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TERMS OF ENGAGEMENT

ONE RELATIONSHIP LIES AT THE HEART OF ALL MEDICAL PRACTICE — that between physician and patient. Szasz and Hollender posited three models for that engagement: active-passivity, guidance-cooperation and mutual participation.1 For most of medical history, the first two held sway, paternalistic and physician-centric. In fact, physician training seems to have been oriented toward such an asymmetric relationship.

This imbalance has been challenged in the last two decades through arguments for a more autonomous and thus patient-centered philosophy. The Institute of Medicine’s 2001 report, Crossing the Quality Chasm: A New Health System for the 21st Century, defined patient-centered care as “providing care that is respectful of and responsive to individual patient preferences, needs and values and ensuring that patient values guide all clinical decisions.” In the years since, numerous attempts have been made to redesign the U.S. health care system toward this end.

In current radiation oncology practice, we spend considerable time discussing options, expected outcomes, side effects and complications with patients. As Neha Vapiwala puts it: “Radiation oncology is a specialty firmly rooted in patient-centered care.” Still, a recently published paper by Narek Sharverdian2 and colleagues suggests room for improvement. In a nationwide survey of 403 patients, the majority found their radiotherapy toxicity experience to be no worse than expected. However, approximately one in three experienced treatment toxicities they wished they had known more about (see page 18).

Neha makes the case that shared decision making (SDM) carries tremendous potential for personalizing every patient interaction and ensuring that the conversation is efficient and productive. Dan Golden writes that patient materials explaining the process of care, side effects, etc. are well above national guidelines for readability levels. Dan is involved in a collaborative effort supported by a Radiation Oncology Institute (ROI) grant to develop and test prototypes of site-specific discussion guides so that they can be made available online to all clinics. Another study funded by the ROI is by David Byun on using virtual and augmented reality tools to increase patient knowledge about radiation therapy and reduce anxiety. These will be invaluable resources to bridge a gap in our care.

Fumiko Chino and Carol Hahn highlight the toll of treatment costs — direct and indirect — on patients and families. The patient interview with Heather Brinkerhoff is heartbreaking. The indirect costs, often hidden, include lost wages or even lost jobs. Here’s a startling statistic: 42% of newly diagnosed cancer patients run through their life savings in two years.3 While there are no solutions in sight, normalizing cost conversations is an essential part of patient-centered care, the authors say.

Dave Adler and Samantha Dawes discuss ASTRO’s efforts to engage patients in advocacy and the guideline process in keeping with the mission to advance radiation oncology by promoting excellence in patient care. An ASTRO membership survey reveals major concerns — prior authorization, restrictive coverage by payers, administrative burden and in private practice, complying with federal quality payment programs. According to a survey in Health Affairs, U.S. physician practices in four common specialties spend, on average, 785 hours per physician per year on reporting quality measures and costs practices an estimated $15.4 billion each year.4 This is inefficient and expensive and distracts us from patients and patient-centered care. Whether the Radiation Oncology Alternative Payment Model or the new MIPS value-based pathway will improve this for radiation oncology is anybody’s guess. The obstacles include lack of interoperability across EHRs and lack of EHR functionalities to facilitate retrieval of data for quality measures. Jim Hayman writes about furthering efforts on interoperability and oncology data standards to move us forward from the current siloed ecosystem (page 11).

Continued on page 5
AS WE BEGIN A NEW YEAR, OUR LIVES OFTEN BECOME EVEN MORE HECTIC. Despite the rush of the holidays and the push to finish lingering projects before a few well-deserved days off, the most reflective among us seem to find the time to contemplate the accomplishments and blessings of the outgoing year and set goals for the coming year. I wish I could always count myself among this contemplative group, but unfortunately, with a packed schedule, I seem to bumble from one thing to the next with great hope, a positive attitude and a prayer that it all works out. This year, however, I have the great opportunity to serve as chair of ASTRO and, among the many blessings this brings, one is the chance to provide a few reflections on our great field and, thus, I am providing myself just a bit of time to do so.

In my Presidential Address at the Annual Meeting in Chicago, I spoke about how and why we, radiation oncologists, are so important to the care of patients with cancer. We pursue discovery — research that is directly translated to improve human health — and this drives our field forward. When we do so, we often cure patients. When we cannot cure, we can relieve suffering. No matter what, we can always provide hope. We are also given the gift to educate extraordinarily talented resident physicians who go on to repeat the cycle. We should be proud of what we do and the leadership we provide in the oncologic community. We are, indeed, very lucky to have found this field.

During my talk, I also mentioned that I have been unable to find a single, credible example of where bringing greater diversity of opinion, perspective and experience to an organization did not result in improved outcomes. Indeed, quite the opposite is typically true. Reflecting on this, where is ASTRO in this regard? As noted in a recent review of our membership, ASTRO has less than 30% women and has very few African American and Hispanic members. I believe this lack of diversity is a risk for our future, as we will not, by definition, have all the voices and experiences at the ASTRO table to help us develop the necessary strategies to keep us relevant for years to come. Moreover, without looking more like the patients we serve, I do not believe we can assure ourselves that we are staying focused on the needs of an increasingly diverse patient population.

Taking my reflections together, I think we are actually in an enviable position to dramatically increase the diversity in our field. As I first noted, radiation oncology is a field that is extraordinarily exciting, scientifically driven and tangibly impacts the health of a large fraction of our country and the world’s population. We can and should make this attractive set of facts more visible to women and students from groups who are underrepresented in our field. I am confident that with creative thinking and the inclusion of many ASTRO member voices, we will become the oncologic specialty that leads in creating the diverse workforce that our field and our patients require.

The ASTRO Board created the Committee on Health Equity, Diversity, and Inclusion (CHEDI) a few years ago to help focus attention and spur action in improving ASTRO’s work in some of these areas. I think it is time for us to move to the next step and ask CHEDI to help the Board develop a bold, multi-year strategy with measurable outcomes to bring more diversity into our field. Yes, this will take time and resources to achieve, but given that we are a field that combines the best of science and medicine, I am confident the plan we develop will be effective in achieving our goals. I think when we pause and reflect at this time of year 10 years from now, we will be thankful we took direct, substantive action to improve diversity, and we will be happy it made us an even more relevant, vibrant leader of the oncologic community.

I wish you all a very happy new year filled with peace, joy and laughter.
2019 WAS A YEAR OF CONTINUING INNOVATION AT ASTRO. Our commitment to serving you, our members, and the patients you treat is steadfast, and our strategic plan continues to drive our work to advance the field of radiation oncology.

ASTRO administered the **Scope of Practice survey** in the spring that asked members if they were interested in expanding the scope of service they provide, and if yes, what areas of service they are interested in expanding. The results will better inform us on the support ASTRO can provide and the tools we can create for members and will be published in 2020. Additionally, ASTRO sponsored a **nationwide survey of U.S. adults treated for cancer** with radiation therapy to gain a better understanding of patient perspectives on their treatments and side effects. The results were published online in November in the Journal of Oncology Practice (See page 18 for full details). Feedback from the survey informed updates to our patient materials, including new videos in development and updated brochures, which are being rewritten to incorporate side effects charts. In addition to the PowerPoint presentations available for members to use in presentations to medical professionals and community groups, we’ve added a disease-site specific presentation on lung cancer, with additional disease sites coming in early 2020.

On the **training and education of our resident physicians**, we heard from many residents over the course of the year regarding needs on training and education. We held meetings, convened conference calls and met with the American Board of Radiology (ABR) and other stakeholders to develop up-to-date curricula for biology and physics. Moving forward, ASTRO will work with the ABR and other interested parties to provide updates to the information on a yearly basis to ensure it remains current.

ASTRO continues to envision and prepare for emerging technologies and scientific advances and, in 2019, launched a new workshop at the Annual Meeting focused on **radiopharmaceutical therapies (RPTs)** to enable members to provide the highest quality of patient-centered care in the use of RPTs. ASTRO is collaborating with the Society of Nuclear Medicine and Molecular Imaging (SNMMI) in the work regarding RPTs, and we are working on joint consensus guidance on patient-centered care for theranostics to be released in 2020.

On the scientific front, ASTRO launched **Industry Research Fellowship** opportunities with Varian and AstraZeneca. These research fellowships will support the next generation of investigators as they conduct research on a myriad of topics including the efficacy and safety of drug-radiation combinations, AI and more. The in-depth ASTRO Research Workshop on Treatment of Oligometastatic Disease was held in June, and attendees overwhelmingly appreciated the sharing of cutting-edge data, some of which had not yet been published.

ASTRO published **three clinical practice guidelines** in PRO this year: Radiation Therapy for Pancreatic Cancer; Radiation Therapy for Basal and Squamous Cell Skin Cancers; and a guideline update on radiation after prostatectomy. ASTRO also published **two consensus papers** on standardizing normal tissue contouring for radiation therapy treatment planning and minimum data elements for radiation oncology. An additional two guidelines have been completed and submitted for publication.

In July, the Centers for Medicare and Medicaid Services (CMS) released the proposed **radiation oncology alternative payment model (RO Model)**. ASTRO provided CMS with input on our concerns with the RO Model and invited CMS officials to
attend the Annual Meeting in September. There, officials met with attendees and key leadership for proactive discussions and to receive feedback. ASTRO has engaged congressional leaders to assist in expressing concerns to CMS and urging CMS to make changes to the model. As of print, ASTRO expects the final rule to be released in January 2020 and continues to advocate for changes to the proposed model.

In response to members practicing in rural communities reporting challenges in providing care, the Board engaged a task force to study the needs of these members. In September, the Board approved many of the task force’s recommendations. Specifically, ASTRO is implementing a peer-to-peer matching system, which will match members for the purpose of virtual physician-to-physician peer review. A new webpage on RTAnswers.org was created to provide transportation and other resources for patients, and we are currently working with the Rural Task Force to use data to formally define what constitutes a rural facility.

ASTRO’s three-year transformation of the Annual Meeting kicked off in September in Chicago. Changes included a redesigned Presidential Symposium, which introduced a debate followed by highly interactive breakout sessions. The overall program allowed for more time for collaboration and networking, and a new focus on physician wellness was introduced. The highly popular Practical Radiation Oncology (PRO) program, which offered community practice physicians a weekend option to attend the Annual Meeting, was offered again this year. We also increased the robust content in our print and digital daily newspapers and e-newsletters, reporting more of the science from the meeting. And for the first time, we compiled a summary of the scientific breakthroughs from the Annual Meeting to help patients and patient advocacy groups better understand the research in the field coming out of the Annual Meeting.

Lastly, we are thrilled to congratulate Stephen Hahn, MD, FASTRO, who was confirmed as the new commissioner of the FDA in December. This is a great way to close out another year of innovation and growth. We look forward to all that 2020 has to offer as we continue to provide you valuable benefits and services. Please let us know how we can better serve you by emailing astronews@astro.org.

On the other hand, the kind of work that supports safe and high quality patient care is that of RO-ILs, which recently recorded the 10,000th reported safety event (page 6). While this would suggest the need for even more direct engagement and diligence of the radiation oncology team in the day-to-day delivery of care, it’s difficult to comprehend the recent CMS change in supervision requirements in hospital-based departments for therapeutic procedures (including radiation oncology) to a laxer general supervision standard.

Also in this issue, Arjun Sahgal and Dave Larson discuss reirradiation of the spine with SBRT, while Sushil Beriwal and Scott Glaser bring you practice-changing highlights from the Chicago Annual Meeting and beyond. Alex Spektor and Neil Martin review useful tools and some challenges in wider implementation of patient-reported outcome measures. Paul Wallner and Brian Davis write on changes in the ABR, including appointment of the first public member to its board to reflect a better perspective on patient and population well-being.

In recent memory, the treatment of AIDS saw a transformation of the doctor-patient relationship. Patients and activists conducted their own research, looked at alternative therapies and questioned their treatment. They secured a meaningful role for patients in all areas of research and treatment.

Cancer patients now have access to many sources of information and support apart from their physician. Our role has evolved from being the chief arbiter of treatment decisions to that of holding a discussion with the patient to help interpret and synthesize information, while debating goals and options. It becomes important to understand the patient’s expectations and recognize that, while it may not be consistent with what our experience tells us is a realistic goal, it must be factored into the shared decision-making process.

Happy New Year and all the very best for 2020 from the Editorial Board at ASTROnews.

References

RO-ILS: RADIATION ONCOLOGY INCIDENT LEARNING SYSTEM recently celebrated its five-year anniversary and 10,000th reported safety event in the fall of 2019. Since its inception in 2014, more than 500 facilities from across the United States have joined RO-ILS to contribute patient safety data to Clarity, the contracted patient safety organization (PSO). Clarity PSO is a federally listed entity that offers health care providers an opportunity to collect and analyze events in a legally protected environment as stipulated by the federal Patient Safety and Quality Improvement Act of 2005. Participation in RO-ILS is free for practices, thanks to the generous support of ASTRO, AAPM, ASRT, AAMD and corporate supporters.

RO-ILS helps with improving patient safety from various angles: the program provides education not only to the health care provider community, but also to the vendor community. Though the data remain confidential, everyone from the end user to the product creators benefits from the lessons learned from the data collected in RO-ILS.

“RO-ILS gives us an opportunity to better understand clinical practice,” said Kolleen Kennedy, president of Proton Solutions and chief growth officer at Varian. “To understand where misadministration occurs and where near misses occur enables us to make our software solutions and hardware platforms more robust, such that user experience is enhanced while clinical workflows are simplified and automated, thereby improving efficiency as well as patient safety.”

Varian has been investing in its commitment to patient safety as a financial supporter of RO-ILS for the past three years and attributes the updates and data received from RO-ILS with helping to identify high-risk decision events, which become a leading factor in portfolio priorities, product design and implementation processes. As participants and supporters both point out, it’s not about calling out a specific product, vendor or facility. Collectively, the data contributes to helping the radiation oncology community as a whole to reduce and prevent errors. “RO-ILS has truly been a catalyst in bringing an aligned motivation of efforts and investment, whether it’s the application of domain expertise or product development, to help drive the entire community forward for better patient safety results,” said Kennedy.

Participants of RO-ILS share similar sentiments. “To really take safety seriously requires more than vigilance, it requires us to be proactive. We need to go out and find our weaknesses and anticipate where things could go wrong,” said RO-ILS participant Jay Burmeister, PhD, of Karmanos Cancer Center in Detroit. Analyzing safety events that were caught before reaching the patient and addressing those error-prone processes is a critical aspect of incident learning. Dr. Burmeister also highlights the value of RO-ILS education, such as aggregate reports and case studies derived from the data and developed by interdisciplinarity safety experts. “RO-ILS not only gives us the ability to track our own deficiencies but also to learn from hundreds of other departments, with the hope that we can identify future problems before they become errors.”

RO-ILS promotes a confidential, collaborative learning environment. Technological advancements have improved radiation oncology care and highlighted the importance of safe, symbiotic human–computer interactions. Vendors develop interventions high on the hierarchy of effectiveness to help prevent and catch errors, and institutions implement standardized processes and safety initiatives, such as peer review and incident learning, to promote safe practice. “We are all in this together. All stakeholders in the field share the same objective, ensuring patients are getting the best care possible — and that means patient safety,” Kennedy concluded.

Learn more at www.astro.org/ROILS.
Senate confirms Stephen Hahn as FDA commissioner

ASTRO CONGRATULATES STEPHEN HAHN, MD, FASTRO, on his December confirmation as the new commissioner of the U.S. Food and Drug Administration.

A well-regarded radiation oncologist and longstanding ASTRO member, Dr. Hahn served on the ASTRO Board of Directors from 2014 to 2018. ASTRO Chief Executive Officer Laura I. Thevenot said, “During his tenure on the ASTRO Board, Dr. Hahn always brought insightful questions to our deliberations. He takes the time to listen to all sides before he reaches a decision, which will be important in this new role. His depth of knowledge will allow him to accomplish the many tasks ahead as FDA commissioner.”

“Dr. Hahn’s impressive background as a triple board-certified physician in medicine, medical oncology and radiation oncology coupled with his broad administrative experiences will allow him to ably lead the thousands of career professionals charged with ensuring U.S. consumer protection and public health,” said Theodore L. DeWeese, MD, FASTRO, chair of the ASTRO Board of Directors. “Our support and respect for Dr. Hahn is based on his proven commitment to patients, science-based decision making, and consumer health and safety. We look forward to his leadership as he steps into this critically important role as FDA commissioner.”

Dr. Hahn most recently oversaw clinical care at MD Anderson Cancer Center. He previously served as chief operating officer at MD Anderson and is widely credited for leading its financial turnaround. He also worked at the National Cancer Institute and was chair of the Department of Radiation Oncology at the University of Pennsylvania. Congratulations, Dr. Hahn, from your ASTRO colleagues!
ASTRO members share their insights in the 2019 Membership Survey

BY TIM SANDERS, ASTRO SENIOR RESEARCH ANALYST

THE ASTRO MEMBERSHIP SURVEY is an annual look into how members feel about their membership and the Society’s initiatives, direction and programs. The 2019 Membership Survey was fielded from May 13 to July 1, 2019. The web-based survey was completed by 1,395 ASTRO members for a response rate of 18%. We appreciate the high level of engagement of our ASTRO members; an 18% response rate is high for a web-based-only survey.

Who responded?
Of the 1,395 members who completed the 2019 Membership Survey, 71% are located in the United States. Two-thirds (64%) of all the members who completed the survey are radiation oncologists. Medical physicists (16%) and radiation oncology residents (12%) are the second and third most commonly reported professions (Figure 1). When we look across both our domestic and international respondents, half of all respondents practice at an academic setting, whereas only 38% practice in a private/community setting. This changes considerably when we look specifically at U.S. radiation oncologists, with 51% practicing at private/community settings and only 43% practicing in an academic setting. Across both domestic and international locations, the vast majority of respondents are hospital based (88% international; 71% domestic).

Other demographic features of our respondents include:
• Two-thirds of respondents are male.
• Increases are seen in the number of millennials completing the survey and decreases are seen in the number of baby boomers completing the survey over the past three years.
• For domestic respondents, a larger concentration of respondents is found east of the Mississippi River, yet 49 of the 50 states are represented, as well as the District of Columbia (Figure 2).
• More than half of all members who completed the survey come from urban areas, while only one in 10 come from rural areas.

Importantly, the respondents to our survey mirror our membership database for profession, gender, geographic region and primary employer.

This representativeness gives us confidence that the survey results are reliable for ASTRO to use as we make decisions about future initiatives, direction and programs.
Feelings about ASTRO

Each year, we ask ASTRO members if they find participation in ASTRO to be a good use of their time. Over the last five years, this number has ranged from 85% to 90%. In 2019, 85% of our members reported that participation in ASTRO was a good use of their time. This high level of volunteer engagement allows ASTRO to build initiatives and programs for all our members.

In general, satisfaction among all respondents remains steady and high over the last three years (Figure 3). Radiation oncology residents report the lowest levels of satisfaction with ASTRO membership, with satisfaction declining over the last three years (Figure 4). Specifically, radiation oncology resident respondents indicate that they would like more educational opportunities and more robust resources like leadership training, facilitated networking and help identifying job opportunities. Female respondents also reported a slight decline (from 82% satisfied in 2018 to 78% satisfied in 2019) in their satisfaction with ASTRO (Figure 5).

How members stay informed about ASTRO’s happenings

Members who completed the survey reported using multiple communication channels to access content from ASTRO. The top four communication channels were:

1. Topical emails from ASTRO
2. ASTROgram (ASTRO’s weekly e-newsletter)
3. ASTRO website
4. ASTROnews (ASTRO’s quarterly magazine)

More than two in five respondents use each of these communication vehicles to stay informed about ASTRO’s services, activities and benefits. Just over a year ago, ASTRO redesigned and relaunched the ROhub. In the survey, we found that over a quarter of members read the daily digest of conversations taking place on the ROhub. We hope this platform continues to be a fruitful vehicle for discussion. Join the conversation or ask more questions about the membership survey on the ROhub at rohub.astro.org.

Daily challenges radiation oncologists face

We continue to see that obtaining prior authorization is the number one challenge facing U.S. radiation oncologists in their daily practice (Figure 6). Prior authorization was a major issue addressed during Advocacy Day in 2019. After receiving nearly 700 survey responses from U.S. radiation oncologists, ASTRO launched a media outreach and legislative campaign to communicate the burdens that prior authorization introduces for cancer patients and their physicians. ASTRO remains focused and committed to this issue on behalf of our members and their patients.

Continued on the following page
Coupled with prior authorization and restrictive coverage policies by payers, administrative burdens and participating in federal quality payment programs are among the top challenges for both academic and private practice. In comparing the 2018 Membership Survey results to 2019, both academic and private practice respondents reported keeping up with the latest developments and emerging technology in the field as more challenging.

**Engagement with ASTRO programs and initiatives**

Four out of five respondents are aware that ASTRO provides research grant opportunities (Figure 7). For more information about grant offerings, please visit www.astro.org/fundingopps. When asked if respondents conducted scientific research (Figure 8), two-thirds indicated that they conduct research and 92% of those who conduct research indicated their research focus is clinical.

Only two-thirds of U.S. radiation oncologists and medical physicists indicated that their practice is accredited by a practice accreditation program. One in five mentioned that their practice was not accredited by an accreditation program but is considering accreditation. For more information regarding accreditation, please explore www.astro.org/APEx.

**Summary**

ASTRO is committed to using this feedback to inform and improve the membership experience and continuing to better the Society for the future. Thank you to everyone who took the time to complete the 2019 Membership Survey. The survey is sent out every summer, so don't miss it in 2020! Your input is essential to make ASTRO work best for you.
PERSONALIZED MEDICINE, VALUE-BASED CARE AND LEARNING HEALTH SYSTEMS are current buzzwords in health care. Each of these concepts focuses on the idea of patient-centered care, which harnesses evidence and experience in order to provide an individualized medical approach. This environment is reliant upon access to computable patient data to allow aggregated statistics on comparative effectiveness and outcomes to facilitate shared decision making. However, the current ecosystem of siloed, nonstandard data dramatically limits the ability of doctors and researchers to learn from patient records. It hinders care coordination and adds to the administrative burdens and costs for all users, including patients. Health care data, in its current form, prevents patient-centered care.

Following the publication of the Minimum Data Elements for Radiation Oncology paper, ASTRO has taken a further step into promoting computable data standards in oncology by joining the Executive Committee of the mCODE (Minimal Common Oncology Data Elements) initiative. mCODE seeks to create a basic oncology-specific FHIR-based (HL7 Fast Healthcare Interoperability Resources) data element set based on real-world use cases. ASTRO joins other leaders — ASCO, the Alliance for Clinical Trials in Oncology Foundation, the FDA and the MITRE Corporation — in spearheading this effort.

mCODE provides both a common data language and an open source, nonproprietary data model for enhancing interconnectivity across systems. The initial data standards cover six domains, of which four characterize treatment with radiation: patient, lab visits, disease, genomics, treatment and outcomes with 73 distinct data elements, using common medical terminology built on existing standards. FHIR resources are assigned standardized identifiers that function like the URL of a webpage. This enables discrete data sharing rather than the document-based exchange that many information systems currently rely on. Once adopted, mCODE can facilitate the ability of clinicians and researchers to provide better treatments for cancer patients by using the invaluable information contained in the EHRs. mCODE will facilitate patient care and inform research by enabling analysis of data across the lifetime of a single cancer patient and across patient cohorts. Opportunities also exist to expand the minimum set of radiation oncology-specific data elements through Common Oncology Data Elements Extensions (CodeX), an HL7 FHIR Accelerator.

Cancer centers, including Partners Healthcare, Intermountain Healthcare, Dana-Farber and MD Anderson, are currently piloting use cases utilizing the mCODE standard. ASTRO is currently facilitating conversations to engage others in the radiation oncology community with leaders in this effort. If your practice is interested in learning more about this effort, please contact ASTRO Senior Quality Improvement Manager Randi Kudner at randi.kudner@astro.org.

ASTRO has learned that the following members have passed away. Our thoughts go out to their family and friends.

Robert J. Barish, PhD, New York, New York
James R. Dolan, MD, Portage, Michigan
Eli J. Glatstein, MD, FASTRO, Philadelphia, Pennsylvania
George Goodman, MD, Vancouver, British Columbia
Frank R. Hendrickson, MD, FASTRO, New Smyrna Beach, Florida

The Radiation Oncology Institute (ROI) graciously accepts gifts in memory of or in tribute to individuals. For more information, visit www.roinstitute.org.
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   e. Total Free or Nominal Rate Distribution: 50; 50
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   a. Paid Electronic Copies: 0; 0
   b. Total Paid Print Copies + Paid Electronic Copies: 7,150; 7,650
   c. Total Print Distribution + Paid Electronic Copies: 7,200; 7,700
   d. Percent Paid (Both Print and Electronic Copies): 99.3; 99.3
18. I certify that all information furnished on this form is true and complete. I understand that anyone who furnished false or misleading information on this form or who omits materials or information requested on the form may be subject to criminal sanctions (including fines and imprisonment) and/or civil sanctions (including civil penalties).
IN THIS ERA OF “PERSONALIZED” APPROACHES TO MEDICAL MANAGEMENT, shared decision making (SDM) and patient-centered care are fairly ubiquitous terms that have become widely accepted as critical components of high quality clinical care. Guidance on optimal ways to incorporate both of these tenets into modern practice, however, is somewhat harder to find. Unlike more tangible outcome measures like tumor control, overall survival and adverse events, outcomes that pertain to the patient experience can be more challenging to describe, and thus, clarity regarding the definition of these terms is an important place to start. The overarching concept of patient-centered care encompasses a variety of efforts focused on patient satisfaction, engagement and treatment compliance. Similarly, SDM is about more than just the decision; it is a form of patient-centered care in which patients and providers are actively and jointly involved in considering the options and ultimately selecting a path forward.

Radiation oncology is a specialty firmly rooted in patient-centered care. From the very first reports of anti-tumor application of ionizing radiation over a century ago, the hopes and expectations of the patient and loved ones remain a central driving force. As our specialty evolved, our dominant focus — and reputation, in many respects — has been biologically- and technically-driven advances, with the perennial goal of optimizing the therapeutic ratio — or as I frame it for patients, “Maximal dose where we want it, minimal dose where we don’t.” On the surface, this may seem like primarily a dosimetric planning issue. But patients play a critical role beyond being the consumers, and I would posit that the therapeutic relationship is more critical than ever to the therapeutic ratio. The most sophisticated and meticulous radiation treatment plan (or drug or surgery) won’t work if the patient is not on board.

Enhance the therapeutic relationship
Unlike more traditional drug therapy and surgery, however, radiation is a “black box” for many patients and non-radiation oncologists, historically feared and often misunderstood. Given the associated stigma, patients’ understanding of the radiation therapy process, of the importance of adhering to a schedule, of reporting treatment-related symptoms and, in turn, of following instructions for symptom mitigation are all important modifiable factors in our pursuit of the optimal therapeutic ratio. When this understanding is absent, patients are at risk of compromising outcomes, presumably unwittingly. In contrast, when patients actively participate in care decisions and provide truly informed consent to management and therapy approaches, a tacit yet explicit partnership develops, unlike the traditional hierarchical relationship of yore (i.e., health care provider tells patients what to do and assumes they will do it). This collaborative model need not preclude respect for providers and their expertise. If anything, it can enhance the therapeutic relationship through improved communication and openness. It can strengthen our claim to a seat at the multidisciplinary cancer care table, demonstrating that we are not just technicians but oncologists. It also need not be another hurdle to overcome in today’s documentation-heavy, resource-light environment.

In fact, SDM, sometimes performed with tools known as clinical decision aids (DAs), carries tremendous potential for personalizing every patient interaction and ensuring that the conversation is efficient and productive. In a typical clinical scenario, radiation oncologists (ROs) render expert opinions on whether or not radiation is indicated, and if so, the options for radiation treatment modality, volume, dose and timing, to name a few. These “decisions” are increasingly often not so much decisions as prescriptions and plans concordant with evidence-based guidelines and accepted standards. While this should result in appropriate and good quality care, it risks losing some patients in the process, as they take a passive role, sign the consent form and later ask everyone else around them what just happened, what treatment they are getting and, in some cases, why they need treatment at all. Nothing is more sobering on this particular point than a final on-treatment visit during which an otherwise mentally competent patient asks you what type of radiation he or she just received.
Elicit goals of care
So, what is one way we can reduce this risk, seemingly not as dangerous as the risk of cancer recurrence, yet still carrying the potential for a suboptimal therapeutic ratio? ROs can remember to always elicit the patient’s goals of care early in the discussion in order to guide subsequent conversation and to ensure that the patient feels heard. Goals of care should include personal preferences and priorities (e.g., tumor control versus side effects) — values which may change for the patient over time and thus need to be modified at key points throughout the care journey. Thankfully, collecting this information is becoming an easier task, given the growing development and use of oncology-specific patient surveys and interactive electronic DAs that can be administered and completed ahead of the visit.

During the actual office encounter, it is important to review this information when available or solicit it when it is not, then return to these goals of care periodically. Even when describing scientifically complex aspects of radiation, ensuring that the discussion connects back to the purpose, to the person in front of you, can help to keep the patient engaged in and at the center of the conversation. Explaining to patients which of your treatment recommendations are and are not aligned with the stated goals of care, and your rationale behind the latter, can engender trust and may in fact help to evolve the patients’ initial goals or, at the very least, to manage their expectations.

Better informed decision making benefits everyone. Furthermore, clinical trials within oncology as a whole, and in particular radiation oncology through leading research organizations like NRG, are increasingly exploring safety and efficacy of cancer interventions through the lens of the study subjects, i.e., the patients. Reliable data on the value of our work and contributions as ROs, which in turn will inform future practice patterns and payer decisions, will require engaged patients providing accurate and thorough reports of their experiences.

There is no better time for ROs to embrace emerging electronic medical record features, online and in-person communication skills workshops, interactive clinical DAs and other available resources to support and enable patient-centered care and SDM in everyday clinical practice. Our specialty has been and will continue to be a leader in advancing radiation science and technology to boost that therapeutic ratio. We can also remind and show our colleagues and the community how we are much more than technicians, and that the center of our every effort remains our patients.

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RECOMMENDED RESOURCES ON SHARED DECISION MAKING:


TO DOCTOR AND DOCERE: INFORMED CONSENT FOR RADIATION THERAPY

BY DANIEL W. GOLDEN, MD, MHPE

RADIATION THERAPY (RT) IS A CRUCIAL COMPONENT OF MULTIDISCIPLINARY CANCER CARE, used in the curative treatment of numerous cancers and to provide palliative treatment for an even broader spectrum of cancers. All patients receiving RT in the United States sign an informed consent form. However, patients and family members frequently do not understand the RT process, potential side effects, or even the goal of treatment and they often desire more information. How can a radiation oncologist ensure a patient understands RT and is prepared to sign an informed consent form?

In modern patient-centered care, the role of the radiation oncologist as a doctor is not just to deliver RT. The word “doctor” is derived from the Latin word “docere” which means “to instruct, teach or point out.” One of the fundamental roles of a doctor is to teach the patient about the recommended therapeutic intervention and what to expect with regard to the outcome and potential adverse effects of treatment. This process of teaching a patient is the foundation of informed consent.

When considering the concept of obtaining informed consent from a patient, it is important to ask what is meant by “informed.” Is the patient passively informed (verb) by the physician, or is the patient informed (adjective) and making the decision to pursue treatment based on truly understanding the potential risks and benefits of treatment?

Inform (verb) – To shape the mind, character, etc.; to instruct, teach, train; to provide with knowledge.

Informed (adjective) – Of a person, the mind, etc.; instructed; educated about or acquainted with a fact, subject, etc.; knowledgeable.

Oxford English Dictionary

If the ultimate goal of obtaining informed consent is to ensure the patient understands the process of RT, goal of care and potential adverse effects, then the physician must use appropriate methods to educate the patient and provide the patient with resources to become informed.

The process of a patient becoming informed begins before the patient enters the RT clinic. The patient has likely already talked to other physicians that are not experts in RT and with family or friends about their personal experiences with RT or read patient education materials. Unfortunately, many of these sources of information may not provide accurate, realistic or understandable information about RT. Our colleagues in other specialties are frequently underinformed about RT and therefore may not be able to provide a patient with accurate information about RT. A majority of these patient materials are demonstrated to be written well above national guidelines for readability levels.

Readability indices usually measure text complexity using a combination of word length (syllables per word) and sentence length (words per sentence). Here are two examples of a similar statement at high and low readability grade levels:

“The tiredness patients experience is usually mild or moderate and is different for each patient.”

Flesch–Kincaid grade level = 11.5

“If you have fatigue, be sure to tell your doctor or nurse. You can say it’s mild, moderate or severe.”

Flesch–Kincaid grade level = 3

Given these limitations of outside information sources, many patients arrive at the RT clinic underinformed or misinformed.

Using multiple teaching methods

To ensure a patient is providing informed (adj.) consent, the physician should use multiple educational strategies to teach the patient about the RT process, expected treatment outcome and potential adverse effects. The traditional initial consultation includes a history and physical followed by an oral discussion of the RT process led by the physician. The patient is usually provided with reading material to review at a later time from resources such as www.RTanswers.org, the National Cancer Institute or other national societies. However, not all patients will learn optimally from an oral discussion and written educational tools. Some patients may prefer visual aids to help explain the process or kinesthetic aids such as a model of their disease site’s anatomy or of the linear accelerator. The physician should utilize multiple teaching methods during the consultation discussion to ensure all learning preferences are addressed.

To provide visual cues during the first consultation discussion, the University of Chicago in collaboration with Tomoko Ichikawa, clinical professor of design
at the Illinois Institute of Technology Institute of Design, developed the Communicating the External Beam Radiotherapy Experience (CEBRE) graphic narrative discussion guide (Figure 1). The CEBRE guide provides visual cues to patients while the nurse or physician is explaining the radiotherapy process. The guide was intentionally designed to be generic and can be used for any disease site treated with external beam radiotherapy. The guide can also be customized with a clinic’s logo and phone number. A perceived benefits study of the CEBRE guide demonstrated that both patients and physicians rated it as usable and likely to reduce patient anxiety.7 The Radiation Oncology Institute is funding development of three site-specific CEBRE discussion guides for breast, prostate and lung cancer (projected availability in late 2021). Additionally, the Communicating the Gynecologic Brachytherapy Experience (CoGBE) graphic narrative discussion guide was recently developed for use with patients receiving cylinder, intracavitary and interstitial treatment. The visual guides are available for download at https://voices.uchicago.edu/roecsg/patient-education.

Physicians also need to think about the words they use while talking to patients. Many patients learn well from the oral discussions; however, the physician must carefully select the words used when communicating. Words that could be identified as “doctor speak” such as “gastrointestinal tract” and “optic nerves” may not be understood by patients. Simpler phrases like “digestive system” and “nerves to the eyes” better ensure that patients understand medical terms.

Lastly, informed consent forms themselves are demonstrated to be written at too high a readability level for many patients to easily understand.8 Radiation oncologists are encouraged to review their clinic’s consent forms. Are the consent forms meeting readability guidelines? Are the forms written so the patients understand what they are signing, or are the forms written as legal documents to protect the clinic from potential liability? Both are valid reasons for the consent forms, and one goal should not be pursued at the expense of the other.

Ensuring a patient provides informed consent starts at the time patients learn they are potentially going to receive RT and does not end until patients receive their first fraction of RT. Physicians must carefully consider the sources of information patients are using to learn about the RT process, expected treatment outcome and potential adverse effects. During initial consultation, the radiation oncologist must fulfill one of the fundamental roles of a doctor — teaching the patient — by utilizing multiple educational methods to ensure the patient is fully informed. Only then should the patient be asked to sign a consent form and proceed with RT.

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Figure 1. A Section of the Communicating the External Beam Radiotherapy Experience (CEBRE) Discussion Guide © 2018 The University of Chicago & Illinois Institute of Technology

Figure 1. The “Planning” and “Treatment” sections of the Communicating the External Beam Radiotherapy Experience (CEBRE) discussion guide. The full guide includes five sections from “Consultation” through “After treatment” along with a “My Information” section for the radiation oncologist to complete with the patient. The CEBRE discussion guide is available for download at https://voices.uchicago.edu/roecsg/patient-education.
ASTRO Patient Survey identifies gaps in patient counseling and informed consent

BY NAREK SHAVERDIAN, MD, RESHPA JAGSI, MD, DPHIL, FASTRO, AND LIZ GARDNER, PHD

ASTRO SPONSORED A NATIONAL SURVEY OF U.S. ADULTS TREATED FOR CANCER WITH RADIATION THERAPY to gain a better understanding of patient perspectives on their treatment experiences. Nearly all patients felt they made the right treatment decision, and experiences with radiation therapy toxicities were generally congruent with expectations. Sizable groups of patients, however, felt inadequately informed about treatment-related side effects across all modalities of cancer therapy. These findings highlight opportunities to improve physician-patient communication and informed consent processes across cancer therapies.

Feeling informed about treatment side effects
Across all major modalities of cancer therapy, approximately one in three patients experienced side effects from treatment that they wish they had known more about (radiation therapy: 37% of 403 patients surveyed, chemotherapy: 36%, surgery: 34%). Moreover, approximately one in five patients felt they didn’t have enough information on the side effects they should expect (radiation therapy: 18%, surgery: 20%, chemotherapy: 26%). These patterns were consistent across gender, education level, age, race, region and the type of cancer treated.

Feeling inadequately informed was strongly associated with the reported severity of side effects. Patients who reported having severe treatment-related side effects were more likely to indicate they did not know enough about side effects. Specifically, 62% of patients who reported having severe treatment-related side effects indicated they were adequately informed whereas 96% of patients who reported minimal side effects felt informed (p<0.001).

The most common radiation-related side effects patients wished they had known more about included skin toxicity, gastrointestinal (GI) symptoms and fatigue. With chemotherapy, patients wanted more information on nerve damage, GI symptoms and fatigue; and with surgery, pain and nerve damage/numbness.

Although notable minorities of patients faced information gaps about treatment-related side effects, respondents were overwhelmingly content with their decisions. Nine in 10 patients said they felt they made the right decision about their treatment regimen.

Expectations versus experiences with side effects
Although patients’ experiences with side effects from radiation therapy were mostly in line with expectations or better than expected, the survey identified gaps where more counseling and education are needed. The side effects of treatment patients were concerned about most frequently before radiation therapy were feeling tired (56%), feeling weak (50%) and skin burning (46%).

When asked about various toxicities, most patients said their experience with any given adverse effect was what they expected or not as bad as expected. However, there were exceptions to this pattern. Notable groups of patients felt more tired (29%) or weak (28%) or experienced worse changes to their energy level (31%) than expected, and 24% experienced worse-than-expected skin burning. These exceptions highlight areas where more in-depth patient counseling could help patients prepare for changes to their quality of life.
When rating their actual treatment-related side effects experience from minimal (0) to severe (100), the average ratings were 45 for radiation therapy side effects, 47 for surgery side effects and 63 for chemotherapy side effects. Treatment-related toxicities increased with the addition of systemic therapy and/or surgery to a patient’s treatment regimen. Fatigue, weakness and pain were significantly more likely to be worse than expected for patients treated with all three modalities, compared to those treated with radiation therapy alone.

Patients who had trimodality therapy also rated their radiation side effects as worse than those who were treated with radiation alone (51 versus 37 out of 100, p<0.01). The impact of multimodality therapy on the patient experience suggests a need for more multidisciplinary coordination to manage side effects.

**Information sources for treatment decisions**

Primary care physicians (PCP) play a key role for patients making decisions about cancer treatment. A majority of patients (55%) talked with their PCP about cancer treatment options, and nine in 10 of these said the PCP’s advice was very important (64%) or somewhat important (29%) in their decision making. Moreover, a fourth of all patients surveyed said their PCP was the only source they consulted.

When patients did consult other information sources, they were most likely to seek out medical or cancer-related websites, family and friends, the experiences of other patients and cancer support groups.

Most patients (68%) perceived their radiation oncologist to have the same or more cancer knowledge as the other oncologists on their treatment team. This view was more common among patients treated for breast cancer (70%) or other cancers (72%) than it was among those treated for prostate cancer (54%) (p<0.001).

This feedback indicates that the voice of the radiation oncologist is important to patients with cancer, and ensuring that patients receive a well-balanced description of the benefits and potential toxicities associated with radiation is important to patients as they navigate the cancer treatment process.

“Nationwide survey of patients’ perspectives regarding their radiation and multidisciplinary treatment experiences,” published online November 20, 2019, in the Journal of Oncology Practice. Co-authors include Narek Shaverdian, MD; Debra Yeboa, MD; Liz Gardner, PhD; Paul Harari, MD, FASTRO; Kaiping Liao, PhD; Susan McCloskey, MD, PhD; Richard Tuli, MD, PhD; Neha Vapiwala, MD; and Reshma Jagsi, MD, PhD, FASTRO.
UNDERSTANDING AND MEASURING WHAT MATTERS TO PATIENTS is central to patient care, process improvement and research. This can take the form of the patient’s health care delivery experience, such as wait times, ability to reach the clinic by phone or parking, or it can focus on a patient’s symptoms, quality of life or functional status. There are well-established patient experience measures in wide use today, but the focus on the latter set of outcomes is a relatively new phenomenon in radiation oncology. Collecting patient reported outcomes (PROs) is helpful to engaging patients in their care, providing insights not always accessible to health care providers and reducing observer biases. While a great deal of progress has been made in incorporating PROs into daily clinical practice, challenges in their effective implementation and use remain. Here we will describe the benefits of PROs in daily patient care, practical aspects of PROs collection and incorporation into clinical workflows and outstanding challenges in using PROs to benefit our patients.

The pros of PROs
Gaining insight into patients’ views of their state of health and symptoms is a crucial component of assessing and caring for patients. Research shows that the severity of symptoms differs significantly between a physician’s assessment and self-reporting from patients. PROs can also provide actionable insight into patient symptoms, allowing health care providers to intervene earlier and more effectively. For instance, a randomized trial of cancer patients receiving chemotherapy demonstrated that the routine collection of PROs is associated with a survival benefit over routine care.1 Patients also can feel more engaged in their care, and PRO collection can streamline visits, as providers can focus on areas where things are not going well. PROs also offer an opportunity for a learning health care delivery system in which outcomes that matter to patients are continually assessed and impactful interventions can be implemented. Finally, PROs represent the fundamental experience of patients as they continue through care and, as such, are fertile ground for clinical and translational research.

The nuts and bolts
PROs are assessed by patient reported outcome measures (PROMs). These are typically validated sets of questions aiming to address either a specific symptom or disease or to generically understand a patient’s health-related quality of life or functional...
status. Symptom-specific measures might address nausea, esophagitis or fatigue while disease-specific measures might bundle together urinary, bowel and sexual side effects for men with prostate cancer. Examples of these questionnaires include those from the European Organization for Research and Treatment of Cancer (EORTC) disease-specific PROMs or the Patient Reported Outcomes version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE). Such symptom-specific PROMs might include the presence, severity and bother of the symptoms. Generic PROMs, such as the Patient-Reported Outcomes Measurement Information System (PROMIS®) Global Health, are developed to understand a more global health state and ask about an individual’s physical, mental and social health. Generally, these tools have been evaluated for their reliability across populations and can be summarized through validated scoring systems that improve the interpretability and actionability of the PROM.

Both types of questionnaires can benefit our patients. During treatment, the routine collection of narrower symptom-specific PROMs can help assess the need for interventions as symptoms worsen. More generic PROMs can help a care team understand the broader support needs of the patient.

An ideal system in radiation oncology would assess baseline function on a generic and disease-specific questionnaire. A shorter set of questions, perhaps selected from PRO-CTCAE, would be collected during treatment to understand the acute toxicities and their resolution, and then in longitudinal follow-up, the patient would return to that baseline set of questionnaires. Further, the sets of questions would be tailored to the disease or the patient’s treatment site. Such a patient- and context-specific approach improves patient engagement and the actionability for the care team.

The challenges
The routine collection of PROMs in radiation oncology faces numerous challenges. These range from picking appropriate PROMs to technical implementation to clinical use. In radiation oncology practice, symptom-specific PROMs of choice may be PRO-CTCAE, as they are cancer-specific and have been used extensively in randomized controlled trials to report on the presence, severity and bother of symptoms in a longitudinal fashion. The perceived barriers to implementation of PROs include changes in clinical workflows, time and effort it would take to collect the PROMs, time for physicians or nurses to access and look through the data that would potentially add an additional burden to a very busy clinical schedule and integration of the PROs with the electronic medical record (EMR). Fortunately, major EMR vendors are in the process of embedding questionnaires within their products, making technical implementation of the PROs easier. Furthermore, there is no existing formula for how to make collected PROs actionable. Individual institutions may come up with different solutions about how to implement and integrate PROs in their own clinical workflows. In our own institution, initial key barriers to PRO use by providers included difficulty in accessing reports within the EMR and having too much data to sift through. However, these initial challenges improved with time. A vast majority of physicians found the data to be valuable, and a significant number of providers felt that PRO collection had changed their discussions with patients and their decision making. Thus, while some initial challenges to implementation of PROs do exist, the providers generally feel that the benefits of PROs outweigh these challenges in the long run.

PROs are an emergent clinical tool that allows physicians to efficiently recognize and act upon patient symptoms, improving patient experience and potentially leading to better outcomes. PROs can also provide the data needed to facilitate process improvement and clinical research. While some challenges in wide implementation across radiation oncology clinical practices remain, integration of PROs into our daily clinical practice will allow us to deliver better care to our patients.

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Financial Toxicity: The unseen side effect that can erode the efficacy of our cancer treatments

BY FUMIKO CHINO, MD, AND CAROL A. HAHN, MD

As the costs of health care have outstripped economic growth, the personal financial burden on patients and families paying for cancer care has been recognized as an increasingly significant issue. Cancer is currently the most expensive disease to treat, with higher out-of-pocket costs than other chronic diseases. As cancer treatment costs have risen, insurers have shifted more of the burden to patients in the form of deductibles, coinsurance and co-payments. In a 2017 national patient opinion survey, 70% of those surveyed felt that costs were the major barrier to receiving quality, timely cancer care, and in 2018, survey data demonstrated that more Americans are worried about cancer’s financial impact (57%) than of dying of cancer (54%).

The term “financial toxicity” has emerged as a way to describe the toxic effects that out-of-pocket costs can create as side effects of cancer treatment. In practical terms for our patients, this manifests as decreased overall well-being, quality of life and quality of care through accumulating economic burdens, compromised medical decision making — including decreased adherence due to costs — and ongoing financial stress through both end of life and survivorship. The ultimate downstream effect of severe financial burden is a greater risk of mortality.

Due to changes in the insurance industry over the last several decades, more patients diagnosed with cancer today are underinsured, meaning they spend more than 10% of their income in out-of-pocket costs for their treatment. Underinsurance and financial toxicity lead to delayed diagnosis and treatment start and poor access to clinical trials. Costs of cancer care extend beyond direct costs for medical care, with non-medical costs like travel and indirect costs like lost wages or poor productivity exacerbating the burden of increasing bills by decreasing household income. Examples of both direct and indirect costs are shown in the table on page 24.

Addressing financial toxicity has recently been called out as an unmet need within radiation oncology. Prior research has shown that receiving radiation therapy has been associated with significant out-of-pocket costs, and that a history of radiation treatment is associated with treatment-related financial problems. One study specific to radiation patients found that almost a quarter had experienced financial toxicity, and more than half of radiation oncologists were concerned about treatment costs negatively affecting their patients. In the first survey using a validated measure of financial toxicity, 15% of patients had grade 2-3 financial toxicity which corresponds to a moderate or severe impact on quality of life. Highlighting the disconnect between intention of providers and patient experience, another study found that, while 43% of radiation oncologists reported someone in their practice often or always discusses financial burden with patients, of those patients who were worried about finances, almost three quarters indicated that physicians and their staff did not help.

Solutions to financial toxicity exist along many frameworks, from government and health policy, to health systems and cancer society guidelines, to patient and provider relationships and shared decision making. Negotiated costs and bundled payments are seen as one way of controlling the ballooning costs of cancer treatment and thereby exerting downward pressure to reduce costs on a national level with trickle-down benefit to patients. Health policy mandating that pricing of new drugs and treatments must be based on their value to patients (i.e., the outcomes and quality provided by treatment related to cost) is also frequently proposed; however many fear that such a restrictive policy would dampen the development of new therapies and innovation. Insurance prior authorization has also been used as a cost control measure that, in theory, ensures that all planned treatment is evidence based; unfortunately, for many it shifts the burden onto
providers to ensure their patient’s care is covered, resulting in treatment delays or compromises in treatment plans in order to meet insurance criteria.

Framework and guidelines are meant to support shared decision making and help drive conversations leading to patient-centered care. The ideal conversation helps physicians provide the highest quality of cancer care tailored to the unique concerns and values of each patient. However, given lack of provider training and unknown out-of-pocket costs, cost is rarely a substantial part of shared decision making. Both patients and providers may feel uncomfortable bringing costs into the conversation, leading some patients to “suffer in silence.” Screening for financial toxicity (either with single question or validated 11-question measure) may help identify those who are struggling with or at risk for financial toxicity. A team-based approach including a social worker, nurse or financial navigator, financial services, and other support staff may help provide the manpower to actually identify what assistance may be available to patients.

Sadly, there is no single solution to financial toxicity. Finding systemic ways to lower health care costs may ultimately work to lessen the burden for patients as a whole, however, are doubtful to have a meaningful benefit for the patient at your next office visit who is struggling to pay for both rent and cancer treatment. Acknowledging that financial toxicity exists and normalizing cost conversations can be a meaningful way for us to ally ourselves with our patients. It starts with a willingness of physicians to work toward big and small solutions to treat and prevent financial toxicity.

In early 2018, Heather Brinkerhoff was busy with her three-year-old son and building her personal training business; her husband, Jason, was an emerging artist with several well reviewed gallery shows. Their young family lived in a “fixer upper” in the Bay Area California, in a two bedroom with enormous potential but requiring Jason to do lots of work to make it the home of their dreams. In May 2018, Jason noted increasing headaches and was ultimately diagnosed with a glioblastoma multiforme. Months later, while still dealing with the stress of neurosurgery, radiation and chemotherapy for her husband, Heather noted increasing abdominal pain. In January 2019, she was diagnosed with pancreatic cancer. A young family faced with two devastating cancer diagnoses would be overwhelmed no matter what, but the financial burden of cancer hit the Brinkerhoffs particularly hard.

Heather Brinkerhoff took time between chemotherapy appointments to share part of her story with us:

I just want to start with saying that we both have always had health insurance. But we’re a young family, and we’re both self-employed. In the last 18 months, we were hit with two horrible cancers, two huge surgeries, radiation, chemotherapy… all while our house was — literally — in pieces. The first thing I realized is that our first insurance plan was tied to a hospital system that just wasn’t able to care for me. I had a complicated hospitalization in January with jaundice and pain, I was in rough shape. I needed to get started with treatment pretty fast. Due to the complexities of my case, it just wasn’t happening and that was very scary. I ended up transferring to another hospital and they were able to get me started quickly, but it was expensive, thousands of dollars. By doing the best thing for my health, and to treat my cancer, I ended up on the hook for $35,000. Read Heather’s full story on www.RTAnswers.org/heatherbrinkerhoff.

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WHENEVER ASTRO’S HEALTH POLICY AND GOVERNMENT RELATIONS LEADERS and staff are faced with a complex, challenging or divisive policy issue, which is often the case, there is a common refrain: What is best for patients? That grounding in patient-centric policy development and advocacy is at the core of ASTRO’s efforts, and there’s no better way to find out what patients want than by asking them.

What we’ve learned is that cancer patients and their advocacy groups are a powerful voice for reforms in the cancer policy arena. Their perspective is too important to get lost in internal debates or political bickering. ASTRO makes it a priority to develop strong, long-term relationships with a variety of cancer patient advocacy groups and collaborates with patient groups on a regular basis, primarily through a partnership called the Cancer Leadership Council (CLC). The approximately 30 groups of the CLC coordinate advocacy agendas and discuss hot policy topics focused on cancer treatments and research. CLC weighs in thoughtfully with policymakers on issues like Medicare policies and payments, insurance coverage, survivorship, quality and more. “Patient advocates in the CLC have responded positively to presentations and informal advice from ASTRO related to payment reform and other policy matters, and ASTRO enjoys the benefits of interactions with advocates who can provide first-hand advice about cancer care and in-depth policy advice from a patient perspective,” said CLC Executive Director Elizabeth Goss.

ASTRO also works with the One Voice Against Cancer (OVAC) coalition led by the American Cancer Society Cancer Action Network. OVAC’s 50 organizational members represent millions of cancer patients and providers, all committed to increasing cancer research funding at NIH and NCI. This strong connection has helped radiation oncology and cancer patients. This collaboration has its work cut out for it with new threats to cancer research funding on the horizon.

Putting patients first is a key tenet of radiation oncology care and advocacy. ASTRO is committed to continuing and expanding upon our partnerships with patient advocates to ensure access to high quality radiation oncology care.

CLINICAL PRACTICE GUIDELINES ARE IMPORTANT TOOLS for improving health care quality and patient outcomes. Historically, guidelines were largely conceived as tools to inform health professionals’ decisions rather than to foster patient involvement in decision making. In 2011, the Institute of Medicine published Clinical Guidelines We Can Trust with guidance on facilitating patient and public involvement and strategies to increase the effectiveness of their participation. Patient and public engagement is now recognized as an essential component of guideline development and implementation by incorporating evidence-based recommendations into shared decision making for patients.

In response, ASTRO evaluated its processes and now routinely includes a patient representative on each guideline. This participation enables patients to provide feedback related to quality of life, shared decision making and treatment issues. Their engagement provides an opportunity to address patients’ values and preferences, which supports the concept of patient-centered and trustworthy guidelines. But it isn’t easy! Finding a patient willing and able to commit to the lengthy process is not without its own challenges, and the technical nature of ASTRO’s guidelines makes finding a candidate more complicated. Additionally, guidelines are posted on ASTRO’s website for a four- to six-week period of public comment. Comments from ASTRO members, patient support and advocacy groups and other potential stakeholders are encouraged.

In 2018, ASTRO further updated its guidelines methodology with the goal of implementing a streamlined process and producing user-friendly guidelines. Going forward, patient-centric materials will be available, with content appropriate for their needs and understanding. This currently includes questions to ask before, during or after treatment that will supplement information on RTAnswers.org. With our latest guideline, the task force is developing a patient summary of the recommendations using less technical language. The aim is to produce guidelines that address both the health professionals’ perspective as care providers and the patients’ values and preferences equally in the decision-making process.
IT’S BEEN A FEW MONTHS SINCE THE 2019 ASTRO ANNUAL MEETING CONCLUDED and it’s time to look back at some of the most exciting and practice defining studies presented. At this meeting, more so than in other recent years, there did not seem to be a particular topic or study that dominated conversation. Rather, there were several randomized studies of interest that reported data for the first time and several important updates to previously reported studies.

The results of the NRG HN-002 were presented during the Plenary session. This was a Phase II study comparing radiotherapy (RT) alone with 60 Gy in five weeks to concurrent cisplatin and radiotherapy with 60 Gy in six weeks for patients with HPV+ squamous cell carcinoma of the oropharynx. Progression-free survival (PFS) for the RT+Cis arm was 90.5% at two years compared to the pre-specified goal of 85%. PFS for the accelerated RT alone arm was 87.6%. Thus, only the RT+Cis arm met the primary endpoint for PFS. While neither of these arms represent a historical standard of care, this trial shows that reduced dose RT has very high PFS and overall survival (OS) with continued benefit of cisplatin and low morbidity in both arms. Phase III NRG HN-005 will compare standard of care of 70 Gy with cisplatin against 60 Gy plus cisplatin or 60 Gy plus nivolumab.

The RTOG 0631 results were also presented during the Plenary. This trial randomized patients with spinal bone metastases to SBRT or single fraction EBRT. The primary endpoint was pain response at three months. SBRT dose was either 16 or 18 Gy in one fraction and EBRT dose was 8 Gy in one fraction. A pain response of at least a three-point improvement in pain score at three months post-treatment was seen in 40% of patients undergoing SBRT and 57% of patients undergoing EBRT. Thus, the study showed that while SBRT appeared safe, EBRT remains standard of care for palliation of symptomatic bone metastases.

A secondary analysis of RTOG 9601 was presented. This study randomized men undergoing salvage radiotherapy for biochemical recurrence of prostate cancer to two years of androgen deprivation therapy (ADT) or not. Overall survival was broken down into four PSA categories (0.2-0.3, 0.31-0.6, 0.61-1.5, and 1.5+). There was an OS benefit in the latter two groups (HR of 0.61 and 1.5+), no significant difference in the 0.31-0.6 group (HR 0.94), and what seemed to be a strong trend to detriment in the 0.2-0.3 group (HR 1.78). Men with a PSA of less than 0.6 had increased other-cause mortality. This analysis strongly supports the idea that not every patient receiving salvage radiotherapy for prostate cancer requires ADT, as increase in non-cancer death from ADT has to be balanced against cancer related death for these patients.

The optimal treatment of post-operative prostate cancer has been a matter of debate for years. At ASTRO 2019, the eagerly anticipated RAVES trial was presented. Patients were randomly assigned to RT to prostate bed four to six months from surgery (adjuvant) or only after PSA rose to above 0.2 (early salvage). At a median follow-up of 6.1 years, the six-year rate of freedom from biochemical failure was 83% in both...
arms (HR=1.11, p=0.69). Early salvage therapy had lower prevalence of grade 2+ genitourinary toxicity. Contemporaneously, across the Atlantic at ESMO, an analysis of the Radicals trial, which had a similar randomization to adjuvant versus early salvage, and the Artistic meta-analysis were presented. Both showed no improvement in PFS for adjuvant therapy compared to early salvage. The longer follow up of these studies could possibly change standard of care to early salvage for most patients. Buy-in from our urologist colleagues in understanding the benefit of early salvage with intervention at low PSA, as done in these two studies, will be critical.

ASTRO 2018 brought some of the biggest breakthroughs for radiotherapy in oligometastatic disease and this trend continued into 2019. The ORIOLE trial was a Phase II study for hormone-sensitive metastatic prostate cancer patients with one to three sites of oligometastatic disease. Patients were randomized to SBRT or observation. The rate of progression at six months was 19% with SBRT and 61% with observation (p=0.005) showing that SBRT may be a reasonable avenue to defer ADT in these patients. Another interesting component of the trial was the use of PSMA-PET scans. Patients who did not have additional disease on PSMA-PET beyond the treated oligometastatic lesions had a 63% chance of not developing additional metastatic disease at 180 days compared to 16% for those with additional lesions noted on initial PSMA-PET. Management of recurrent prostate cancer could change significantly as we incorporate advance PET imaging for these patients.

In the gynecological world, the most significant presentation was an update to the PORTEC-3 study. This study randomized high-risk post-operative endometrial cancer patients to RT alone or chemoradiotherapy (CRT). A median follow-up of six years demonstrated an OS benefit in all-comers of 5% (81% versus 76%) at five years. This benefit was most pronounced in stage III patients who had a five-year OS of 78% versus 68% and serous histology (71% versus 53%). The authors concluded that when this data is looked at alongside data from GOG 258, for stage III patients the addition of chemotherapy offers a clear survival advantage while the addition of radiotherapy results in significantly better loco regional control. The incorporation of these findings could be a challenge in North America, as standard of care for adjuvant treatment there for stage III disease has shifted toward chemotherapy alone compared to radiation therapy in PORTEC 3.

Additional coverage of key scientific breakthroughs from the 2019 Annual Meeting can be found at www.astro.org/showdailies.

Scott Glaser, MD, is an assistant professor of radiation oncology and chief of brachytherapy and gynecological radiotherapy at City of Hope National Medical Center in Duarte, California.

Sushil Beriwal, MD, MBA, is a professor of radiation oncology at the University of Pittsburgh School of Medicine and residency program director at UPMC Hillman Cancer Center.

In between learning about the latest science, attending educational sessions and visiting the Innovation and Solution Showcase, Annual Meeting attendees participated in a Tweet-Up to network “in real life” with fellow radiation oncology social media influencers.
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ASTRO’s Innovation and Solution Showcase provides members the chance to discover the latest and greatest technology, products and services in the radiation oncology field. As a thank you, Ambassadors and Annual Meeting sponsors enjoy a special opportunity to meet with ASTRO leadership in an Annual Meeting tradition.

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From the ABR

PATIENT-CENTERED ASSESSMENT POLICY DEVELOPMENT AND EXAM INSTRUMENTS

AT THE AMERICAN BOARD OF RADIOLOGY (ABR), our mission “to certify that our diplomates demonstrate the requisite knowledge, skill and understanding of their disciplines to the benefit of patients,” is patient-centric, and all exams related to diagnosis and treatment of disease are directed to that focus. In 1999, the Accreditation Council for Graduate Medical Education (ACGME), responsible for development of requirements, evaluation and oversight of graduate medical education programs, and the American Board of Medical Specialties (ABMS), the umbrella organization for its 24 Member Boards, adopted six Core Competencies felt to represent the essential skills and knowledge for high quality medical care. As would be expected, the basic elements of the Core Competencies relate directly to care of the individual patient, including: 1) Practice-based Learning and Improvement, 2) Patient Care and Procedural Skills and 3) Medical Knowledge. The three remaining Core Competencies could be more broadly interpreted to relate to patient and caregiver relationships and broader populations, including: 4) Systems-based Practice, 5) Interpersonal and Communication Skills and 6) Professionalism. While assessment of the first three competencies may seem well suited to the longstanding tools employed for assessment of medical skills and knowledge, assessment of the latter three presents a somewhat greater challenge.

In 2019, the ABR appointed its first public, non-ABR diplomate member to its Board of Governors (BOG). Toby Gordon, ScD, will be an invaluable member of the BOG to assist in policy development with a clear perspective of patient and population well-being, perhaps somewhat different from that of many of the Board’s volunteer physician leaders. Dr. Gordon is a distinguished educator, having joined the faculty of Johns Hopkins University Bloomberg School of Public Health in 2010 as an associate professor, with expertise in areas of health care policy, hospital management, health systems and technology commercialization. In her short tenure with the ABR, she has had a profound impact on broadening the perspective of its clinician volunteers.

The ABMS Member Boards have also agreed that assessment tools for initial certification (IC) and Maintenance of Certification (MOC) should include patient-related material not directly tracked to diagnosis or treatment. For radiation oncology (RO), these topics are collectively termed non-clinical skills and include patient safety, bioethics, research design and interpretation, quality assurance, quality improvement, professionalism and biostatistics. Because of the potentially vast amount of material available in the literature related to these varied domains, the RO trustees have developed a syllabus that is intended to include some of the most important issues. The syllabus is available on the ABR website and items (questions) developed for all assessment instruments are taken directly from that syllabus. The syllabus will be updated every three to four years, with revisions announced well in advance of subsequent exams so candidates have adequate time for preparation.

The ABR RO trustees will continue to work with all stakeholders to enhance their ability to appropriately assess candidates for IC and diplomates enrolled in MOC for the benefit of the patients they serve.

References
JOURNALS HIGHLIGHTS

HIGHLIGHTS FROM INTERNATIONAL JOURNAL OF RADIATION ONCOLOGY • BIOLOGY • PHYSICS

July 15, 2019
Stereotactic Body Radiation Therapy for Localized Prostate Cancer: A Systematic Review and Meta-analysis of Over 6,000 Patients Treated on Prospective Studies
Jackson et al.
This systematic review analyzed biochemical recurrence-free survival (bRFS), physician-reported toxicity and patient-reported outcomes after prostate SBRT. Thirty-eight prospective series, comprising 6,116 patients, were identified through PubMed and EMBASE. Through their performance of meta-analyses with random-effect modeling and in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analyses statement, the authors determined there is much evidence supporting the use of prostate SBRT. Favorable tumor control, patient-reported quality of life and levels of toxicity have been widely reported when SBRT is used to treat localized prostate cancer.

October 1, 2019
The Cancer Bell: Too Much of a Good Thing?
Williams et al.
This prospective clinical trial investigated patient-reported distress scores at the end of treatment (EoT) and at follow-up for two groups: one group of patients participated in a “bell-ringing ceremony” upon the completion of treatment and the other did not. The authors hypothesized that patients who participated in a bell-ringing ceremony would create a defined end to treatment and lessen “end distress” based on the peak-end rule. Surprisingly, patients who rang a bell at EoT reported higher distress scores than patients who did not, both on the EoT day and upon follow-up. The authors suggest that a sudden and emotional ending could play a part in magnifying the distress associated with treatment. Listen to the podcast: https://www.redjournal.org/content/podcast

September 1, 2019
Protons versus Photons for Unresectable Hepatocellular Carcinoma: Liver Decompensation and Overall Survival
Sanford et al.
The authors sought to compare clinical outcomes of photon versus proton ablative radiation therapy in patients with unresectable hepatocellular carcinoma (HCC). Patients treated between 2008 and 2017 with nonmetastatic, unresectable HCC not previously treated with liver-directed radiation therapy and who did not receive further liver-directed radiation therapy within 12 months after completion of index treatment were included. The primary outcome was overall survival, with secondary endpoints that included incidence of non-classic radiation-induced liver disease and locoregional recurrence. At a median follow-up of 14 months, proton radiation therapy was associated with improved survival.

November 1, 2019
Inhibition of CDK4/CDK6 Enhances Radiosensitivity of HPV Negative Head and Neck Squamous Cell Carcinomas
Göttgens et al.
In this paper, the authors highlight a therapeutic strategy to improve the radiosensitivity of human papillomavirus negative (HPV-ve) head and neck squamous cell carcinoma (HNSCC) patients. The expression of p16 in HPV+ve HNSCC is thought to mediate radiosensitivity via inhibition of cyclin-dependent kinase (CDK) 4/6. The authors used a clinically approved CDK4/CDK6 inhibitor, palbociclib, and assessed its effect on radiosensitivity in HNSCC. Palbociclib led to decreased induction of BRCA1 and RAD51 after irradiation. Homologous recombination was diminished and repair of radiation-induced DNA damage was delayed in the presence of palbociclib, leading to increased chromosomal damage.
HIGHLIGHTS FROM PRACTICAL RADIATION ONCOLOGY

Articles in Press
Physician Assisted Suicide (PAS)/Physician Aid in Dying (PAD) at the End of the Day
M.A. O'Rourke

The Gift of Dying with Control
C.D. Blanke
Two selections from Practical Radiation Oncology’s “Narrative Oncology” section independently address their experience with the ethical dilemma of Physician/Medical Aid in Dying. Mark Allen O'Rourke, MD, writes that patients deserve unconditional protection from suicide and that legalizing Physician Aid in Dying “is not a step down a slope but rather a drop off of a cliff.” C.D. Blanke, MD, describes the process for Medical Aid in Dying in the state of Oregon and summarizes information from the Oregon Death with Dignity Act’s 2018 data summary. Dr. Blanke writes that “offering a terminally ill patient autonomy and control is the opposite of harm.” The Narrative Oncology section features submissions that describe the unique challenges of the radiation oncology profession throughout the world.

September–October 2019
Radiation Therapy for Pancreatic Cancer: Executive Summary of an ASTRO Clinical Practice Guideline
Palta et al.
A new ASTRO guideline reviews evidence for the treatment of pancreatic cancer. As systemic methods for distant control improve, local control and the role of radiation therapy in treatment become more pressing questions. This guideline is based on a systematic literature review and addresses seven key questions including dose fractionation, toxicities and treatment volumes. As more research becomes available, the options for multidisciplinary care for pancreatic cancer will likely continue to evolve.

HIGHLIGHTS FROM ADVANCES IN RADIATION ONCOLOGY

October–December 2019
ASTRO Journals’ Data Sharing Policy and Recommended Best Practices
Tegbaru et al.
This article explains the ASTRO journals’ data sharing policy, which goes into effect on January 1, 2020. In support of FAIR (findable, accessible, interoperable, and reusable) data principles, the ASTRO journals will be asking authors to include a data availability statement with each submission that indicates whether data are being shared, and if so, how the data may be accessed. The article includes example data statements, a list of data repositories, more information on the principles behind data sharing and best practices for researchers. CME credit available for this article at academy.astro.org.

Wang et al.
Wang and colleagues performed an analysis of the Surveillance, Epidemiology and End Results (SEER) database to estimate the relative risk of second malignancies in cancer patients who receive radiation therapy (RT). The authors analyzed data from over 2.8 million patients based on their selection criteria. Their results showed that, overall, patients who receive RT have a relatively higher risk of developing a second malignancy beginning 10 years after diagnosis. However, this increase in risk was not uniform across disease sites. The risk of second malignancy varied based on sex, age group and disease site with some groups showing lower risk for a second malignancy after receiving RT. The authors conclude that the risk of a second malignancy, while part of the decision-making process, is likely outweighed by the potential benefits of radiation therapy.

The Special Medical Physics Consult Process for Reirradiation Patients
Paradis et al.
This report from the University of Michigan outlines the institutional approach to treating patients returning for additional courses of radiation. The reirradiation special medical physics consult (ReRT-SMPC) workflow consists of an iterative planning process whereby prior dose information is integrated along with current treatment objectives by physicists in conjunction with dosimetrists and physicians. The authors suggest that development of a standardized analysis tool for reirradiation will be helpful for treating patients safely and predicting toxicity.
HISTORICALLY, PREVIOUSLY RADIATED SPINAL METASTASES HAVE BEEN REIRRADIATED with an even lower biologically effective dose (BED) than initially delivered, simple conventional fields applied, and a sub-therapeutic BED with respect to tumor control. A randomized trial by Chow et al. that included 425 patients with painful non-spine and spinal metastases, concluded that re-irradiation with 8 Gy in 1 fraction or 20 Gy in 5 fractions was somewhat efficacious with an overall response rate of ~50%, and a complete pain response rate of only ~10%. The lack of efficacy associated with conventional palliative reirradiation is likely secondary to the lack of dose delivered, as ultimately how can one expect efficacy when treating a resistant tumor with a lower BED than initially delivered? Given the traditionally poor prognoses of patients with metastatic disease, the intent to control pain versus local control and the fear of retreating the spinal cord, this practice persisted. It was in 1995 that a neurosurgeon, Allan J. Hamilton, pushed the limit and designed an invasive body frame to re-treat spinal metastases conformally and reported feasibility in a small series of five patients. He set the stage to do more for these patients, but despite the complex invasive body immobilization device, they could only deliver a palliative reirradiation dose (8-10 Gy in 1 fraction) versus an ablative dose, as the technology was lacking.

It was the development of near-rigid non-invasive body immobilization apparatus, sub-centimeter multileaf collimators, on-board image-guidance systems and robotic technology allowing for six-degree of freedom corrections that presently allows for relatively routine re-treatment of spinal metastases with SBRT and delivery of ablative doses (e.g., 24 Gy in 1 or 2 fractions, 24-29 Gy in 3 fractions, and 30-40 Gy in 5 fractions). The BED associated with SBRT is essentially two to eight times greater than what would be delivered conventionally, and the assumption is that better rates of complete pain response and local tumor control will be realized. However, it took time for spine SBRT to be adopted, and beyond the skepticism that dose matters for bone metastases, one of the major initial barriers was a fear of causing radiation myelopathy. There were essentially no data to guide spinal cord tolerance specific to high dose hypofractionated SBRT especially in the reirradiation indication. With time, several series were published showing safety and efficacy of the treatment, and spinal cord tolerance guidelines emerged upon analyses of an initial bolus of radiation myelopathy cases specific to one-to-five fraction spine SBRT and that included for reirradiation.

In 2019, despite guidelines, including those from the International Stereotactic Radiosurgery Society (ISRS) on spine SBRT (including reirradiation), we still do not have the evidence to firmly support spine SBRT as a superior treatment. The two major randomized Phase III trials (RTOG 0631 and the Canadian SC24 study) comparing SBRT to conventional radiation are close to being reported; however, they are for de novo patients and not reirradiation. If it is clear from these trials that spine SBRT results in superior outcomes, then a re-treatment randomized trial will unlikely accrue, and re-treatment SBRT will be adopted as a standard of care. However, if these trials are negative, the profession should respond with a randomized trial dedicated to the reirradiation indication, as patients are living longer than previously expected, and there is potential to do better for these patients when the consequence of uncontrolled spinal metastases is pain and malignant spinal cord compression. Until then, the practice of reirradiation with SBRT is reasonable, especially in the oligometastatic patient.

Disclosure to the patient of the lack of high quality evidence is needed, as although the technique is mature, the level of evidence is not.

Arjun Sahgal, MD, is deputy chief of radiation oncology at Sunnybrook Odette Cancer Center in Toronto.

David Larson, MD, PhD, FASTRO, is professor emeritus of radiation oncology at the School of Medicine, University of California, San Francisco.

Continued on the following page
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