to do to optimize patient satisfaction but the most fiscally sound as well. Pursuit of navigation-assisted oncologic care has been shown to increase timeliness of patient care, which has been reflected in significantly higher patient satisfaction scores among the highest-quality studies.<sup>2</sup>

Navigation is of particular importance for underrepresented minority patients where evidence has shown that African American, Hispanic American and Native American patients are less likely to receive guideline-concordant oncologic care than Caucasian patients. Consequently, increased adoption of navigation has the potential to reduce oncologic treatment access disparities in surgical oncology, medical oncology and radiation oncology. This is the hypothesis of the Navigator-Assisted Hypofractionation (NAVAH) program we have implemented at University Hospitals Seidman Cancer Center (Case Western Reserve University School of Medicine) with the gracious support of several supporters, most prominently the National Cancer Institute and ASTRO.3

The importance of navigation is increased in centers without multidisciplinary disease site clinics allowing surgical, medical and radiation oncologists to see the patient in a coordinated fashion. Without such coordination, patients can easily fall prey to delays in appointment scheduling, which can lead to treatment delays and consequently substandard care, which risks compromising their overall survival. Having the guidance of a navigator helps the patient maintain as straight and short of a path from diagnosis to completion of optimal treatment as possible.

It is important to remember that even following completion of optimal therapy in a timely manner, there is often much trauma awaiting patients, including potential long-term physical and financial toxicity of treatment.<sup>4</sup> As these aspects continue to increase in complexity, the importance of navigation in optimizing oncologic outcomes becomes ever-increasing over time.

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Ursula Burnette, MA, is a breast cancer survivor and the principal patient navigator for the Navigator-Assisted Hypofractionation program addressing African-American breast cancer patients at University Hospitals Seidman Cancer Center. Her work is funded by the National Cancer Institute. Twitter: @DrMcClellandLab



### Identifying and Addressing Obstacles: Lessons from the Anti-Racism ACCURE Study



BY MATT MANNING, MD, FASTRO, AND CHRISTINA YONGUE, MPH, MCHES

**INSTITUTIONAL RACISM IS A TERM** that generates a variety of responses. If the outcome of an individual within an institution is better or worse based on race, there must be structures in place to create those disparate results. A well-known quote sometimes attributed to W. Edwards Deming is that "Every system is perfectly designed to get the results it gets." In its current form, our health care system produces worse results for Black patients. American Cancer Society data showed that in the most recent five-year period, Black men had a 6% higher incidence of cancer but 19% higher mortality than white men.<sup>1</sup> How is our health care system designed to create these results? To what extent does radiation oncology contribute to racial health disparity? Do all of your patients have equal access to radiation therapy and satisfactory quality care experiences? Maybe so, if all of your patients have reliable transportation, flexible schedule, childcare, family support and trust the health care institution. It could be said that our privileged patients have equal access and better health outcomes due to treatment completion. Sadly, the rigorous daily routine of outpatient radiation oncology is not equally accessible to all patients.

Over 20 years ago, the Greensboro Health Disparities Collaborative (GHDC) was formed to respond to, empower and facilitate communities in defining and resolving issues related to disparities in health (pictured at the top of page 19). They began

these efforts focused on racial inequities in cancer treatment. Originating with community organizers, using anti-racism principles, the GHDC engaged in community-based participatory research with a combination of qualitative and quantitative research. First, they developed a research question collaboratively and conducted an exploratory study, funded by the National Institutes of Health, to document examples of differences in cancer treatment completion by race. Then, after years of intentional strategies to sustain what could be called a "community-universitymedical partnership," the GHDC implemented the Accountability for Cancer Care through Undoing Racism and Equity (ACCURE) study from 2012-2017. ACCURE implemented multimodal systemic changes applying transparency and accountability to eliminate differences in treatment completion. ACCURE was designed to combat structural racism in health care, which is a strategy of institutional improvement that benefits all patients. At baseline in the ACCURE study, Black patients with stage 1 and 2 lung cancer completed either resection or SBRT at a rate of 64% compared to 76% for white patients. Using a realtime registry alerting clinicians when patients missed milestones in care and an enhanced nurse navigator trained in anti-racism and proactive engagement protocols, the completion rates increased to 96% for both Black and white patients (Figure 1).<sup>2,3</sup>



The Greensboro Health Disparities Collaborative

Through this work, the GHDC and its partner hospitals identified common obstacles to care and worked to create solutions. There were many varied socioeconomic, cultural and institutional system barriers. The barriers faced by each patient are unique and require curiosity and intentional work to identify and work through.

In the category of socioeconomic obstacles, common barriers include access to transportation. Through a patchwork approach, including bus vouchers, gas cards and ride share services, cancer centers can potentially lessen this burden. Other socioeconomic barriers can include missed work or lack of childcare. While these may be more challenging, solutions can only emerge when we seek to understand and overcome them.

In the category of institutional system barriers, it was also discovered that there were barriers with rescheduling appointments for patients, bridging communication gaps between patients and oncologists, requesting more affordable medications, and reengaging patients after lapsed treatment. By empowering the nurse navigator with proactive engagement protocols and anti-racism training, these types of barriers are more easily identified and overcome through the



### Treatment Completion

additional two-way communication protocols used.4

More insidious cultural obstacles include mistrust of the health care system and sometimes a lack of clear communication of the consequences of not completing cancer treatment. These more subtle obstacles can be identified and addressed through the work of the nurse navigator and clinicians who were increasingly aware of racial disparities. Using clinical tools like the Kleinman's Explanatory model, providers were prompted to ask follow-up questions to understand how a cancer diagnosis impacts patients emotionally. Through this strategy, nurses and physicians were able to better understand what may drive patients to avoid treatment or not trust.

A common way to describe patients who did not complete cancer treatment in the past was "noncompliant." This terminology blames patients for not overcoming barriers to care, which misses the context surrounding the patient's humanity and the complexity of causation. Shifting the focus of responsibility to our health care system can move the blame to providers and hospitals who are well-funded and incentivized to eliminate barriers and overcome obstacles that our patients face. 🕂

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View references for this article on page 30.

Figure 1: Completion of Lung Resection or SBRT before and after the ACCURE Intervention



### **FINANCIAL NAVIGATION:** Key to the Puzzle

BY KIRAN DEVISETTY, MD

#### WE ALL HAVE THAT ONE PATIENT

we remember for some unique scenario, and one that has always stuck with me was a healthy engineer whom I had previously enrolled into RTOG 0534. When I was seeing him in follow-up a few years later, he had new neurologic symptoms that I worked up to find out was an unresectable grade 2 astrocytoma. Naturally, since his PSA was undetectable, we discussed definitive radiation therapy as an option, but his first response was to decline. When I asked why, he said he needed to leave behind some money for his wife to survive.

The term "financial toxicity" was first made official in a 2013 Oncologist paper,<sup>1</sup> but it has been ever present and significant long before. Over the past few years, there have been concerted efforts to improve literacy within the medical community, yet it remains a prognostic and predictive factor that is independent of insurance coverage, especially in the era of high deductible health care plans. A 2022 Kaiser Family Foundation survey of over 2,300 patients with health care debt found that 63% of respondents cut spending on food/ clothing/basics and 17% declared bankruptcy or lost their home.<sup>2</sup> When surveying debtors on causes of U.S. bankruptcies, researchers determined in 2007 that 62.1% were medically related, and when they updated their results for 2016, that rate was 66.5%.3

The data for financial toxicity specific to radiation oncology is limited. A survey of 157 patients with questions focused on the financial impact of radiation therapy reported 28% loss of job, 24% loss of income, 20% difficulty paying for housing, 15% difficulty paying for transportation and 13% difficulty paying for meals. A concurrent survey of 210 radiation oncologists found 53% were very concerned about costs of therapy, but despite that, 75% did not discuss this with their patients nor perform a routine screen for financial burden.<sup>4</sup> Interestingly, only 11% of patients wanted to discuss cost of care with their radiation oncologist, whereas a similar patient survey from Germany (i.e., universal health coverage) reported 44% wanted the same.<sup>5</sup>

Beyond the usual billing complexities of deductibles, coinsurance and co-payments, radiation oncology has a unique practice in which much of the billable patient care is repetitive (e.g., daily treatments that could require daily co-pays) and sometimes independent of a patient encounter (e.g., treatment planning). Add in the separation of professional and technical/facility billing (i.e., receiving two bills often from the same date of service) and arcane description of services (e.g., "guidance for localization of target volume, includes intrafraction tracking if performed"), patients essentially need a cipher in order to

decode their explanation of benefits — all while trying to handle the physical, emotional and logistical challenges of a cancer diagnosis and treatment.

There is no easy solution to provide the financial education and assistance required. For both the physician and patient, it can be difficult to discuss and process both the medical and financial aspects of treatment at the same visit. One option is to integrate an appropriate distress screening tool with financial questions at the time of intake (e.g., NCCN Distress Thermometer) that can serve as a trigger for additional support after the visit. Of course, this means that there needs to be an investment by the health system into social work and/or financial counseling services that often do not have direct billable events. Many of my medical oncology colleagues have dedicated financial counselors, and it's time we as a field consider the same. Anecdotally, we have seen an improved rate of treatment adherence and insurance coverage for these services that should indirectly offset their costs.

To complement this need for financial support, there must also be increased price transparency in the cost of care. As a field, we have done an admirable job of abbreviating the length of treatment, which has led to improved patient outcomes and costs. However, there is significant variability in the cost of care that



### Prior Authorization makes patients feel 'incredulous and hopeless'

BY ALEXANDRA BAEZ AND FUMIKO CHINO, MD



**TREATMENT** that accompany a cancer diagnosis have harmful effects on patient quality of life and treatment outcomes; in some cases, financial toxicity can be as harmful as the disease itself. Although almost all patients with cancer have health insurance to help with the costs of their care, prior authorization processes can both delay care and increase financial burdens for patients.

Prior authorization can compromise patient access to care. Although prior authorization is intended to promote evidence-based cancer treatments and reduce unnecessary care, it requires both clinicians and patients to navigate an often complex and restrictive approval process. The issues caused by prior authorization practices are not exclusive to private health insurance policyholders. According to a 2022 health policy analysis conducted by the Kaiser Family Foundation, almost all Medicare Advantage enrollees (99%) are in plans that require prior authorization for some services.<sup>1</sup> Prior authorization practices delay the delivery of medically necessary care and can ultimately have serious adverse effects on a patient's health.

For physicians, there is a general consensus that prior authorization is harmful to patients. A 2021 American Medical Association (AMA) survey found that 91% of surveyed physicians report that prior authorization has a negative clinical impact on patient health. For example, 93% of physicians reported delays in care, and 34% reported that the delays led to a significant decline in patient well-being.<sup>2</sup> According to a member survey conducted by ASTRO in 2019, prior authorization practices consistently led to delays or outright denials of cancer care. Almost all (93%) radiation oncologists respondents reported that their patients were delayed from cancer treatment due to prior authorization, and about a third (31%) reported that this delay lasted longer than five days.<sup>3</sup> A survey conducted by the American Society for Clinical

"We believe that all patients should have timely access to evidence-based care as recommended and provided by their cancer team."

> Oncology (ASCO) in 2022 reveals frequent denials of therapy (87%) and significant delays (96%) perpetuated by prior authorization; it also noted increased patient out-of-pocket costs (88%). Additionally, oncologists reported that patients denied approval were forced to either pay out-of-pocket for their cancer care or deviate from their initial intended course of treatment and receive the "second choice" plan (93%).<sup>4</sup> In other words, the patient's health insurance company stood in between the patient and their oncologist's preferred method of treatment for cancer.

> For patients with cancer, the ramifications of prior authorization denials or delays can be fatal; over a third of physicians surveyed by ASCO ascribed patient loss of life due to restrictive authorization processes (36%).<sup>4</sup> In June 2022, the AMA coauthored an amicus brief about how prior authoritative delays caused a patient "immense suffering and, ultimately, her life." While awaiting approval from her health insurance company, the patient was unable to receive a diagnostic MRI. Once the scan was finally approved after substantial delay, it revealed sarcoma in her hip. During this delay in care, cancer progressed without treatment; by diagnosis, the patient required a more radical amputation surgery and ultimately died of disease. The brief lays part of the blame with the prior authorization process.5

> For oncologists trying to navigate simultaneously adhering to insurance policy rules and treating patients, prior authorization is an administrative nightmare. According to a 2019 national survey conducted

> > Continued on following page

to attain the oncology trainee perspective, prior authorization approval processes negatively affected their medical training; 69% of trainees reported having to participate in the process (78% of radiation oncology trainees). Most respondents (71%) reported concern for the quality of care being administered to patients due to prior authorization.<sup>6</sup>

A 2021 survey conducted on insured non-elderly adult patients shows that patients are not only impacted physically but are also frequently forced to get involved in the administrative tasks required by prior authorization.<sup>7</sup> Patient involvement in these complicated pre-approval processes and administrative tasks create unnecessary stress and anxiety in patients. Sadly, despite over 70% of radiation oncologists respondents reporting that their patients regularly express concerns to them about the delays caused by prior authorization,<sup>3</sup> the wealth of knowledge on the patient perspective of prior authorization is slim. Patients are the ones who are directly affected by the constrictive pre-approval processes of prior authorization, yet they are rarely asked about their fears and anxieties of being denied lifesaving treatment. Research conducted from our study team at Memorial Sloan Kettering has focused on the patient perspective including rising anxiety and erosion of trust when faced with prior authorization for cancer care. Thematic analysis of patient statements includes expression of frustration, distrust of the insurance company, helplessness and lack of transparency. One patient said, "The fact that my care would be denied during active cancer treatment, meaning my cancer diagnosis was not enough of a reason to approve cancer care, is unconscionable. It makes me feel incredulous and hopeless..." Our future research is focused on the patient experience of prior authorization. How are patients being affected emotionally, physically and fiscally by the restrictive approval process and how do we effectively measure the downstream cancer outcomes?

As advocates for our patients, it is essential that radiation oncologists take the proper action to demand change in prior authorization policy. The potent combination of data and ASTRO member prior authorization patient advocacy stories have contributed to legislative and regulatory action. H.R.3173, the "Improving Seniors'Timely Access to Care Act," passed through the House in Fall 2022, aims to improve prior authorization among Medicare Advantage plans.<sup>8</sup> While the bill has stalled in the Senate due to a significant cost estimate, new Medicare Advantage regulatory rules hold great promise. In December 2022, the Centers for Medicare and Medicaid Services issued proposals consistent with H.R. 3173 that would streamline prior authorization by making it an electronic process while establishing national standards for documents to reduce administrative burden.<sup>9,10</sup> An electronic infrastructure would allow for real-time prior authorization decisions for services and items that are categorized as "routinely" approved and increase transparency.

While H.R.3173 and the proposed rules are important steps in the right direction, they are not cancer-specific policies and focus exclusively on the role of prior authorization in Medicare Advantage plans. As advocates with a powerful voice, it is imperative that radiation oncologists continue to share with policy makers (local, state and national) the true implications prior authorization has on patients with cancer. We can do so by composing messages that highlight the priorities of radiation oncologists to our elected officials and by participating in events like ASTRO Advocacy Day, being held on May 22-23 in Washington, DC. This two-day event features talks with guest policy experts, policy issue briefs, Hill meeting training and more.

We believe that all patients should have timely access to evidence-based care as recommended and provided by their cancer team. The prior authorization process needs to be reevaluated for its efficiency and value — and placed in a patient-centered framework.

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Fumiko Chino, MD, is a cancer researcher, Assistant Attending in Radiation Oncology, and co-lead of the Affordability Working Group at Memorial Sloan Kettering. Her research is focused on the financial toxicity of cancer care, survivorship, health care disparities, equity and access.





In this article, we highlight two facilities and key principles that guided their design processes to create inviting spaces that enhance the experience of patients and their caregivers.

### MAKING SPACE FOR THE INDIVIDUAL: A COMPREHENSIVE DESIGN PROCESS AT THE DANISH CENTRE FOR PARTICLE THERAPY

BY SIMONE BERTELSEN, COMMUNICATIONS OFFICER, THE DANISH CENTRE FOR PARTICLE THERAPY

#### ANYONE CONSTRUCTING A RADIATION THERAPY

**CLINIC** must face two inevitable design constraints. One is to design the bunker to protect surroundings from radiation, and the second is the consideration for the patient's delicate situation with a life-altering disease. The staff and architects behind Danish Centre for Particle Therapy (DCPT) in Aarhus, Denmark, wanted to cater to these needs early on in the design process, putting the patient at the very center and following a Scandinavian minimalistic design tradition. Several initiatives were taken to make the building express this vision and create a welcoming environment with an open space construction, while also integrating a new center within an existing hospital structure.

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The Danish Centre for Particle Therapy (DCPT) is located at Aarhus University Hospital in Aarhus, Denmark, and started providing patient treatments in January 2019. As the only proton facility in the country,<sup>1</sup> the center is part of the public health care sector, providing access to proton beam radiation therapy to all relevant patients.



High ceilings, daylight and wooden features greet patients, caregivers and visitors when entering the center.



Changing cabinets for patients are integrated in the interior design and marked by bright colors on the way to each of the three gantries.



rooms. A glass roof covers the middle of the center, providing daylight throughout the four seasons.

One key factor was to ensure daylight for patients and staff. DCPT is constructed with a glass roof in the middle, creating plenty of natural light. A 'shield' of weathering steel surrounds the building, creating both a distinct and coherent look from the outside.

At DCPT, a safe and accessible treatment experience for patients and their relatives is underlined by the interior design. The ground floor contains reception, the waiting area, scanners and treatment facilities and is characterized by natural light, voluminous green plants and an open space with high ceilings. Wooden panels and natural materials create a warm atmosphere. Furniture was carefully selected to fit the vision of both an inviting space for dialogue and options for secluded waiting areas for those seeking more privacy.

The far end of the waiting area is designated for pediatric patients and their families. Danish artist Søren Bencke has created a playful universe with adventurous characters for the children to follow through their own treatment course. The open floor space is inviting for electric racing cars that some children prefer to drive to their appointments, and toys are welcome alongside the many teddy bears that inhabit the DCPT "jungle."

Consultation rooms and offices are located above the treatment facilities and decorated with selected artwork. The facility also provides space for a large research group on the top floor and for staff and visitors alike.

Easy wayfinding was a high priority. A key principle for wayfinding at DCPT is that patients always have the same entry point. Treatment preparations including scanners are all located on the left side of the building and gantries on the right side. The technical side of the construction is hidden from patients and visitors. When arriving for treatment, scanning or consultations, patients enter the building the same way every time, "checking in" on a small scanner, and the treatment team picks up each patient.

Entering the three gantries, patients meet a hallway decorated with bright colors and lighting design by artist Malene Bach, with colorized doors for patients, and white doors for staff members. Wooden changing cabinets and light sculptures interact with the colorful mazes of each of the treatment rooms.

A comprehensive design process with these guiding principles has merged the technical requirements with a welcoming atmosphere, making room for both the individual patient and their caregivers and for staff members to enjoy their everyday work life at DCPT.

Photos the cover and pages 23 and 24 credited to Tonny Foghmar, Aarhus University Hospital.

<sup>1</sup>The DCPT building and equipment is funded by the A.P. Møller Foundation, the Danish state and Central Denmark Region. The Alan Walker Cancer Care Centre (AWCCC) is located in the Northern Territory in Darwin, Australia, at the Royal Darwin Hospital. The radiation oncology department opened in 2010 and incorporates culturally sensitive outreach programs, which have contributed to more than doubling the utilization of cancer treatments among Indigenous cancer patients.

### ALAN WALKER CANCER CARE CENTRE

BY KAR GAIM, CO-DIRECTOR, MANAGER AND DIRECTOR, RADIATION THERAPY, ALAN WALKER CANCER CARE CENTRE

Indigenous Australians used to be 50% more likely to die from cancer than non-Indigenous Australians. This gap is even more significant in the Northern Territory (NT) as 30% of the population are Indigenous.<sup>1</sup>

In addition to well-researched cultural barriers and lifestyle factors, NT Indigenous people experience other major challenges that contribute to the cancer outcomes gap. These challenges include enormous geographical distance, poor access to timely and appropriate care, lack of understanding of cancer by community health workers, low rates of cancer screening, limited rural cancer care providers, oncology staffing shortages, late disease presentation, complex psychosocial and socioeconomic issues, unmet supportive care needs, inadequate services for post-treatment care and surveillance, and overall poor health literacy among patients and their families, not least in relation to cancer.

The radiation oncology service at the Alan Walker Cancer Care Centre (AWCCC) increased uptake of radiation therapy among Indigenous cancer patients from 22% (2001 figures) to 48% only one year after it opened in 2010.<sup>2</sup> Completion rates for radiation therapy courses have gradually increased to 95%. A recent publication indicated that increased life expectancy for the Indigenous population was primarily linked with fewer life years lost to cancer over the period 1999-2018.<sup>3,4</sup>





Painting is a significant activity to connect with home and community A patient and her sister (her escort) support her cancer journey.

#### AWCCC Model of Care for Aboriginal people

AWCCC has a Territory-centric model of care and solutions to address the unique challenges faced by the patients and health system. The AWCCC organizational cultural framework includes environmental safety, cultural awareness, kinship, barriers to care, unconscious bias and respectful engagement with patients to gain their trust. The approach is based on individualized patient care coordination, early and effective patient engagement, a holistic organizational approach to cultural security, education to improve health literacy around cancer, and building strong relationships with primary and community care providers.

Care coordination starts with early engagement with patients, family and health care providers upon referral or diagnosis. This engagement is interprofessional and involves doctors, cancer care coordinators, Aboriginal liaison officers, interpreters and community health teams with a strong focus on telehealth communication with patients and their families to optimize treatment participation. Telehealth has been the norm since (and before) the center opened 13 years ago (distinct from the explosion of telehealth in the last few years).

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Cultural interpreters are trained to understand he principles in oncology care to ensure accurate translations and interpretations.



Patient consultation is more effective where the patient is most comfortable, such as an outside consultation space.

AWCCC provides cancer training programs to upskill and support community doctors, nurses, Aboriginal Health Practitioners, community workers and Aboriginal Interpreters to understand complex concepts and terminology from early detection to post-treatment surveillance. In particular, ensuring staff, patients and families understand the steps in the treatment process and the role, for example, of linear accelerators in treating cancer, has been critical. Culturally appropriate ceremonies and practices, such as smoking ceremonies, blessing of the linacs and providing outdoor consultations and waiting spaces have been central to the design and delivery of the service.

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RO trainee Peter Nguyen conducts a cancer education session for the curriculum at the Batchelor Institute (Tertiary Institution for AHPs in the Top End).

### HISTORY

BY PAUL E. WALLNER, DO, FASTRO; FEI-FEI LIU, MD, FASTRO; RICHARD W. TSANG, MD, FASTRO; AND TIMOTHY J. WHELAN, BM, BCH, FASTRO

### **Giants of Radiation Oncology:** Biographical sketches from the ASTRO History Committee

### M. Vera Peters, MD (1911 - 1993)

MILDRED VERA PETERS (she dropped the Mildred in college) was born and raised on a farm in what was then rural Ontario, Canada, now a part of metropolitan Toronto. Life was never easy, especially after her father's sudden death when she was only 11, the youngest of seven children. Following his death, Vera and her siblings spent much of their free time doing farm chores. Vera's mother, a teacher, emphasized the importance of education to all her children. Despite significant financial pressure and her early education in a one-room schoolhouse, it was clear that Vera was intelligent. The family was able to scrape together the funds to send her and five of her six siblings to college.

As an undergraduate at the University of Toronto, Vera initially majored in mathematics and physics, but then transferred to a six-year program at the University's medical school. During her undergraduate years, Vera's mother developed breast cancer. Her primary management was then standard-of-care, a Halstead radical mastectomy. Her disease subsequently recurred on the chest wall, at which time she was treated by Gordon Richards, MD, often referred to as the father of Canadian radiation oncology. Dr. Richards was the first president of the National Cancer Institute of Canada and chair of the first radiation oncology training program in Canada. He treated Vera's mother with a cotton vest containing an array of radium needles. This management did not control her disease and she ultimately succumbed to breast cancer in 1933, but her mother's experience stimulated an initial interest in oncology and radiation therapy.

Following her graduation from medical school in 1934, M. Vera Peters, MD, spent two years in a surgical residency where she had an opportunity to reconnect with Dr. Richards. She subsequently entered his training program and upon completion, joined the staff at the Ontario Institute of Radiation Therapy at Toronto General Hospital (TGH), where she and Dr.



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Richards became long-term colleagues and scientific collaborators. From her earliest days at TGH, it was apparent that Dr. Peters was a gifted clinician and scientist who was devoted to her patients and mentees, many of whom were young women. When Princess Margaret Hospital opened in 1958, Dr. Peters worked there until her retirement in 1976.

Early in her career, based on her experience with her mother's illness and encouraged by Dr. Richards, she began to focus her clinical and research interests on breast cancer and Hodgkin lymphoma (HL) then called Hodgkin disease, a malignancy that was universally fatal.

During the 1930s, Dr. Richards and Dr. Peters observed that a small cohort of patients with HL had survived for extended periods. Peters reviewed the records of this small group and was one of the first to develop a staging classification for the disease. She recognized that they had presented with limited disease and had been treated with localized radiation, but unfortunately, often with significant complications or a subsequent relapse in adjacent lymph node regions. Using their new 400 kVp X-ray unit, they began to employ higher doses of radiation with more extended fields of treatment, noting significant improvement in survival. Dr. Peter's initial report of these observations was first published in the American Journal of Roentgenology and Radium Therapy in 1950 and presented to an international HL conference in Mexico City in 1956. Henry Kaplan, MD, recently named chair of the Department of Radiology at Stanford University, attended that meeting and recognized the potential

Continued on following page

impact of the new findings. Dr. Kaplan proceeded to use Dr. Peters' retrospective findings to develop prospective randomized multidisciplinary clinical trials that ultimately led to further breakthroughs in the management of HL, which is now considered a highly curable entity.

In a 1953 paper, Dr. Peters indicated that although the overwhelming majority of breast cancer patients seen at TGH had undergone a Halstead mastectomy, the radiotherapy department was seeing an increasing number of patients who underwent simple mastectomy followed by radiation to the chest wall, and a smaller cohort, who, for various reasons, had been treated primarily with local excision followed by radiation to the breast, +/- lymph nodes. Dr. Peters reported that these patients had fared as well as those treated with radical mastectomy. She became convinced that the future of breast cancer management lay in less radical surgery, and despite Dr. Richards' early disapproval, convinced several of her surgical colleagues to begin using excision alone followed by radiation in selected patients. Her prospective experience with this cohort

was first reported in 1967 and a subsequent case control study in 1975. In the face of extraordinary criticism from the surgical community, she convinced colleagues around the world of the validity of her findings, and numerous prospective randomized clinical trials affirmed her observations. Her reports formed the foundational basis for current breast conservation management techniques.

During her illustrious career, Dr. Peters was honored by the government of Canada, including, and uniquely for a radiation oncologist, issuance of a commemorative postage stamp in 2020. She received honorary doctorates from two universities, and in 1979, the fifth Gold Medal ever awarded by ASTRO. Dr. Peters also enjoyed a full and rewarding personal life, as Mrs. Kenneth Lobb (a high school physical education teacher) and mother of two daughters. M. Vera Peters was a gifted clinician and visionary investigator who had a profound impact on the lives of innumerable patients and the practice of radiation oncology and serves as an important role model for young women in medicine.

View references for this article at <u>www.astro.org/Spring23News</u>.

# 2023 CORPORATE AMBASSADORS

ASTRO PROUDLY RECOGNIZES THE ONGOING COMMITMENT OF OUR CORPORATE AMBASSADORS FOR THEIR OUTSTANDING YEAR-ROUND LEADERSHIP AND PROMOTIONAL SUPPORT OF RADIATION ONCOLOGY.

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## QUALITY Improvement

RANDI KUDNER, ASSISTANT DIRECTOR OF QUALITY IMPROVEMENT, ASTRO

### Patient experience as a quality indicator

#### SO OFTEN, THE FOCUS IN RADIATION THERAPY is

the treatment. However, the transition to value-based care has required health care providers to focus more on patient experience. Experience can encapsulate a myriad of different elements that go beyond the disease status. Assessment of patient experience, paired with Aggregated APEx data shows that, historically, these areas were low performing but each area has meaningful improvement at the time of the facility visit after quality improvement measures have been implemented. The improvement highlights the value of APEx's Self-Assessment review.

other evaluations, is vital to achieving a comprehensive understanding of quality and safety in a radiation oncology practice.

The Agency for Healthcare Research and Quality (AHRQ) defines patient experience as whether something that should

happen in a health care setting actually happened.<sup>1</sup> AHRQ goes further to state that patient experience should not be conflated with patient satisfaction, which is defined as whether a patient's expectations about a health encounter were met. AHRQ itemizes nine distinct areas that contribute to patient experience:

• Access to care

- Communication
- Office staff
- Coordination of care
- Self-management
- making

  Health promotion

Shared decision

- and education
- Access to specialists
- Cost of care

Several articles in this *ASTROnews* discuss the factors listed above and ASTRO has developed programs to help practices assess and improve these areas. ASTRO's APEx – Accreditation Program for Excellence® assists radiation oncology practices by evaluating current processes and comparing them to national expectations. Each of the AHRQ domains is included in the APEx assessment and is measured through certain activities like sharing end of treatment summaries with referring physicians, thorough and timely patient education, access to translation services, financial counseling and referral for therapeutic interventions. These are all reviewed during the Self-Assessment phase of the program and reassessed during the on-site or virtual facility visit.

APEx helps improve areas related to patient experience 100% 80% 60% Providing Supporting care Providing Providing financial comprehensive frequent patient coordination counselina patient education education Self-Assessment Facility Visit

At its core, patient experience and satisfaction are both based on communication and a partnership between patient and clinician. Consistent and thorough patient education is essential to communicating realistic expectations and enabling shared decision making. What should be included though, and how often is education needed? Written and verbal patient education

should be provided before any procedure begins as part of the informed consent process, and at least once during the course of treatment, and should include:

- a discussion of treatment options and rationale for radiation therapy;
- treatment intent;
- treatment expectations; and
- management of treatment-related side effects.

ASTRO's RTAnswers.org provides print and video patient education options in multiple languages. How recently have your practice's patient education materials been updated? What do you offer to patients and how often? ASTRO encourages all radiation oncology practices to review current educational materials and processes to strengthen patient understanding and experience. Better yet, start an APEx application, joining the more than 400 radiation oncology practices in APEx, and let ASTRO help you assess and enhance the patient experience.

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#### Continued from FINANCIAL NAVIGATION: KEY TO THE PUZZLE

stems from the complexity of our coding system, regional differences in reimbursement and nuances of treatment planning. This can make it difficult to estimate out-of-pocket costs for patients when obtaining prior authorization. One consideration is for departments to design their own in-house "bundles" of frequently used codes for common treatment plans that can facilitate insurance processing prior to treatment.

There are other facets of care coordination we should consider to mitigate financial and logistical burden, especially during posttreatment follow-up. Often patients see multiple physicians in short periods of time, when in fact these can be spaced out and alternated with the assistance of a navigator. Coordinating imaging, multiple laboratory requests and outpatient visits on the same day can save the patient extra trips, inconvenience and costs. Sometimes it is the little things that can make a big difference. I believe we all realize medicine is both a calling and a business, but these don't have to be mutually exclusive. With the appropriate perspective, support and education, the system can be made to work in a way that we can effectively treat cancer and not produce a financial toxicity that can be self-defeating.

For my patient, after engaging a team that included a social worker, professional biller and technical biller, we were able to provide an accurate estimate of costs and additional support such that he understood he could afford it without exhausting his finances. He then agreed to radiation and now remains with no evidence of disease a few years later, having survived two cancer diagnoses with enough financial stability to not regret his curative treatment.

Kiran Devisetty, MD, is a Clinical Associate Professor at Mercer University School of Medicine and chair of ASTRO's Code Utilization and Application Committee (CUAC).

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Now that we are gearing up for ASTRO's Annual Meeting in San Diego, we invite authors who have submitted abstracts for the Annual Meeting to submit their research as articles for any of ASTRO's journals. The journals welcome pre-submission inquiries and full submissions through Editorial Manager. Links to each submission site may be found at redjournal.org, practicalradonc.org and advancesradonc.org.

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### Hear the Latest ASTRO Journals Podcasts

We encourage you to catch up on recent ASTRO journals podcasts!

- In the Red Journal, Editor-in-Chief Sue Yom, MD, PhD, FASTRO, spoke with Drs. Kaitlyn Lapen, Patricia Holch and Galina Velikova on the future of electronic patient-reported outcomes.
- In *Practical Radiation Oncology*, Dr. Jeffrey Brower discussed the ASTRO clinical practice guideline for radiation therapy in endometrial cancer with Drs. Matthew Harkenrider and Paola Gehrig.
- Lastly, in *Advances in Radiation Oncology*, Dr. Ashley Cetnar led a discussion with Drs. Arnab Chakravarti, Nilendu Gupta, Ahmet Ayan and Jessica Fleming on developing a FLASH research program.

### JOURNALS

### HIGHLIGHTS



HIGHLIGHTS FROM INTERNATIONAL JOURNAL OF RADIATION ONCOLOGY • BIOLOGY • PHYSICS

An Introduction to Meta-Analysis Lehrer et al.

In this Statistics for the People article by Lehrer et al., the authors discuss the value of meta-analysis, a statistical method that allows investigators to quantitatively combine the results of multiple studies identified in a systematic review. Depending on the clinical question and type of outcome of interest, different effect size measures can be used, such as proportions, odds ratios, hazard ratios, risk ratios and mean differences. Although multiple types of metaanalyses are used in the medical literature, the most frequently encountered are those using study-level data. Thus, it is essential for investigators to conduct a rigorous systematic review and carefully assess each candidate study before inclusion in the meta-analysis.

#### **Geographic Accessibility of Radiation Therapy Facilities in Sub-Saharan Africa** *Nadella et al.*

In this article for our Around the Globe section, Nadella et al. describe accessibility measured as travel time by road to radiation therapy in Sub-Saharan Africa. This study used geographic information systems modeling techniques, including a list of radiation therapy facilities obtained from the Directory of Radiotherapy Centres. The authors then ranked countries using three measures of access: two-hour geographic access, units per capita and units per cancer case.



### HIGHLIGHTS FROM PRACTICAL RADIATION ONCOLOGY

Neoadjuvant Therapy in the Post-German Rectal Trial Era: Making Sense in the Absence of Consensus Hui et al.

This Topic Discussion from Hui et al. discusses their approach to neoadjuvant therapy for locally advanced rectal cancer, based on the data they currently have and through shared decision making with patients to help them select the treatment that best aligns with their preferences and values. Total neoadjuvant therapy has become an increasingly used approach in which most, if not all, chemotherapy is delivered before surgery to improve compliance and to address micrometastases early. To avoid surgical morbidity, a "watch-and-wait" approach, in which total mesorectal excision is deferred, has also been studied for patients who achieve a clinical complete response after chemoradiation.



### HIGHLIGHTS FROM ADVANCES IN RADIATION ONCOLOGY

Prostate Cancer Outcomes in Patients Living with HIV/AIDS Treated with Radiation Therapy: A Systematic Review Vaziri et al.

This critical review article from Vaziri et al. aims to summarize the evidence on the management of prostate cancer (PCa) with radiation therapy in people living with HIV/AIDS (PLWHA) who are diagnosed with PCa. Advances in surgery, radiation therapy and chemotherapy have significantly improved the way in which PCa is managed. Despite this, there is a paucity of data describing management and outcomes of PCa in PLWHA. Historically, PLWHA may have been excluded from participation in many National Cancer Institute-sponsored clinical trials, limiting the generalizability of any conclusions to this patient population. Thus, the purpose of this systematic review is to evaluate the clinical outcomes and toxicity of PLWHA diagnosed with PCa treated with definitive radiation therapy.



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