

Opportunities to Improve Palliative Care in Urology

Proceedings of the 2022 AUA Quality Improvement Summit

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Background and Context

The World Health Organization (WHO) defines palliative care as treatment that “improves the quality of life of patients and that of their families who are facing challenges associated with life-threatening illness, whether physical, psychological, social or spiritual.”¹ The value of palliative care is indisputable. It improves patient and caregiver satisfaction and lowers the financial burden on both individuals and medical institutions.²⁻⁵ Palliative care can be started early in the disease process, preferably at the time of diagnosis, engaging the patients’ values, beliefs, culture, and social system to individualize care and provide the highest possible quality of life that is aligned with the patients’ own goals.⁶ However, the United States is facing a projected physician workforce shortage.⁷ Currently, there are not enough palliative care specialists to fulfill the needs of all patients with terminal or advanced disease who qualify for palliative care.^{8,9} Estimates suggest that by 2030, there will be a ratio of one palliative care physician for every 26,000 patients.¹⁰ This shortage of palliative care physicians in the U.S. is especially concerning due to the aging of the population. In the next twenty years, the number of palliative care physicians is expected to grow by less than 1%; however, the number of patients eligible for palliative care will increase by 20%.¹⁰ The shortage of palliative care providers can have a major impact on quality of care and quality of life.

A potential solution to this shortage is primary palliative care: palliative care that is delivered by non-palliative care specialists, often in collaboration with specialty palliative care providers.^{6,8,11} Urology is an ideal field for incorporating primary palliative care into usual practice. The relationships urologists develop with their patients can span decades, providing the opportunity and trust for in-depth conversations necessary for optimal person-centered care, if training in this area is provided. Creating a sustainable, scalable model for a primary palliative care in urology is possible and can serve as a template for other specialties.

To spearhead this effort, the American Urological Association (AUA) held a Quality Improvement (QI) Summit to develop strategies for integrating primary palliative care into urology practice. Co-directed by John L. Gore, MD, MS and Jonathan Bergman, MD, MPH, the summit brought together specialty palliative care providers with clinicians from various urological subspecialties including general urology, oncology, stone disease, and female pelvic medicine and reconstructive surgery (FPMRS). The QI Summit comprised three sessions: two 2-hour webinars and a 4-hour in-person meeting. The two webinars, [Building a Primary Palliative Care Model for Urology](#)¹² and [Perspectives on Increasing the Use of Palliative Care in Advanced Urologic Diseases](#)¹³, were held in May of 2021. Both utilized a live-virtual format, which allowed for interactive panel discussions and question and answer sessions. The in-person portion of the summit, initially scheduled to coincide with AUA’s Annual Meeting in September 2021, was postponed to May 15, 2022 due to the continued COVID-19 public health emergency.

Key Themes

Throughout the three-part summit, six key themes emerged from the presentations, panel discussions, and question and answer opportunities. These are presented below.

The patient’s goals and preferences should drive their plan of care.

- The patient’s experience with their illness and treatment should be the central concern.
- Asking “what matters the most to you?” is a great way to initiate the palliative care conversation.
- Urologists should routinely ask patients “how are you doing?” and “how are you doing with ___?” to assess the patient’s symptom management and overall quality of life.
- The urologist should identify the patient’s prognosis, actively discuss goals of care, communicate the risks and benefits of the patient’s treatment options, and continue to assess the patient’s concerns and caregiver needs.

Early initiation of palliative care is crucial.

- Palliative care should be considered whenever the patient’s quality of life is threatened by illness or treatment, when the patient needs help adopting to the illness or treatment, when the patient has reached end of life, or if the patient has multiple comorbidities.

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- Palliative care should, ideally, be initiated prior to surgical intervention.
- The initiation can be gradual. For example, some visits may be best suited for conversations about physical symptom management, others for mental health screening.
- Early initiation of palliative care may prevent downstream problems. For example, we avoid potential ethical concerns if the patient's preferences and goals are determined prior to a patient becoming critically ill.

Primary palliative care is a team effort.

- The patient and the family/support person(s) are extremely valuable members of the team.
- A team may look different in different practice settings, but it may include a urologist, an APP, a nurse navigator, a social worker, a pain management specialist, a palliative care provider, the patient's primary care provider, a pharmacist, a physical therapist, an occupational therapist, and a chaplain, among others.
- Harness the expertise of the team members to help manage the patient's palliative care needs.
- Each team member should have clearly defined roles and responsibilities.
- The responsibility of meeting the patient's needs should be shared, but there should be one person responsible for ensuring the patient's care is being coordinated effectively.

In order for the model to be successful, urologists need to receive education on palliative care.

- Some ways to provide educational opportunities include:
 - Inviting palliative care practitioners to present at urology grand rounds.
 - Requiring urology trainees to meet standard palliative care competencies throughout their residency.
 - Offering a palliative care rotation during residency or offering the opportunity to any interested urologist to shadow a palliative care practitioner.
- There are a number of helpful educational resources available:
 - The AUA developed a module on palliative care for the Urology Core Curriculum. This module covers the definition and importance of palliative care, how it is used in urology, primary palliative care delivery skill development, and resources.¹⁴
 - Northwestern Medicine's EPEC Program covers fundamental palliative care skills in communication, ethical decision-making, psychosocial considerations and symptom management.¹⁰
 - CAPC is a national organization dedicated to increasing the availability of quality health care for people living with serious illness. CAPC provides healthcare professionals and organizations with the training and tools to meet this need.¹⁵
 - The Palliative Care Network of Wisconsin has a link to resources including, "Palliative Care Fast Facts and Concepts."¹⁶

The primary palliative care model may look different in different care settings.

- There is no "one size fits all" approach to implement primary palliative care in urology. A small private practice will have a different model than a large academic medical center, and a practice that specializes in FPMRS conditions may approach it differently than a practice that focuses on advanced prostate cancer. Different models will have to be adopted to how it works best for that practice.
- How the team is structured and how the team communicates with one another will look different in various settings.
- There are various strategies a practice can use to begin to implement this model:
 - Create a palliative care team and hold meetings to discuss patient's plan of care and concerns.
 - Implement a multi-disciplinary style tumor board with palliative care involved.
 - Incorporate palliative care flowsheets and alerts in the EHR.
 - Use patient-reported outcome measures to identify patient need for various aspects of palliative care.
 - Develop/implement easy-to-use checklists of questions to ask patients to identify needs.

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- Track whether patients have advance care plans, goals of care conversations, and health care surrogates (encourage these, if not).
- Leverage telehealth to have discussions about palliative care.
- Integrate quality of life assessment into practice and screen for symptom and mental health issues.

It is imperative to collect data throughout the implementation process.

- Important metrics include:
 - Rate of screening and re-screening for palliative care needs
 - Rate of referral to palliative care providers
 - Decision regret of treatment choice (e.g. surgery versus chemotherapy)
 - Intensity of care at the end of life
 - Caregiver burden
 - Availability of resources for caregivers
 - Frequency of palliative care utilization by setting
 - Utilization and cost of care for those receiving palliative care
 - Financial toxicity for the patient and caregivers
 - Post-operative outcomes
 - Health-related quality of life
 - Social mobility and satisfaction with level of social interaction

List of Publications and Products from the QI Summit

1. Recording of webinar #1, [Building a Primary Palliative Care Model for Urology](#), on AUAUniversity.¹²
2. Recording of webinar #2, [Perspectives on Increasing the Use of Palliative Care in Advanced Urologic Disease](#), on AUAUniversity's YouTube channel.¹³
3. AUAUniversity Urology Core Curriculum module, [Palliative Care](#), authored by Dr. Pauline Filippou and Dr. Jonathan Bergman.¹⁴
4. AUAUniversity Podcast episode, [Primary Palliative Care in Urology](#), hosted by Dr. Jay D. Raman with Dr. John L. Gore and Dr. Jonathan Bergman.¹⁷
5. Manuscript (in development), [Primary Palliative Care in Urology](#), authored by Dr. Jonathan Bergman, Dr. Pauline Filippou, Dr. Karl Lorenz, Dr. Anne Suskind, Dr. Charles D. Scales, Dr. Kevin Koo, and Dr. John L. Gore.

QI Summit Proceedings

Webinar 1: Building a Primary Palliative Care Model for Urology

Session 1: Current State of Palliative Care

Evidence for Sub-Specialty Based Primary Palliative Care

Katherine Fero, MD, MAS

Dr. Fero began by noting that the US population is aging, and an increasing number of patients are living longer with severe urological problems.^{18, 19} With this increased life expectancy and higher burden of disease comes an increased need for palliative care.²⁰ Unlike hospice, palliative care can be initiated concurrently with active curative treatment at any stage of the disease process. Palliative care has repeatedly been shown to increase patient and family satisfaction and decrease costs associated with repeated hospitalizations, multiple tests and interventions, and the utilization of expensive services such as intensive care units (ICUs) and emergency rooms (ERs).²¹⁻²⁴ Currently there are not enough palliative care specialists and the gap between

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the number of providers and the number of people needing palliative care is only expected to widen.^{7,9} One solution is to consider other providers who can deliver palliative care in the context of their own practices.

Dr. Fero conducted a systematic literature review to determine if generalists and non-palliative care specialists are successful in providing primary palliative care. She found a large body of literature on primary palliative care delivered by general practitioners. This literature included substantial evidence on how to identify patients with palliative care needs; models of care; barriers and facilitators to the delivery of care; patient outcomes; and ways to evaluate services. In contrast, the available literature on primary palliative care delivered by specialists was sparse, and surgeons were underrepresented. Nevertheless, there is substantial information from work done in primary care that can be fine-tuned and adapted to urology.

To integrate primary palliative care principles into a urology practice with the goal of providing excellent patient-centered care, Dr. Fero proposed a 4-part strategy. 1) Plan: determine the extent to which palliative care will be prioritized, and educate providers. 2) Do: implement strategies that have been shown to be successful in meeting patients' palliative care needs. 3) Study: track outcomes such as patient satisfaction, cost utilization, symptom management, and place of death. 4) Act: refine the delivery of care and improve with each iteration.

Dr. Fero concluded by noting that urologists are ideally situated to provide primary palliative care. A urologist will typically meet patients early in their disease course and follow them over a long period of time, thus establishing strong relationships that allow the deep communication required for effective palliative care. In fact, most urologists are already providing some level of palliative care. If education, resources, and support are provided, urologists will be able to provide primary palliative care with an even greater impact and, likely, long before the need for a specialty palliative care consult.

Aspects of Palliative Care that Most Benefit Patients

Karl Lorenz, MD, MSHS

Dr. Lorenz began his presentation with the story of a patient who had severe pain across one side of his head stemming from a tumor in his neck. He was referred to a surgeon who performed a thorough evaluation, ordered the appropriate studies, and scheduled him for a follow-up visit. However, this patient never returned for that visit. The patient later told Dr. Lorenz that he had lost all trust in the surgeon, because that provider had not addressed his pain. Unfortunately, this patient eventually died of a highly curable head-and-neck cancer. This story is a reminder that good surgical care begins with the concerns of the patient.

Palliative care places the patient's experience with his or her illness as the central concern, addressing not only the physical manifestations of illness, but also the emotional, social, and existential impacts of the disease and its treatment. By nature, palliative care is interdisciplinary, involving physicians, social workers, chaplains, psychologists, and pharmacologists, among others. For surgeons, palliative care includes identifying the patient's prognosis and proactively communicating the risks and benefits of treatment, managing pain and other distressing symptoms, and considering the patient's personal goals and caregiving needs. Additionally, palliative care involves tending to the family member or caregiver.

Dr. Lorenz differentiated between two categories of patients who require palliative care: those who face a life-limiting illness regardless of how long they are expected to live, and those who experience serious physical, emotional, or social impacts from a non-terminal disease or its treatment. He emphasized the importance of having a goals of care conversation and conducting a risk assessment early in the palliative care discussion. Identifying the individual's experiences, goals, and potential future complications early in the disease process while they still have agency is essential to patient and caregiver satisfaction.

Often the vulnerabilities that patients bring to the office are cumulative and unapparent to the physician, so awareness of proactive methods to identify those with palliative care needs, and what those specific needs are, is crucial. Such methods include applying a rule (such as considering a palliative care approach for all diagnoses of advanced cancer), using predictive models and analytics (which are becoming more available), and using screening approaches (like the risk assessment index [RAI]).⁷ Palliative care should be considered

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whenever quality of life is threatened by illness or treatment, whenever patients need help adapting to illness or its treatment, and whenever end-of-life management is needed. In medicine, a question commonly used to determine if the patient is a good candidate for palliative care is: will this patient likely die within the year? For urology, an equivalent question might be: is this patient seriously ill? There are a variety of approaches to identifying patients early, but it is most important to be systematic and proactive.

Dr. Lorenz noted that evidence to support palliative care in surgical specialties is sparse but informative. For example, one study found that perioperative mortality was reduced among both frail and non-frail surgical patients using systematic frailty screening and a multidisciplinary case review involving anesthesia, critical care, and palliative care. Among the frailest patients in this study, only four patients had to be treated and assessed by a multidisciplinary group to avoid one death.²⁵ Another study that focused on the experiences of families and caregivers of veterans who died following high-risk surgeries found that the implementation of palliative care services resulted in reports of high quality of care, communication, and support.²⁶

Palliative care is also appropriate for patients with multiple comorbidities and those needing transitional support and care coordination. Palliative care principles are useful for identifying and managing risk in the context of surgical decision-making to ensure the right treatment for the right person. Integrating palliative care into surgical care is new, and we are all learning. A web-based educational resource that provides a generalist approach to learning palliative care skills is the Education in Palliative and End of Life Care (EPEC) program at Northwestern University Feinberg School of Medicine.¹⁰ EPEC is an example of a primary palliative care intervention and education program that includes a core curriculum with adaptations for emergency medicine, pediatrics, neurology, and the care of veterans. It also contains an educational program for family caregivers. It includes text-based educational modules, slides that can be adapted for training purposes, and videos that can help with instructional role play.¹⁸

When asked how to broach the topic of palliative care with a patient, particularly one with a long life expectancy, Dr. Lorenz's suggestion was to begin with an inquiry. For example, a urologist could ask if the patient has ever lost anyone they love and if they have learned anything about their own preferences from that experience. Often patients do not have specific end-of-life wishes, but they have values and goals that can help inform treatment choices. It can also be important to address the fundamental or minimal quality-of-life goals a patient would have if something catastrophic happens. Dr. Lorenz concluded by emphasizing that it is essential to know who the patient's proxy is and to have these conversations with that person in the room, because 50% of those who name a proxy do not discuss these issues with the identified individual.

Patient Perspective: How Doctors Can Best Support Patients at the End of Life

Renata Louwers

Renata Louwers began by thanking the AUA for including the caregiver's perspective in the conversation about palliative care. Ms. Louwers was her first husband's caregiver before he lost his life to bladder cancer in 2014. She has written eloquently about her personal experience with exceptional palliative care and how it made a difference to both her and her husband's quality of life. She then shared her essay, "We can offer you some helpful resources", which was previously published in *The Intima*, an online journal of narrative medicine.²⁷

The essay began with a description of how difficult it was to advocate for help when her husband was on the verge of being discharged from the hospital with inadequate resources to help her manage his medications, his catheter, his fever, and, above all, his intolerable pain. From Ms. Louwers' perspective, hospice care had failed, resulting in this hospitalization. The resources the hospital social worker offered at discharge were either woefully inadequate or prohibitively expensive, even for an upper-middle-class couple with good insurance coverage. It was only when she adamantly refused to take her husband home that the hospital staff facilitated his transfer to San Francisco's Zen Hospice Project. At Zen Hospice, Renata and her husband experienced the full benefit of exceptional palliative care for the final two weeks of his life. Her husband's physician helped her to make difficult end-of-life decisions, and the staff not only relieved her of her caregiving responsibilities but prioritized her well-being as well. As she writes, "I could finally be a wife instead of a caregiver." The isolation

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of caring for a suffering loved one at the end of life was replaced with a compassionate community of providers who recognized the importance of supporting both husband and wife in their time of transition.

Delivery of Palliative Care Services in Urology

Jonathan Bergman, MD, MSHS

Dr. Bergman's involvement with palliative care began approximately ten years ago when he and Dr. Lorenz studied end-of-life care in men with terminal prostate cancer. They found that the management of these patients tended to be very aggressive, involving multiple outpatient visits, hospitalizations, imaging, chemotherapy, and radiation therapy. Hospice was underutilized and initiated much later than would have been beneficial.²⁸

Dr. Bergman began this session by noting that while the AUA, American Society of Clinical Oncology (ASCO), the National Academy of Medicine, and geriatric societies all recommend that patients with advanced disease receive palliative care; however, resources are limited.²⁹⁻³¹ There are only 4,400 palliative care physicians in the US, which equates to 1 palliative care physician for every 11,000 Medicare deaths.^{32, 33} Yet less than 20% of patients with urological cancer receive specialty palliative care.²⁸ He then made the case that palliative care offered by urologists is a realistic solution because they build long-term relationships with their patients, many of whom get advanced disease, and are often the physicians who know them best.

With this in mind, Dr. Bergman piloted a primary palliative care program at the West Los Angeles Veterans Affairs (VA). The program involved three interventions: an educational module, point-of-care reminders, and palliative care integration. The educational module utilized a short web-based instructional program modeling a palliative care approach to a patient with stage IV bladder cancer. Investigators added point-of-care reminders, such as prompts to discuss the prognosis and goals of care, and to make sure pain, depression, family support and advanced care planning were addressed, were added to the electronic health record (EHR). They integrated palliative care by making sure that all patients with advanced disease received a palliative care consult early in their disease course. In this way, palliative care needs could be co-managed by urologists and palliative care specialists.

A qualitative analysis of this program revealed that initially all the supportive care was done by the palliative care specialists; however, over time, the system evolved such that the urologists began doing the symptom assessments themselves, asking about pain, depression, and goals of care. The educational module changed urologists' attitudes about care priorities and those changes were durable over time.^{34, 35} Following the interventions, urologists placed a higher priority on asking about pain, goals of care, and patients' preferences regarding end-of-life care than they did previously. They also demonstrated an increased understanding of advance care planning, quality of care indicators, and cost of care.³⁶ The biggest concern urologists had was that incorporating primary palliative care into clinic visits would increase the time needed for each visit and disrupt the clinic flow. When this did not happen, the program was readily accepted.

Once the primary palliative care program was implemented, hospice utilization almost doubled from 30–60% to 81%.³⁷ Almost all patients in the program had an advance directive, a Portable Medical Orders form (POLST), or both, and a review of these advance care plans revealed that most patients did not want aggressive care at end-of-life. Addressing advance care planning early in the disease process gave patients time to consider their preferences for end-of-life care, so if aggressive management was implemented, it was by choice and not by default. Patient satisfaction was very high because quality of life was maintained, which is not common for people with advanced disease. One area that still needs work is depression, which affected 43% of patients in the program, comparable to the rate in the community.³⁸ Dr. Bergman concluded by expressing his hope that this summit can be a forum for moving beyond the discussion of primary palliative care to planning its implementation for the benefit of patients.

Session 2: Panel Discussion: When is Palliative Care Needed?

Moderators: Jonathan Bergman, MD, MPH; John Gore, MD, MSHS

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A brief question and answer session preceded this panel discussion, during which Ms. Louwers stressed the importance of correcting the misunderstanding that palliative care signals the end of life, that it is the same as hospice care, and that a referral to palliative care means the primary physician has failed. She noted that this stigma is held in the general community as well as among physicians. An attendee asked Dr. Lorenz how urologists and palliative care specialists can collaborate. He said patients often get referred to palliative care through a circuitous route, and referrals often spring from interpersonal relationships that develop between referring physicians and palliative care specialists. He noted that these are the early days of integration, and demonstrations of effectiveness build trust and collaboration. He also emphasized the need to systematize the process. Another attendee asked Dr. Fero and Dr. Lorenz if a precision medicine analog exists for palliative care. Dr. Fero made the distinction between primary palliative care, which is like a big umbrella under which any provider can take a patient-centered approach, and specialty palliative care. Dr. Lorenz proposed changing the term precision medicine to precision care, thus replacing the emphasis on biological diversity with a focus on the diversity of social determinants such as environment, personal characteristics, family, spiritual beliefs, culture, race, and language.

Panel Discussion: Oncology

Scott Gilbert, MD, MS; Bruce Jacobs, MD, MPH

Dr. Gilbert and Dr. Jacobs discussed the case of a 68-year-old male with muscle-invasive bladder cancer in order to highlight points at which palliative care could be introduced into his treatment trajectory. The patient had a past medical history significant for hypertension, diabetes, chronic obstructive pulmonary disease (COPD), and anxiety. He smoked a pack of cigarettes a day and worked as a farmer. He and his wife were tearful when they received the diagnosis. The patient chose to bypass neoadjuvant chemotherapy because of concerns about time away from work during the active farming season and chose immediate surgery for a cystectomy with an ilial conduit diversion. He returned two years later with metastatic disease to his bone and an extensive pelvic recurrence causing substantial pain, abdominal discomfort, and weight loss. Pain management was difficult in the urology clinic, and salvage chemotherapy provided little relief. He chose to forgo immunotherapy and died at home a couple of months later.

Drs. Gilbert and Jacobs identified three points during this patient's care trajectory that the incorporation of primary palliative care would have been beneficial. The first was at the time of diagnosis of advanced disease, which is an ideal time to initiate primary palliative care. For example, his history of anxiety and tearful response to hearing the diagnosis could have prompted the use of a distress screening questionnaire which could have led to involvement by social work. The second opportunity was on his return to clinic two years after surgery, when pain management became an issue that was difficult to address. The final opportunity was the point at which he declined further treatment and chose to return home to be with his family. This would have been a reasonable time to transition to hospice care. Drs. Gilbert and Jacobs also noted that his prioritization of farm work and his stoicism influenced his choice to decline initial chemotherapy and most likely prevented him from disclosing the degree of pain he was experiencing until it reached a level that was difficult to manage. The introduction of primary palliative care early in his illness could have enabled his physicians to identify these personal characteristics and take a more proactive approach.

Panel Discussion: Stone Disease

John Leppert, MD, MS; Margaret Pearle, MD, PhD; Charles Scales, MD, MS

Drs. Leppert, Pearle, and Scales discussed the benefit of primary palliative care for patients without a terminal illness but with multiple comorbidities. They noted that palliative care helps patients to live within the goals of care, not just die within the goals of care.

Dr. Scales presented the case of a 75-year-old non-ambulatory female nursing home resident who was referred to him for a 5cm right-sided complete staghorn calculus discovered during her hospitalization for urosepsis. Her comorbidities included morbid obesity, urinary incontinence, COPD requiring home oxygen, type 2 diabetes, obstructive sleep apnea, a seizure disorder, along with moderately impaired renal function. Given her overall health, she was not a good candidate for a percutaneous nephrolithotomy, the primary

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treatment of choice. She was also at high risk for complications from alternative treatment options, including uteroscopy with laser lithotripsy, laparoscopic nephrectomy, and robotic pyelotomy. The conclusion of a combined geriatrics and anesthesia preoperative evaluation clinic to which she was referred was that surgical intervention was risky given her frailty and comorbidities. They recommended pulmonary and physical therapy and reevaluation before surgical intervention be reconsidered. Most importantly, the patient had clear goals of care. She wanted to avoid surgery and maximize her quality of life. She wanted to focus her treatment on managing her urinary incontinence, which was her most distressing symptom, controlling her pain, and minimizing her risk for further urinary tract infections. In her case, these goals of care guided the team's treatment plan.

This case is an example of how the early implementation of palliative care principles, for a patient with a non-terminal disease but severely impaired overall health, can help to prioritize treatment choices. In the discussion of this case, Dr. Pearle noted that urologists often focus on maintaining the drainage of urine in patients with stone disease, but that consideration of how their interventions affect the patient is important. Dr. Leppert added that a palliative care approach could be very helpful in parsing out the complex interactions between the diagnosis of the stone, the management of the patient's comorbidities, the patient's primary complaints, and the overall goals of care. Dr. Scales concluded that in cases like this, a multidisciplinary approach is key, with urologists playing a strong role in communication.

Panel Discussion: Female Pelvic Medicine & Reconstructive Surgery

Anne Suskind, MD, MS; Karl Lorenz, MD, MSHS

Dr. Suskind began her discussion by noting that urinary incontinence is one of the most prevalent and burdensome conditions of aging. Over 50% of people experience urinary incontinence during their final year of life.^{39, 40} A Canadian study of nursing home residents found that 80% of study participants ranked urinary incontinence as their most burdensome symptom, over and above pain, while healthcare providers ranked it as merely a moderate burden.⁴¹ This discrepancy is important for both palliative care physicians and urologists to consider.

Dr. Suskind noted that the complexity of caring for individuals with urinary incontinence is less about the treatment and more about managing symptoms, maximizing comfort, and preserving the patient's dignity. She mentioned the work of Dr. Harvey Chochinov, who has observed that dignity can be easily lost when the body cannot be controlled. Dignity is a human right maintained by preserving independence, sustaining relationships, minimizing the burden that illness places on others, and ensuring privacy and personal space.⁴² Urinary incontinence is a prime example of the threat to dignity.

Both Dr. Lorenz and Dr. Suskind acknowledged that family caregivers, nurses, and nurses' aides carry most of the responsibility in caring for people with urinary incontinence. The quality of these relationships, which demand vulnerability on the part of the patient, matters a great deal to the comfort of the patient and may be influenced by multiple factors, including personal characteristics and cultural values. Dr. Lorenz concluded by noting that because patients develop long-term relationships with their urologists, they trust their urologists to help them navigate problems such as urinary incontinence. A palliative care approach can help urologists be sensitive to the continence needs of their patients and can result in a more satisfying and effective therapeutic relationship.

Panel Discussion: General Urology

Micheal Darson MD, FACS

Dr. Darson presented the case of a 70-year-old male with benign prostatic hyperplasia (BPH) and Parkinson's disease to illustrate how palliative care could be integrated into a general urology practice. The patient was referred to Dr. Darson once his BPH and Parkinson's had progressed and oxybutynin and tamsulosin were no longer effective for his bladder symptoms. He underwent urodynamic cystoscopy and a transrectal ultrasound, was diagnosed with bladder outlet obstruction, and received minimally invasive treatment for his BPH. While the procedure was initially successful, over time, his symptoms returned, and he also developed urinary

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incontinence. He was treated with pelvic floor physical therapy, posterior tibial nerve stimulation, and mirabegron, all of which helped, but as his Parkinson's worsened, so did his incontinence. As is common in such cases, the patient's significant other was his sole caregiver and the burden of care, especially the increase in laundry due to the incontinence, eventually impacted the health of the caregiver.

Dr. Darson agreed with the other panelists that it is beneficial to begin thinking about palliative care early in the relationship and to "load the boat" by bringing in other providers to help manage the patient's care. These can include a pain management service, physical therapy, occupational therapy, and social services. Aspects of palliative care that a general urologist can implement include individualizing care, maintaining awareness of the overall progression of the illness, and being vigilant about continuously reevaluating the treatment plan. Making sure that the office is easy to navigate for both patient and caregiver is another area in which a urologist can have a positive impact. Finally, the involvement of palliative care specialists is valuable for overall care coordination and in-depth communication with the patient and the caregiver.

Questions and Answers

During a brief question and answer session, an attendee questioned how cultural sensitivity might change the conversation about palliative care. Dr. Gilbert noted that this has emerged as an important topic over the past few years. Having a diverse staff and translators who can help explain culturally informed responses and cue the doctor on what may or may not be culturally appropriate is helpful. Dr. Jacobs added that having patients bring their spouse or a friend to the appointment can help to give context to the patient's wishes and clarify the direction they might want to take. Dr. Bergman agreed and emphasized the value of involving the family early, before the illness becomes too advanced.

An audience member asked for additional guidance on the topic of pain management. Dr. Lorenz suggested that the distinction between a pain management specialist and a palliative care specialist may be a false one. Management of the patient's pain is worthwhile regardless of whether the patient is receiving treatment with curative intent or not. He proposed that interventional pain management procedures may be underutilized. Finding ways to collaborate for the patient's benefit is more important than the specific roles played by different physicians or services.

[Webinar 2: Perspectives on Increasing the Use of Palliative Care in Advanced Urologic Disease](#)

Session 1: Evidence Synthesis: Palliative Care Innovations in Surgery

Pauline Filippou, MD

Dr. Filippou began by noting that the consensus from the previous webinar was that the implementation of primary palliative care skills by urologists can make a big difference in the lives and care of patients and their families. The delivery of primary palliative care within the context of a urology practice is a skill requiring training, practice, feedback, although its development has not yet been prioritized in medical training or continuing medical education and there are not yet urology-specific interventions.

Dr. Filippou performed a systematic review of the literature to find out what educational interventions designed to improve primary palliative care delivery have been implemented in surgical settings. She focused her search on the eight domains of palliative care defined by The National Consensus Project: 1) structure and process of care, 2) physical aspects of care, 3) psychological and psychiatric aspects of care, 4) social aspects of care, 5) spiritual, religious, and existential aspects of care, 6) cultural aspects of care, 7) care of the patient nearing the end of life, and 8) ethical and legal aspects of care.⁴³ Dr. Filippou found that only two (spiritual, religious, and existential aspects and cultural aspects) have not been targeted in educational interventions. Social aspects of care is the domain most frequently addressed. This domain includes communication skills and the discussion of prognoses. Multiple pedagogical tools were used in the interventions, including lectures, web modules, small-group work and case-based learning, and for varying amounts of time ranging from 1–2 hours to several months. All the interventions, regardless of their structure or duration, resulted in improvements in recognition

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of the value of palliative care, knowledge of palliative care, and receptivity towards palliative care. The majority of the interventions also resulted in skill improvement and increased provider confidence.

Dr. Filippou concluded her discussion by stating that urologists are already providing some level of primary palliative care as part of their regular practice, but to do it effectively, particularly in complex situations, requires skill. Urologists can build on work already done in the surgical arena to improve their delivery of primary palliative care. Training modules that use prerecorded videos of demonstrations of exemplary skill delivery are already available and can be easily adapted to urology-specific care, making widespread implementation feasible.

Session 2: Panel Discussion: Ways to Implement Palliative Care into Practice

Moderator: Jonathan Bergman, MD, MPH

The Palliative Care Physician Perspective: Integrating Primary Palliative Care into Practice

Joshua Hauser, MD

Dr. Hauser began by distinguishing between primary and tertiary (or specialty) palliative care. He referred to work done by Drs. Timothy Quill and Amy Abernethy, in which primary palliative care is defined as basic management of pain, depression and anxiety, and initial discussions regarding prognosis, treatment goals, and end-of-life care.⁴⁴ Specialty palliative care involves the more complex management of refractory pain, severe anxiety, depression, and grief, assistance with conflict resolution and existential crises, and advanced or deeper communication skills.

Dr. Hauser proposed two ways to integrate palliative care and urology. The first is to agree upon a list of diseases or disease states that warrant consultation by specialty palliative care. The other is to give urologists palliative-care-specific training using an educational project such as the EPEC program.¹⁰

To illustrate how EPEC can be used to train urologists to provide primary palliative care, Dr. Hauser gave the example of an ongoing study by Dr. Benzi Kluger in which the standard care of patients with advanced Parkinson's disease is being compared to standard care with the addition of primary palliative care.⁴⁵ In this study, primary palliative care is incorporated into the usual care of patients with Parkinson's disease in three ways: a day-long training session using EPEC-based materials adapted for neurology, online resources made available for ongoing reference, and longitudinal coaching and mentoring. Outcomes include quality of life markers, hospice referrals, and length of life. The length-of-life outcome was inspired by a foundational study by Dr. Jennifer Temel, which found that providing palliative care to patients with lung cancer improved the length as well as the quality of their lives.⁴⁶

In conclusion, Dr. Hauser proposed several questions to consider when integrating palliative care and urology. These include considering what education may be beneficial to non-physician caregivers, what lessons can be gleaned from multidisciplinary cancer clinics in urology that might be relevant for palliative care in urology, whether referrals to specialty palliative care will encourage or discourage the use of primary palliative care, and how to define meaningful outcomes for the integration of primary palliative care and urology.

The Resident Perspective: Experiences and Barriers in Palliative Care in Urology

Farnoosh Nik-Ahd, MD

Dr. Nik-Ahd began by observing that many residents choose urology because it is a surgical field in which long-term relationships with patients can be established and the full spectrum of disease can be addressed. Palliative care enhances this patient-focused approach. Urology residency gives young physicians a lot of exposure to patients with palliative care needs. Residents are often required to deliver bad news, especially with new cancer diagnoses, and they are frequently the first to discuss treatment options. They also routinely address issues pertaining to quality of life, daily function, symptom management, and goals of care, particularly in the context of making treatment decisions.

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The challenges residents face when delivering primary palliative care include managing complex psychosocial needs for which there is a paucity of formalized training and, therefore a reliance on multidisciplinary care, including help from palliative care specialists. Residents have time constraints; for example, they may be in the operating room and miss observing complex conversations with patients and difficult pain management decisions. Finally, there is no dedicated curriculum specific to implementing palliative care principles in urology.

Dr. Nik-Ahd proposed an immersive palliative care training approach that would involve teaching residents new skills in a structured setting with graded responsibilities and exposures, similar to a surgical training approach. This would mean establishing standardized competencies with focused didactic sessions for each skill. An example could be providing workshops on discussing goals of care or navigating challenging diagnoses. Several strategies employed by general surgery residency programs could be used by urology residency programs, including incorporating palliative care into morbidity and mortality reports and tumor board conferences, providing quick reference cards for communication phrases and pain management strategies, and inviting residents to be members of institutional bioethics teams.⁴⁷⁻⁴⁹ Dr. Nik-Ahd concluded by proposing that incorporating palliative care training into urology residency programs will help urologists provide better care for their future patients, particularly as the U.S. population ages and as patients present with increasingly complex needs.

The Fellow Perspective: Barriers to the Incorporation of Primary Palliative Care in Urology

Lee A Hugar, MD, MSCR

In this session, Dr. Hugar identified five provider-related barriers to incorporating palliative care in urology: 1) insufficient communication skills training, 2) the need for emotional resilience, 3) inadequate experience with symptom management, 4) prognostic uncertainty, and 5) the surgical mindset. He began by noting that palliative care training is severely lacking, especially in the surgical specialties. For example, surgeons receive an average of 10 hours of palliative care training, compared with their oncology and intensive care colleagues who receive an average of 30 hours and 50 hours, respectively.⁵⁰ A 2018 study found that the less training providers have in palliative care skills, the more aggressive their interventions are for complex patients.⁵⁰ Dr. Hugar then expanded on the five barriers.

First, he emphasized that communication skills are fundamental to effective palliative care delivery. A founder of the surgical palliative care movement, Geoffrey Dunn, compared good communication to good surgery. Both require experience, courage, organizational skills, assistance, and the proper setting. Delivering bad news is like performing an invasive procedure; both are life-changing events for the recipient.⁵¹ Then he noted that when navigating the course of advanced disease, emotional resilience is essential for both the physician and the patient. Difficult conversations about prognosis and end-of-life issues can be emotionally draining for the provider, and being able to respond to the patient's and caregiver's emotions takes skill. He noted that while urologists have a great deal of experience in managing acute urologic symptoms, they have minimal experience in managing other common symptoms that have a major impact on quality of life, such as depression, anxiety, chronic pain, and fatigue. He acknowledged that although prognosis is essential for decision making, it is notoriously difficult. Finally, he asserted that a surgical mindset, while necessary for problem-solving and operating skills, can interfere with a palliative care mindset. For example, a sense of personal responsibility, a focus on the cure at the expense of quality of life, and a perception of adverse events as personal failures can all interfere with a patient-centered approach.⁵²

Dr. Hugar then proposed several ways to address these barriers and incorporate palliative care skills into clinical practice. For example, communication skills can be improved by education and practice.⁵³ Emotional intelligence and emotional resilience can be optimized by using materials like talking maps designed to address patients' emotional needs and identify areas of greatest concern.⁵⁴ Multiple resources are also available to help physicians with symptom management, including the American College of Surgeons' (ACS) palliative care guide⁵⁵, the European Urological Association's (EAU) pain management and palliative care guidelines⁵⁶, and the National Comprehensive Cancer Network's (NCCN)³⁰ palliative care guidelines. Prognostic estimates can be improved by using probabilistic multivariable models rather than subjective assessments, which can streamline referral to specialty palliative care.⁴⁵ Finally, the surgical mindset can be

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modified by building relationships with palliative care teams, adding patients with refractory or complex systems to tumor board discussions, and including conversations about advanced care planning or limited prognosis at morbidity and mortality conferences.

Dr. Hugar concluded by describing patient barriers to palliative care, such as a lack of knowledge about palliative care. A recent study found that only 30% of US adults have heard of palliative care and only half of those know what it is.⁵⁷ Other barriers include a lack of referrals and logistical concerns in managing multiple outpatient appointments.⁵⁸ These problems can be addressed by providing physicians access to educational resources, locating palliative care within outpatient clinics, educating the community about the benefits of palliative care, and systematizing primary palliative care.

The Junior Faculty Perspective: Challenges and Barriers to Integrating Palliative Care in Early Practice

Kevin Koo, MD, MPH, MPhil

Dr. Koo began by acknowledging that, for a junior faculty member, the combined demands of a new practice, research development, and teaching responsibilities are barriers to incorporating primary palliative care in urology. Taking these pressures and time constraints into consideration, Dr. Koo proposed three overlapping strategies for integrating palliative care principles into an early-career urology practice. These include: 1) elevating quality of life considerations; 2) empowering the care team; and 3), recognizing the pressure to operate.

In tertiary care and academic centers, there is a potential bias among patients, referring physicians, and urologists that patients should be offered multiple or advanced treatment options and that there is always something more that can be done. However, aggressive interventions may not align with patients' goals of care. By emphasizing the importance of quality-of-life concerns and providing education about the role of palliative care in terminal and non-terminal disease, urologists can allow patients to individualize their options and simultaneously relieve their anxiety about feeling compelled to receive the most aggressive care.

Empowering a care team to provide high-quality and consistent palliative care requires that all team members feel comfortable in their roles and align with the same goals. Knowing who will oversee complex palliative care management plans is essential to their implementation. This could be a dedicated nurse or advanced practice provider (APP) coordinator, or the clinic could be part of a multidisciplinary group with a program to integrate palliative care when needed. Empowering the team also means providing training resources or additional support if necessary. Finally, collaboration with junior faculty palliative care specialists can result in mutually beneficial relationships.

Palliative care involves a holistic approach to symptom relief and goal setting, which may appear to undermine the unspoken pressure to operate felt by most junior faculty. This pressure is a natural and valid consequence of years of intensive surgical training, the desire to perfect and preserve surgical skills, and the need to demonstrate productivity by maintaining a high surgical volume. However, by implementing palliative care, the needs of the patient are prioritized, and this ultimately benefits clinical outcomes, surgical volume, and the confidence and reputation of the physician.

Senior Faculty Perspective: Barriers to Palliative Care

Martha K. Terris, MD

Dr. Terris began by stating that, traditionally, senior faculty have regarded palliative care as belonging to the domain of social work, primary care, perhaps medical oncology, but not urology. Senior faculty have several concerns that prevent them from embracing palliative care, not least of which is a misunderstanding of the difference between hospice and palliative care. The subject of aging is sensitive for older physicians, pain management is problematic in the current climate, and there is a longstanding belief in the culture of medicine that not being aggressive enough equates to professional failure. Moreover, there are economic incentives to perform more procedures and a fear of litigation if one chooses not to intervene.

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She reiterated that the lack of awareness about palliative care is a major impediment, again noting the importance of clarifying the difference between palliative care and hospice. She noted that senior faculty are already using conservative approaches, such as watchful waiting for prostate cancer, small renal masses, and non-obstructing stones, but do not consider this palliative care. Capitalizing on these non-aggressive approaches and labeling them as palliative care will help senior faculty to understand it as a treatment strategy rather than see it as a failure to help. She suggested that palliative care can become part of the conversation by including the topic in AUA meetings and QI Summits and inviting specialists in other fields such as physical therapy, occupational therapy, gerontology, and social work to share their knowledge and resources at urology grand rounds. In addition, palliative care can become a topic that is addressed in educational forums such as journal clubs and lectures. She also noted that senior faculty can be asked to supervise QI projects on palliative care topics assigned to residents, which may encourage those faculty to develop an interest in palliative care. Finally, Dr. Terris concluded by noting that introducing primary palliative care into a practice can revitalize a career, give the practice longevity, and help fight burnout.

Questions and Answers

The question-and-answer session, which followed the panel discussion, focused mainly on the logistics of providing primary palliative care in a urology setting. Dr. Hauser recommended thinking about palliative care in terms of teamwork, with much of the work being done by nurses and social workers but recognizing the gravitas that comes with a doctor's recommendation. Asking the patient one or two questions such as "What is most important to you?" or "What is most meaningful to you?" can start the conversation yet take relatively little time. Dr. Filippou addressed additional concerns about how much time palliative care conversations would add to a short clinic visit. She also shared that research shows that when physicians implement palliative care practices, they save time by efficiently engaging patients in fruitful conversations. In answer to a question about the financial burden of end-of-life care, Dr. Filippou responded that palliative care could help with financial toxicity by ensuring that patients receive meaningful care that is consistent with their wishes, rather than the high-cost, high-utilization care that is often provided by default. When asked about relevant and trackable outcomes, Dr. Hugar suggested determining the patients' preferences up front and then correlating their disease trajectories and end-of-life experiences with those preferences. Additionally, symptoms can be tracked using a distress thermometer or the Edmonton Symptom Assessment System (ESAS).⁵⁹

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Keynote Address: Growing Perioperative Palliative Care in the Veterans Affairs Health Care System
Scott Shreve, DO; Karleen Giannitrapani, PhD, MPH

Dr. Shreve began with a discussion of the effect of the COVID-19 pandemic on quality of end-of-life care at the VA from 2019 through 2021. The Bereaved Family Survey (BFS)⁶⁰, which is sent out to families 6 to 8 weeks after an inpatient death, is designed to assess the family's satisfaction regarding the end-of-life care their loved one received. For the first time in several years, there was a decrease in satisfaction, most likely due to a shift in location of death. In 2019, 44% of the deaths in the VA occurred in hospice beds. Once COVID-19 took hold, the number declined to a low of 24% in 2021. There was a concurrent increase in ICU deaths from 40% in 2019 to 64% in 2021. From a family satisfaction standpoint, death in a hospice setting is considered higher quality of care than death in the ICU.

Dr. Shreve also presented data from the BFS that shows a statistically and clinically significant increase in the perceived quality of end-of-life care with at least one palliative care consult compared with usual care at the VA. With a designated hospice and palliative care unit, there was an even greater increase in the perceived quality of care.

Additionally, Dr. Shreve described an investigation of the intersection of palliative care and surgery services at the VA. He quantified outpatient surgical referrals to the palliative care specialty service at six VA facilities and found that some surgery departments referred their high-risk patients to palliative care much more frequently

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than others. The way patients were referred to palliative care also varied. In some cases, a collaborative relationship between surgeons and palliative care providers facilitated the referrals, and in others, it was through the systematic use of a needs assessment.

To determine why palliative care consults were less common for surgical patients than for patients from other services, Dr. Giannitrapani conducted interviews with surgeons and palliative care teams. She asked why referrals often occur late in the disease course, sometimes within days of the patient's death, and how collaboration between the two services can be improved. She found that surgeons were often unclear about the difference between palliative care and hospice, and some also felt that they were being treated as high-level technicians and that discussions about surgery were being held before they were consulted. In contrast, palliative care physicians believed that goals of care could be clarified, and some unnecessary interventions could be avoided if they were consulted preoperatively. They felt that they were often consulted too late, once the decision to intervene surgically had already been made, so any clarification of goals of care at that point would be confusing to the patient. Both surgeons and palliative care physicians agreed on the importance of building relationships and having surgeons involved in discussions about goals of care.

Dr. Giannitrapani then proposed four high-level strategies for improving goals of care conversations in the perioperative period. The first is to develop and maintain collaborative and trusting relationships by ensuring that surgeons are included in goals of care conversations and that palliative care physicians are involved in defining goals of care and managing symptoms. The second strategy is to provide sufficient interdisciplinary palliative care staffing either in-person or by telehealth. Both surgeons and palliative care physicians agreed that a lack of staffing is unsustainable. The third strategy is to establish a method of screening patients to identify those who would benefit from palliative care. The final strategy is to involve the palliative care teams early, ideally in advance of a surgical procedure.

Dr. Giannitrapani then identified the following six factors that contribute to the development of collaborative relationships between palliative care physicians and surgeons:

1. Being present, available, and responsive. This could be working together in the same location, frequent communication, sharing notes in the EHR, or working together on a tumor board.
2. Understanding roles. Ensure understanding and support without overstepping professional boundaries.
3. Establishing communication. Know the leaders of each team and communicate at the appropriate levels.
4. Recognizing the contributions of the supporting staff, including physical therapists, speech therapists, nurses, and others.
5. Working as a team, which requires consistent communication between all involved.
6. Building the relationship, which takes a willingness to work across disciplines.

Dr. Giannitrapani noted that there is ample evidence that using well-established organizational behavioral principles is effective in building highly functional teams. This is encouraging for the interdisciplinary team building that is required to provide quality care for patients. She concluded the session by informing summit participants of a partnership between the VA Palliative Care Services and the National Surgery Office in which she and Dr. Shreve plan to pilot an intervention to improve perioperative palliative care at three VA sites with the hope of eventually scaling it nationally.

Panel Discussion: Optimal State of Palliative Care in Urology: How Can We Operationalize a Primary Palliative Care Model?

Moderators: Jonathan Bergman, MD, MPH; Martha Terris, MD

Panelists: Scott Gilbert, MD, MS; Farnoosh Nik-Ahd, MD; Jaime Goldberg, MSW, LCSW; Bruce Jacobs, MD, MPH

Dr. Jacobs began by noting that urologists must first understand what palliative care is, and that they require formal training in order to implement palliative care in their clinics in a routine and systematic manner. Dr. Nik-Ahd stated that such training should include predetermined competencies for each level of training. Ways to enhance communication skills should be a key focus of training. The panel noted that urologists should be

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encouraged to ask questions such as, “What do you want your care to look like?”, “How bothered are you by your symptoms?” and “What conversations have you already had?” Communication skills training also should focus on how to deliver bad news and how to address quality-of-life concerns. Ms. Goldberg stated that effective training also should infuse the philosophy of palliative care, including concepts such as self-reflection and introspection, cultural humility, empathetic response to both patient and provider emotions, viewing the patient and family as the unit of care, and the significance of financial barriers that will require policy and system changes. Ms. Goldberg noted that urologists may need guidance on use of screening tools to help identify palliative care needs (e.g., the Patient Health Questionnaire-2⁶¹ and ESAS⁵⁹ for mental health screening) and readily accessible resources that can help them address issues that arise (e.g., lists of medications or diets that contribute to nausea, non-pharmacologic options for symptom management).

Panelists emphasized that urologists can adjust approaches for providing primary palliative care for the unique attributes of their practices. They should recognize, and then capitalize, on the resources that are readily available (e.g., specialty palliative care teams in hospitals, social workers or nurse practitioners, etc.). However, they agreed that, at a minimum, the urologist and at least one other provider should be involved, each bringing a distinct set of skills and clearly defined roles. For example, the urologist would focus primarily on conversations about the condition and treatment, while a social worker would provide referrals for appropriate supportive services. Dr. Bergman emphasized making the patient’s primary care provider aware of the plan, so that there are multiple eyes on the patient.

Dr. Koo acknowledged the barrier of time constraints. He noted that spending a few extra minutes to discuss palliative care needs with a patient eventually can occur organically in conversation. The panel mentioned that EHR prompts can help to remind urologists to have these conversations with their patients. Again, the panel emphasized that while no single approach will work for everyone, there are many ways for urologists to help deliver palliative care to their patients.

The panel concluded by pointing to the following resources:

- the AUA Core Curriculum’s course on palliative care¹⁴
- the Palliative Care Network of Wisconsin has a link to resources including, “Palliative Care Fast Facts”¹⁶
- the Center to Advance Palliative Care (CAPC) offers tools and training.¹⁵

Panel Discussion: What Clinical Innovations and Other Interventions Are Needed?

Moderators: Karl Lorentz, MD; Joshua Hauser, MD

Panelists: Kevin Koo, MD, MPH, MPhil; Micheal Darson, MD; Desiree Sanchez, MD; Jaime Goldberg, MSW, LCSW

Dr. Sanchez suggested that in order to adapt to rapidly changing practices in medicine and minimize barriers to delivering primary palliative care, urologists should focus on awareness, expertise, time, and resources. She noted that the barriers of awareness and expertise can be achieved through education, and she proposed integrating a one-month rotation in palliative care or the opportunity to shadow a palliative care provider during residency. She also suggested that the American Board of Urology (ABU) incorporate NCCN Distress Management Guidelines⁶² into the ABU exam. Dr. Hauser noted that at his institution, physicians who have completed a palliative care rotation consult with palliative care specialists more often than those who have not. Dr. Darson added that meetings, Continuing Medical Education (CME) courses, and poster presentations are helpful for urologists who are already out in practice to gain expertise in the field. One way to address time constraints is to have a palliative care e-consult or telehealth group with conversations stored in the EHR. An attendee of the summit volunteered that her practice uses a third-party monitoring group that communicates with the patient and sends the practice updates. Another way to address time constraints is by having a dedicated advanced practice provider (APP) manage palliative care needs. Dr. Darson addressed the problem of limited resources in a small practice. He currently researches the resources provided by his patient’s insurance company and refers patients to those. He noted that the addition of a nurse navigator in his practice would be helpful to help navigate the resources offered by insurance companies.

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Dr. Koo noted that it would be helpful to have tools that can be implemented in any urology practice, including resources on language. Ms. Goldberg mentioned the importance of language and asking patients about emotions, resources, and coping mechanisms. Dr. Hauser shared two questions he routinely asks patients to address the symptoms and the “big picture”: “How are you doing?” and “How are you doing with []?” He also noted the importance of engaging with the caregivers to assess their quality of life and what challenges they are facing.

Dr. Lorenz concluded the discussion by noting that healthcare professionals need to be better at identifying who is responsible for managing the palliative aspects of the patient’s care. He emphasized the need to conduct more research to determine how to address the palliative care needs of patients in private practice.

Panel Discussion: What Outcomes Should We Track?

Moderators: John L. Gore, MD, MSHS; Pauline Filippou, MD

Panelists: Lee Hugar, MD, MSCR; John Leppert, MD, MS; Anne Suskind, MD, MS; Karl Lorenz, MD, MSHS

The panel discussed various palliative care outcomes that could be tracked over time and at different stages of illness and treatment that urologists should consider as they implement primary palliative care in their practices. Dr. Hugar suggested tracking screening and rescreening, the utility of telehealth, and the intensity and cost of end-of-life care. His practice uses the PROMIS-29 survey to monitor quality of life.⁶³ He also proposed measuring decisional regret, for example, if they regretted their decision to pursue chemotherapy or surgery and if they made their choice based on how the information was presented or for another reason. Dr. Leppert suggested tracking how the delivery of palliative care differs in different settings. Dr. Koo added that tracking the rate of referral to specialty palliative care could help to characterize what is appropriate for primary palliative care.

Dr. Gore noted that palliative care is often associated with de-utilization of care. Dr. Hugar suggested that care utilization and cost of care for patients receiving palliative care should be measured. He added that decreased cost and de-utilization of care should not be goals of palliative care, but they are often outcomes.

When asked how clinicians track and identify frailty, the panel responded that the Timed Up and Go test⁶⁴ is a good assessment of frailty but is not helpful for tracking changes. Life-space mobility is more useful for tracking functional mobility over time.⁶⁵ Dr. Gore questioned how one might measure the different variables associated with incontinence. Dr. Suskind acknowledged that incontinence is complex and difficult to measure because some patients are very upset by it, and some are not. Dr. Lorenz emphasized that quality of life should be a main concern. For example, we should examine overall bother and if the patient is satisfied with their level of social interaction.

The panel emphasized the importance of tracking outcome measures for family and caregivers, as well. Dr. Suskind proposed defining trackable metrics, including caregiver burden and resources or programs available for caregivers. Dr. Lorenz said that patients often withdraw care for fear they will bankrupt their families, so tracking financial toxicity in addition to other outcomes could provide important information. For patients, some additional metrics include advanced care planning, goals of care, pain, depression, other mental health symptoms, and social isolation. Dr. Lorenz noted that few patients have an advance care plan, and if they do, their surrogate is often not aware that they are listed on it. He suggested measuring the number of patients with an advance care plan, so the patient’s values, goals, and preferences of care can be incorporated into their care. Dr. Lorenz also noted that the BFS used by the VA is valuable measurement tool for assessing both patient and caregiver experiences.⁶⁰

Closing Remarks

John Gore, MD, MSHS

Dr. Gore concluded the summit by thanking the panelist and attendees for engaging and robust conversations. He expressed his excitement for future opportunities to operationalize and implement a primary palliative care model for the field of urology.

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