

# Palliative Care

---

## Editors:

Michael A. Liss, MD, MAS, FACS

## Authors:

Pauline Filippou, MD; Jonathan Bergman, MD, MS

## Last Updated:

Sunday, March 5, 2023

## 1. What is Palliative Care?

### 1.1 Definitions

Palliative care encompasses specialized medical care that provides an added layer of support to relieve pain, symptoms, and stress for people with serious illness and their families.<sup>1</sup> Serious illness affects the quality of life and the ability to function for both patients and their loved ones. Studies suggest that the undertreatment of pain and disabling symptoms for patients with serious illness occurs across all types and stages of disease is commonly attributed to conflicts about who should make healthcare decisions, impairments in caregivers physical and psychological health, and depletion of family resources.<sup>2</sup> Palliative care provides additional assistance through specific knowledge and clinical skill delivery to patients and their loved ones to help manage and navigate serious illness and improve quality of life.

Eight domains outline the practice of palliative care.<sup>3</sup> We describe the key components of the eight domains below.

- Structure and Processes of Care: Palliative care principles and practices can be integrated into any health care setting, delivered by all clinicians, and supported by palliative care specialists who are part of an interdisciplinary. Palliative care begins with a comprehensive assessment and emphasizes patient and family engagement, communication, care coordination, and continuity of care across health care settings
- Physical Aspects of Care: Physical care of seriously ill patients begins with an understanding of the patient's goals in the context of their physical, functional, emotional, and spiritual well-being. The care plan focuses on relieving symptoms and improving or maintaining functional status and quality of life. The management of symptoms encompasses pharmacological, non-pharmacological, interventional, behavioral, and complementary treatments. Physical care, acute and chronic symptom management across all care settings are accomplished through communication and collaboration between all professionals involved in the patients' care.
- Psychological and Psychiatric Aspects of Care: The palliative care interdisciplinary team

conducts comprehensive developmentally and culturally sensitive mental status screenings of seriously ill patients and communicates to the patient and family the implications of psychological and psychiatric aspects of care in establishing goals of care and developing a treatment plan, addressing family conflict, delivering grief support and resources from the point of diagnosis onward, and providing referrals for patients or family members who require additional support.

- Social Aspects of Care: Social determinants of health have a strong and sometimes overriding influence on patients with serious illnesses. Palliative care addresses environmental and social factors that affect patient and family functioning and quality of life. The palliative care interdisciplinary team partners with the patient and family to identify and support their strengths and address areas of need. Palliative care also includes assessing the need for social support, including transportation, housing, food access safety and availability of a social support system, and providing referrals and resources to local service providers.
- Spiritual, Religious, and Existential Aspects of Care: Spirituality is expressed through beliefs, values, traditions, and practices and is recognized as a fundamental aspect of patient and family-centered palliative care. Palliative care interdisciplinary teams serve each patient and family in a manner that respects their spiritual beliefs and practices.
- Cultural Aspects of Care: Assessing and respecting values, beliefs and traditions related to health, illness, family caregiver roles and decision-making are the first step in providing culturally sensitive palliative care. Information gathered through a comprehensive assessment is used to develop a care plan that incorporates culturally sensitive resources and strategies to meet the needs of patients and family members. Respectful acknowledgment of and culturally sensitive support for patient and family grieving practices is provided.
- Care of the Patient Nearing the End of Life: This domain focuses on the days leading up to and just after the patient's death. The comprehensive assessment and management of pain and other physical symptoms, and social, spiritual, psychological, and cultural aspects of care, are critically important as the patient nears death. The interdisciplinary team provides developmentally appropriate education to the patient, family and/or other caregivers about what to expect near death, and immediately following the patient's death. Hospice care is recognized conceptually and philosophically as the best care for patients nearing the end of life. Discussions regarding hospice as an option for support are conducted so that patients and families can understand eligibility and the benefits and limitations of accessing this care model. Early access to hospice support is facilitated whenever possible to optimize care outcomes for the patient and the family.
- Ethical and Legal Aspects of Care: The palliative care interdisciplinary team honors patient preferences, and decisions made by legal proxies or surrogate decision-makers. It is important to note that in all cases surrogates' obligations are to represent the patient's preferences or best interests. Familiarity with local and state laws is needed relating to advance care planning, decisions regarding life-sustaining treatments, and evolving treatments with legal ramifications.

## 1.2 Palliative care vs. Hospice

Hospice is a model of palliative care restricted to the end of life. All hospice is palliative care, but not all palliative care is hospice. Both care models aim to reduce stress and relieve the physical and psychosocial consequences of serious illness. However, key differences exist between palliative care and hospice care models (**Table 1**).

**Table 1**

|                      | <b>Palliative Care</b>  | <b>Hospice</b>   |
|----------------------|---|--|
| Eligibility          | Based on family and patient need  | Clinician certified prognosis < 6 months given the natural progression of the disease              |
| Timing               | Appropriate at any stage of serious illness from diagnosis to bereavement                                       | Life expectancy < 6 months and bereavement   |
| Concurrent treatment | Can be provided concurrently with all appropriate treatments and services                                       | Patients must forego curative treatment for terminal illness                                       |
| Payment              | Fee for service provider billing under Medicare Part B<br>Contracts with payers using a range of payment models | Patient agrees to give up insurance coverage of disease treatment Medicare and other payer benefit |

### 1.3 Palliative Care Delivery

A palliative care program requires a team to comprehensively address patient and family needs across the eight domains of palliative care. Palliative care teams are comprised of certified clinicians that provide expert consultation and/or co-management of patients with serious illness. Palliative care teams are interdisciplinary, usually consisting of clinical providers, pharmacists, social workers, and chaplains. The interdisciplinary palliative care team works alongside treating clinicians to provide an added support concurrent with disease treatment. Training and formal board certification to practice palliative care are available for medicine, nursing, social work, and chaplaincy. Specialty palliative care is defined as palliative care delivered by one of the above-described health care professionals trained to be palliative care specialists.

While palliative care is a medical subspecialty, the principles and many of the palliative care practices can and should be employed by all clinicians working with seriously ill patients. Primary palliative care is defined as palliative care that is delivered by health care professionals who are not palliative care specialists. Examples of groups performing primary palliative care are primary care clinicians; physicians who are disease-oriented specialists (such as urologists and oncologists); and nurses, social workers, pharmacists, chaplains, and others who care for this population but are not certified in palliative care.

Palliative care can be provided in the inpatient or outpatient setting. As of 2016, 75% of hospitals with more than 50 beds reported having a specialty palliative care inpatient team.<sup>4</sup> Palliative care should be provided for seriously ill patients where they live and receive care, including at home, as a hospital inpatient, outpatient clinics, assisted living facilities and nursing homes, and within an inpatient hospice setting. Around 80% of patients with serious illness reside at home, while 15% reside in long-term care facilities, <5% are inpatient in hospitals, and 1% are in hospice.<sup>4</sup> Thus, comprehensive outpatient palliative care delivery infrastructure is necessary to meet the needs of patients with serious illness and their caregivers. Unfortunately, the palliative care staffing shortage is widespread in the US with only 4400 board-certified providers, making equitable delivery of care difficult. Geographic, socioeconomic and racial barriers exist to equitable palliative care access, creating a disparity in the care of patients with serious illnesses and their families.

## 2. Why Palliative Care is Important

The benefits of integrating palliative care into the management of patients with advanced disease are well established. Initial level-one data was reported for individuals with metastatic non-small-cell lung cancer.<sup>5</sup> When including palliative care in care management, patients experienced better quality of life, had less pain and depression, received less aggressive end-of-life care, had a decreased need for hospitalization, and lived longer. Similar benefits have been consistently seen in subsequent studies of patients with heart failure,<sup>6</sup> genitourinary and gynecologic malignancies,<sup>6</sup> liver failure,<sup>7</sup> gastrointestinal malignancy,<sup>8</sup> renal failure,<sup>9</sup> and pediatric oncology.<sup>10</sup>

## 2.1 Palliative Care Referral Timing

Palliative care is appropriate from diagnosis of a serious disease, throughout treatment, through end of life care, and through bereavement. Palliative care is appropriate at any age and at any stage of serious illness. Referral to palliative care often occurs late in the disease course.<sup>11</sup> However, early involvement of palliative care alongside curative treatment, defined as involvement of specialist palliative care shortly after diagnosis of advanced or progressive disease, has been shown to have more beneficial effects on quality of life and symptoms intensity among patients with advanced cancer, compared to those given standard care with involvement of palliative care several months into treatment initiation.<sup>12</sup>

Level one evidence also demonstrates that early integration of palliative care can improve quality of life even when palliative care is delivered by telephone. In Project ENABLE (Educate, Nurture, Advise, Before Life Ends), patients living in remote areas receiving telephone-based palliative care in addition to standard care had improved quality of life compared with those treated with usual care alone.<sup>12</sup> However, the telephone-based efforts have not been scaled beyond a study timeframe, and the external validity of the results remains in question.

## 2.2 Cost-effectiveness

Palliative care integration in advanced disease care leads to decreased global healthcare costs, often associated with a reduction in aggressive care that is not tied to reduced overall survival. Seminal studies demonstrated that cost savings largely derived from reduced intensive care unit stays, laboratory testing, and medication use.<sup>13</sup> As death approaches, enhanced communication between providers and patients often leads to reduced cost. Conversations about goals of care, often driven by palliative care, lead to a 35% reduction in cost and improved quality of death in the final week.<sup>14</sup> Interestingly, these discussions and avoidance of aggressive care do not shorten survival. Approximately 25% of United States' healthcare spending occurs in the last year of life,<sup>15</sup> and these costs can be significantly reduced by the involvement of palliative care.<sup>16</sup> As patient complexity and number of comorbidities increases, so do the cost-savings achieved by inclusion of palliative care.<sup>17,18</sup> Early integration of palliative care alongside standard of care achieves even better cost-savings than later referrals.

## 2.3 Addressing the needs of patients with advanced disease

While several attributes of advanced disease care are deemed important by patients, caregivers, family, and providers, freedom from pain consistently ranks as the most important factor that all want addressed and treated.<sup>19</sup> Over half of patients with advanced disease have severe pain, which is often underdiagnosed and untreated.<sup>20</sup> Other attributes of high priority include preparation for death, treatment as a whole person, and honest discussions about prognosis and treatment options. Interestingly, patients are more concerned than family members and caregivers about being a burden on others and making arrangements to support the surviving family after death.<sup>21</sup> Specialty palliative care can address these concerns in a multifaceted manner, improving the quality of life for

the patient and their family members.

The burden of debilitating disease and symptoms in individuals with advanced disease is typically hidden. Approximately 40% of patients with advanced cancer, for instance, have moderate or severe depression, although this can be reduced to ~15% if diagnosed and treated appropriately.<sup>5</sup> Systematically identifying who within a care team should diagnose and treat depression has not been described, and patterns of care thus differ widely in different settings.

Spirituality is a key component of care for those with advanced disease. Spirituality may or may not be linked with religious beliefs, but approximately 90% of patients desire spiritual support as death approaches. In the vast majority of cases, patients report that these needs are unmet.<sup>22</sup> Although alternative models exist, responsive spiritual care can be achieved by involving a chaplain as part of the care team. When spiritual needs are addressed, the quality of life improves.<sup>23</sup>

Despite these manifold needs and the ability for specialty palliative care to address them, few patients are aware of palliative care and its **benefits**. Providers are likewise undereducated, leading to a critical gap in care.

## **2.4 Palliative care improves surgical outcomes**

Palliative care improves surgical outcomes for individuals with **advanced disease**. In patients undergoing high-risk surgery, palliative care consultation is associated with improved survival, overall care, communication, and family support. Despite this, only 1% of patients undergoing high-risk surgery receive a palliative care consultation before surgery, revealing a lacuna in management consistent with the underuse of palliative care in the outpatient setting.<sup>24</sup> Among patients undergoing treatment for metastatic urologic malignancies, only 10-20% receive palliative care.<sup>25</sup> Surgeons receive minimal education about the palliative needs of **patients**.

Palliative care involvement in the perioperative period, including before palliative (as opposed to curative-intent) surgeries is associated with better symptom resolution and fewer postoperative complications than similar operations performed without input from palliative care.<sup>26</sup>

Integrated palliative care may also enhance communication and patient understanding of goals of care before treatment, including surgery. Up to 80% of patients with incurable, metastatic malignancies undergoing chemotherapy believe that an achievable goal is a complete cure.<sup>27,28</sup> Advocates have supported early palliative care for surgical patients with advanced disease, but operationalizing these recommendations remains beyond our ken.<sup>29</sup>

## **2.5 (Aspirational) standard of care**

In response to the amassed data highlighted above, almost every professional association, governing body, and regulatory agency recommended the integration of palliative care into the management of individuals with advanced diseases:

**Table 2**

| Institution  | Recommendation   | Year |
|--|--|------|
| American Urological Association/American Society for Radiation Oncology/Society of Urologic Oncology (AUA/ASTRO/SUO) <sup>30</sup> | Palliative care team members may also play a key role when treating men with symptomatic metastatic disease. Palliative care itself is an interdisciplinary, holistic approach to managing an advanced disease such as prostate cancer with a guarded prognosis. It can include controlling symptoms that are physical, psychological, spiritual, and social. The goal of palliation is to prevent and relieve suffering and to support the best possible QOL for the patient and family   | 2021 |
| National Academy of Medicine (NAM) <sup>31</sup>   | (1) All people with advanced serious illness should have access to skilled palliative care or, when appropriate, hospice care in all settings where they receive care (including health care facilities, the home, and the community). (2) Professional societies and other organizations that establish quality standards should develop standards for clinician-patient communication and advance care planning that are measurable, actionable, and evidence-based. (3) Educational institutions, credentialing bodies, accrediting boards, state regulatory agencies, and health care delivery organizations should establish the appropriate training, certification, and/or licensure requirements to strengthen the palliative care knowledge and skills of all clinicians who care for individuals with advanced serious illness | 2015 |



|  |  |      |
|--|--|------|
|  | who are nearing the end of life. (see reference for full recommendations)  |      |
| American Society of Clinical Oncology (ASCO) <sup>32</sup> | Inpatients and outpatients with advanced cancer should receive dedicated palliative care services, early in the disease course, concurrent with active treatment. Referral of patients to interdisciplinary palliative care teams is optimal, and services may complement existing programs. Providers may refer family and friend caregivers of patients with early or advanced cancer to palliative care services  | 2016 |
| World Health Organization (WHO) <sup>33</sup>              | (1) to develop, strengthen and implement, where appropriate, palliative care policies to support the comprehensive strengthening of health systems to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels, with emphasis on primary care, community and home-based care, and universal coverage schemes; (2) to ensure adequate domestic funding and allocation of human resources, as appropriate, for palliative care initiatives, including development and implementation of palliative care policies, education and training, and quality improvement initiatives, and supporting the availability and appropriate use of essential medicines, including controlled medicines for symptom management (3) to provide basic support, including through multisectoral partnerships, to families, community volunteers and other individuals acting as caregivers, under the supervision of trained professionals, as appropriate: (4) to aim to include palliative | 2014 |

|  |  |      |
|--|--|------|
|  | care as an integral component of the ongoing education and training offered to care providers, in accordance with their roles and responsibilities, according to the following principles (see reference for full recommendations)   |      |
| National Comprehensive Cancer Network (NCCN) <sup>34</sup> | (1) Institutions should develop processes for integrating palliative care into cancer care both as part of usual oncology care and for patients with specialty palliative care needs (2) All cancer patients would be screened for palliative care needs at their initial visit, at appropriate intervals and as clinically indicated (3) Patients, families and caregivers should be informed that palliative care is an integral part of their comprehensive cancer care (4) Educational programs should be provided to all health care professionals and trainees so that they can develop effective palliative care knowledge, skills and attitudes (see reference for full recommendations) | 2021 |

Despite the fact that integration of palliative care is recommended by each of these organizations, and that palliative care services are now reimbursed by the Centers for Medicare and Medicaid Services, palliative care for the majority of patients with advanced disease remains aspirational.<sup>35</sup> The palliative care workforce is insufficient to provide the care recommended by guidelines, a key factor for implementation that the guidelines consider but do not resolve. Innovative models are needed that are scalable and adaptive to manifold health systems.

### 3. Palliative Care and Urology

#### 3.1 Burden of Palliative Care Needs in Urology

As the urologic population ages, the burden of palliative care needs continues to grow.<sup>36</sup> Experts expect that adults over the age of 65 will outnumber children for the first time in 2034, and almost half of urology outpatient visits are made by patients over the age of 65. With advancing age, serious illness burden increases, as do patients' palliative care needs. Pain and the prevalence of depression increase as we age.<sup>37,38,39</sup> Psychosocial burdens increase while, in the United States, support decreases.<sup>40</sup> Despite the significant palliative care needs of the urologic population, these needs remain unmet, and a scalable approach to addressing them has yet to be designed or implemented.

#### 3.2 Current State of Palliative Care Utilization

Palliative care is currently underutilized in urology. Among patients with **muscle-invasive bladder cancer**, as few as 4% receive palliative care, a trend that is not improving over time.<sup>41</sup> For patients with metastatic prostate, kidney, and bladder cancer, the use of palliative interventions range from 12% to 20%, again with no increased adoption with time.<sup>25</sup>

Palliative care underutilization is linked with significant rates of high-intensity care among individuals dying of urologic malignancies. Almost half of patients dying of bladder cancer receive high-intensity end-of-life care, and few receive palliative care in an appropriate time frame.<sup>42</sup> Men dying of prostate cancer similarly receive excessive high-intensity care in the last six months of life, including frequent rounds of chemotherapy, procedures, inpatient hospital admissions, and even cardiopulmonary resuscitation.<sup>43</sup>

Integrating palliative care in urology has been proven feasible and well-received by patients and practitioners. In a pilot study setting, when palliative care was integrated early into the management of urologic patients with advanced malignancy, patient satisfaction was high, quality of life was maintained, symptoms were well-controlled, and over 80% of patients who died received hospice.<sup>44</sup> Integrating palliative care within a urology setting was enthusiastically supported by patients and providers.<sup>45,46</sup>

Another point of entry to trigger palliative care co-management is high-risk surgery. In individuals undergoing radical cystectomy, concurrent palliative care improves outcomes, including fatigue, depression, quality of life, and posttraumatic growth.<sup>47</sup>

### 3.3 Primary Palliative Care Treatment Options

Options to bestow the benefits of palliative care upon urologic patients beyond a trial setting are currently limited. The palliative care workforce is severely strained, with only 4400 palliative care-trained clinicians in the **United States**. Over the coming two decades, a “workforce valley” is expected within palliative care, which will further diminish palliative care-led expansion options.<sup>48</sup>

“Primary palliative care” in a model in which the aspects of palliative care that benefit patients most are assessed, but care is delivered by non-palliative-care **clinicians**. In trial settings, primary palliative care has been achieved with geriatricians,<sup>49</sup> oncologists,<sup>50</sup> and specialists<sup>51</sup> as the hub of palliative-related care. However, broad implementation of primary palliative care on a population level has yet to be developed. Models for collaboration would include initial delivery of aspects of palliative care by non-palliative care specialists, buttressed by formal palliative care teams when **needed**.

### 3.4 Primary Palliative Care Model led by Urology

Patients and their families identify a need to improve care for urological patients with advanced **disease**. Models for achieving this are evolving and **undefined**. Educational interventions teaching aspects of palliative care to non-palliative care clinicians exist and have been successful but have yet to be broadly employed.<sup>52</sup>

A potential primary palliative care model for urology evolved from a pilot intervention where palliative care clinicians initially co-managed all patients with metastatic urologic malignancies. Over time, urologists assumed many aspects of care initially provided by palliative care doctors and served as a hub of **palliative care for patients**. In this model, the aspects of palliative care that benefit patients most are identified, and the urologist assesses patient needs and either addresses them or coordinates care with other providers. The deep, meaningful, long-standing relationships between urologists and their patients justify a urologist serving as the hub of primary palliative care.

In urologic oncology, the urologist could assess pain, depression, family needs, and prognosis, and address some of these aspects of care while coordinating treatment with other providers depending on **expertise**. Given robust data about the benefits of palliative care for patients with advanced cancer, pursuing primary palliative care in urologic oncology is a natural angle for primary palliative care in urology.

Benign urology also offers many promising avenues to pursue primary palliative care. The particular dignity associated with continence and cleanliness lends itself to impactful and innovative work in primary palliative care in **Female Pelvic Medicine and Reconstruction**. While the aspects of primary palliative care in this population may differ from those that benefit patients with cancer, the potential impact on patients and populations is robust. Likewise, patients with urolithiasis often have complex physical and psychosocial needs that affect treatment choices and patient **outcomes**. Developing a unique primary palliative care model targeted at this population could affect treatment choices and patient outcomes. Geriatric urology and general urology also offer opportunities to build

systems of care that will provide the benefits of palliative care to patients with advanced **disease**.

Despite these exciting opportunities to grow palliative care in urology, several potential challenges may impede progress. Broad education of the urologic community is lacking but supported by trainees and program **leaders**. Competing demands challenge urologists to pursue primary palliative care, and coordination of a multidisciplinary team with the urologist at the hub of care may allow systems to be built that meet patient and provider **needs**. If urologists assume this task, the rewards are likely to be meaningful and **enduring**.

## 4. Primary Palliative Care Delivery Skill Development

### 4.1 Communications Skills in Advanced Disease

Facilitating a discussion about serious illness can be challenging. A few key **communication skills** can produce more effective and empathetic conversations with patients and their families.

### 4.2 Breaking Serious News (Adapted from VitalTalk.org)

Discussing serious news or potentially bad outcomes is a standard communication task in clinical care. However, physicians' awareness on effective ways to communicate serious news is low.

Multiple frameworks exist for the guidance of having conversations to deliver serious news.

Generally, the following five components are addressed during these conversations to promote an effective conversation between clinician, patient and family member.

- Setting and preparation: Ensure the conversation is happening in a physical setting that the patient feels comfortable with (e.g., in-person versus over the phone). Ensure the clinician delivering the news has the necessary information at hand. Ensure the setting is private and all support systems the patient desires are present (e.g., spouse, family members).
- Gauging understanding and asking permission: It is important to assess what medical information the patient already knows, followed by an ask for permission to deliver the information you are planning to.
  - "What thoughts have you had since the biopsy?"
  - "What's your perspective on the situation?"
  - "What did you take away from the conversation with your other doctors?"
  - "Is it ok if I shared with you what I know?"
- Informing, starting with a headline: During a discussion with a patient, clinicians often try to preface the delivery of a piece of bad news with a significant amount of medical information (e.g., describing findings of imaging results, or trends of lab tests, or background leading up to a surgical error before stating the surgical error). Referred to as 'burying the headline,' this can lead to patients and family members missing the key takeaway, the piece of serious news, from the conversation. Instead, begin the serious news with a warning shot ("I wish I had better news, things are different now) to allow patients and families a few seconds to prepare for the information being shared. Then, deliver the information clearly with a one sentence headline of

what you want them to take away. Avoid medical jargon

- “The imaging we did shows that the cancer has returned, meaning it is now incurable.”
- “Your father’s labs show that his diabetes is not controlled, putting him at high risk for his kidneys to not work well.”
- “The procedure showed that your bladder isn’t working to let you pee effectively, and it will not work again in the future.”
- Respond to emotion: If patients and families respond to the headline with emotion, it often means they understand and have internalized the information you have delivered. A lack of emotion should cue you to rephrase your headline and may be a signal that the information was not appropriately processed. Acknowledging emotions explicitly demonstrates empathy and facilitates a patient-centered conversation.
  - Name the emotion: “It sounds like you are frustrated”
  - Understand the gravity: “I can’t imagine what you are going through.”
  - Respect their perspective: “I can see you really care about your father.”
  - Support the patient: “We will do everything to help navigate this process with you”
  - Explore emotions: “Can you tell me more about...”
  - Silence: Allow space for the patient and family to respond. Embrace several seconds of silence!
- Equip the patient for the next steps: Discuss potential next steps moving forward, to provide a clear outline of future care plans. Don’t dismiss concerns the patient and family have and be sure to adequately address them (avoid saying statements like “everything will be ok.”) Asking the patient and their family how you can be most helpful moving forward can have a powerful impact.
  - “I want you to be prepared for the next steps. Can I explain the possible treatment plans moving forward?”
  - “Given this situation, how can I best support your care?”

### 4.3 Facilitating Informed Consent Discussions

Aligning a patient’s treatment plan with their goals of care is crucial. Shared decision-making is often employed in the context of serious illness to discuss treatment options with patients and their families, engage patients and their families in decision making regarding those potential treatment outcomes and ensure that treatment aligns with goals of care. However, describing complex treatment options and often uncertain prognosis in the setting of different treatment options is difficult. A conceptual model of shared decision making, such as the Best Case/Worst Case framework, can aid clinicians in managing the difficulties and complexities of conversations surrounding the communication of treatment options to patients and families. This framework combines narrative description and a written graphic aid to illustrate choice and potential outcomes amongst treatments. Clinicians use stories to describe how patients might experience a range of possible outcomes in the best case, worst case, and most likely scenario when pursuing different treatment options, and thus help patients and families choose treatment options most aligned with

goals of their care. For a 10 minute, easily accessible video describing this conceptual framework and how to use it, visit <https://www.youtube.com/watch?v=FnS3K44sbu0>.

Use of the Best Case/Worst Case framework amongst surgeons has been shown to shift communication in decision-making conversations from an isolated surgical problem to a discussion about treatment alternatives and outcomes,<sup>53</sup> and when employed in an ICU setting to improve end-of-life communication amongst clinicians and family members.<sup>54</sup>

## 4.4 Prognostication

Patients and their families often ask about prognosis when discussing serious illness. Physicians are quite inaccurate when attempting to prognosticate, and tend to be overly optimistic. One study showed that physicians tend to overestimate prognosis by a factor of 5, and are only able to determine a somewhat accurate prognosis in 20% of cases.<sup>55</sup> This inaccuracy was not restricted to certain kinds of physicians or patients with certain types of ailments, it was seen across the board. Interestingly, as the duration of the physician/patient relationship increased, the prognostic accuracy decreased. The longer the relationship was between the physician and patient, the worse the prognostic ability of the physician was. This trend toward relaying optimistic survival time to patients and families may adversely affect the quality of care given to patients at the end of life.

Appropriate prognostic information is essential for informed end-of-life care planning. A patient understanding of prognosis has been shown to change decision making regarding care at the end of life. In one study, self-estimated patient prognosis when longer was directly associated with patients electing more life-prolonging and aggressive care.<sup>56</sup>

Several strategies can be employed to improve prognostication amongst clinicians. When discussing prognosis, do so in a setting of ranges of times (“hours to days, days to weeks, weeks to months, months to years” can help remove the inaccuracy that comes when tying potential prognosis to a number (e.g., 6-12 months). The self-imposed question, ‘Would I be surprised if this patient was alive in a year’ has been shown to improve the accuracy of prognostication in the last year of life to about 75%.<sup>57</sup> Asking yourself this question and answering ‘no’ should trigger a reevaluation of the patient’s care plan and goals of care to ensure the two are aligned. Finally, **multiple** excellent modules exist to help improve communication surrounding prognosis with patients and families.

## 5. Resources

- **Center to Advance Palliative Care**
  - The Center to Advance Palliative Care, or 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.
- **VITAL talk**
  - The premier training organization for clinicians seeking to advance their communication skills. Free classes, quick guides and online videos provide easily digestible quick tips for

improving communication.

- Best case/worst case communication tool

## 6. Key Takeaways

- Palliative care is specialized multidisciplinary medical care that provides support to relieve pain, symptoms and stress for people with serious illness and their families.
- While hospice is a model of palliative care restricted to the end of life, palliative care can be delivered at any stage of illness alongside curative treatment
- Palliative care is underutilized in urology: earlier and more frequent palliative care consultation should be considered
- Because of the palliative care provider shortage, it behooves all urologists to develop some basic primary palliative care delivery skill training. Communication skill development in effectively breaking serious news, facilitating informed consent discussion, and prognosticating are reviewed.

## Presentations

Palliative Care Presentation 1

## References

- 1 CAPC. An In-Depth Look At Palliative Care And Its Services.  
<https://www.capc.org/training/an-in-depth-look-at-palliative-care-and-its-services/>
- 2 Morrison RS, Meier DE: Palliative Care. N Engl J Med 2004; 350:2582-2590. DOI: 10.1056/NEJMcp035232
- 3 National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, 4th edition. Richmond, VA: National Coalition for Hospice and Palliative Care; 2018. <https://www.nationalcoalitionhpc.org/ncp>
- 4 CAPC: 2019 State-by-State Report Card on Access to Palliative Care in our Nation's Hospitals.  
<https://reportcard.capc.org/>
- 5 Temel JS, Greer JA, Muzikansky A, et al: Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer. N Engl J Med 2010; 363:733-742 DOI: 10.1056/NEJMoa1000678  
<https://www.nejm.org/doi/full/10.1056/nejmoa1000678>
- 6 Diop MS, Rudolph JL, Zimmerman KM, Richter MA, Skarf LM. Palliative Care Interventions for Patients with Heart Failure: A Systematic Review and Meta-Analysis. J Palliat Med. 2017;20(1):84-92. doi:10.1089/jpm.2016.0330 <https://pubmed.ncbi.nlm.nih.gov/27912043/>



- 7 Baumann AJ, Wheeler DS, James M, Turner R, Siegel A, Navarro VJ. Benefit of Early Palliative Care Intervention in End-Stage Liver Disease Patients Awaiting Liver Transplantation. *J Pain Symptom Manage*. 2015;50(6):882-6.e2. doi:10.1016/j.jpainsymman.2015.07.014 <https://pubmed.ncbi.nlm.nih.gov/26303186/>
- 8 Temel JS, Greer JA, El-Jawahri A, et al. Effects of Early Integrated Palliative Care in Patients With Lung and GI Cancer: A Randomized Clinical Trial. *J Clin Oncol*. 2017;35(8):834-841. doi:10.1200/JCO.2016.70.5046 <https://pubmed.ncbi.nlm.nih.gov/28029308/>
- 9 Gelfand SL, Schell J, Eneanya ND. Palliative Care in Nephrology: The Work and the Workforce. *Adv Chronic Kidney Dis*. 2020;27(4):350-355.e1. doi:10.1053/j.ackd.2020.02.007 <https://pubmed.ncbi.nlm.nih.gov/33131649/>
- 10 Levine DR, Mandrell BN, Sykes A, et al. Patients' and Parents' Needs, Attitudes, and Perceptions About Early Palliative Care Integration in Pediatric Oncology. *JAMA Oncol*. 2017;3(9):1214-1220. doi:10.1001/jamaoncol.2017.0368 <https://pubmed.ncbi.nlm.nih.gov/28278329/>
- 11 Wentlandt K, Krzyzanowska MK, Swami N, Rodin GM, Le LW, Zimmermann C. Referral practices of oncologists to specialized palliative care. *J Clin Oncol*. 2012;30(35):4380-4386. doi:10.1200/JCO.2012.44.0248 <https://pubmed.ncbi.nlm.nih.gov/23109708/>
- 12 Haun MW, Estel S, Rücker G, et al. Early palliative care for adults with advanced cancer. *Cochrane Database Syst Rev*. 2017;6(6):CD011129. Published 2017 Jun 12. doi:10.1002/14651858.CD011129.pub2 <https://pubmed.ncbi.nlm.nih.gov/28603881/>
- 13 Morrison RS, Penrod JD, Cassel JB, et al. Cost savings associated with US hospital palliative care consultation programs. *Arch Intern Med*. 2008;168(16):1783-1790. doi:10.1001/archinte.168.16.1783 <https://pubmed.ncbi.nlm.nih.gov/18779466/>
- 14 Zhang B, Wright AA, Huskamp HA, et al. Health care costs in the last week of life: associations with end-of-life conversations. *Arch Intern Med*. 2009;169(5):480-488. doi:10.1001/archinternmed.2008.587 <https://pubmed.ncbi.nlm.nih.gov/19273778/>
- 15 Riley GF, Lubitz JD. Long-term trends in Medicare payments in the last year of life. *Health Serv Res*. 2010;45(2):565-576. doi:10.1111/j.1475-6773.2010.01082.x <https://pubmed.ncbi.nlm.nih.gov/20148984/>
- 16 Smith S, Brick A, O'Hara S, Normand C. Evidence on the cost and cost-effectiveness of palliative care: A literature review. *Palliative Medicine*. 2014;28(2):130-150. doi:10.1177/0269216313493466 <https://journals.sagepub.com/doi/10.1177/0269216313493466>

- 17 May P, Garrido MM, Cassel JB, et al. Palliative Care Teams' Cost-Saving Effect Is Larger For Cancer Patients With Higher Numbers Of Comorbidities. *Health Aff (Millwood)*. 2016;35(1):44-53. doi:10.1377/hlthaff.2015.0752 <https://pubmed.ncbi.nlm.nih.gov/26733700/>
- 18 Cassel JB, Kerr KM, McClish DK, et al: Effect of a Home-Based Palliative Care Program on Healthcare Use and Costs. *J Am Geriatr Soc* 64: 2288- 2295, 2016. doi: 10.1111/jgs.14354 <https://agsjournals.onlinelibrary.wiley.com/doi/full/10.1111/jgs.14354>
- 19 Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA*. 2000;284(19):2476-2482. doi:10.1001/jama.284.19.2476 <https://pubmed.ncbi.nlm.nih.gov/11074777/>
- 20 Knudsen AK, Brunelli C, Kaasa S, et al. Which variables are associated with pain intensity and treatment response in advanced cancer patients?--Implications for a future classification system for cancer pain. *Eur J Pain*. 2011;15(3):320-327. doi:10.1016/j.ejpain.2010.08.001 <https://pubmed.ncbi.nlm.nih.gov/20822941/>
- 21 Hack TF, McClement SE, Chochinov HM, et al. Assessing Symptoms, Concerns, and Quality of Life in Noncancer Patients at End of Life: How Concordant Are Patients and Family Proxy Members?. *J Pain Symptom Manage*. 2018;56(5):760-766. doi:10.1016/j.jpainsymman.2018.07.019 <https://pubmed.ncbi.nlm.nih.gov/30076964/>
- 22 Balboni MJ, Sullivan A, Amobi A, et al. Why is spiritual care infrequent at the end of life? Spiritual care perceptions among patients, nurses, and physicians and the role of training. *J Clin Oncol*. 2013;31(4):461-467. doi:10.1200/JCO.2012.44.6443 <https://pubmed.ncbi.nlm.nih.gov/23248245/>
- 23 Daaleman TP, VandeCreek L. Placing religion and spirituality in end-of-life care. *JAMA*. 2000;284(19):2514-2517. doi:10.1001/jama.284.19.2514 <https://pubmed.ncbi.nlm.nih.gov/11074785/>
- 24 Yefimova M, Aslakson RA, Yang L, et al. Palliative Care and End-of-Life Outcomes Following High-risk Surgery. *JAMA Surg*. 2020;155(2):138-146. doi:10.1001/jamasurg.2019.5083 <https://pubmed.ncbi.nlm.nih.gov/31895424/>
- 25 Lec PM, Lenis AT, Brisbane W, et al. Trends in palliative care interventions among patients with advanced bladder, prostate, or kidney cancer: A retrospective cohort study. *Urol Oncol*. 2020;38(11):854.e1-854.e9. doi:10.1016/j.urolonc.2020.04.029 <https://pubmed.ncbi.nlm.nih.gov/32430252/>
- 26 Miner TJ, Cohen J, Charpentier K, McPhillips J, Marvell L, Cioffi WG. The palliative triangle: improved patient selection and outcomes associated with palliative operations. *Arch Surg*. 2011;146(5):517-522. doi:10.1001/archsurg.2011.92 <https://pubmed.ncbi.nlm.nih.gov/21576604/>

- 27 Weeks JC, Catalano PJ, Cronin A, et al. Patients' expectations about effects of chemotherapy for advanced cancer. *N Engl J Med*. 2012;367(17):1616-1625. doi:10.1056/NEJMoa1204410 <https://pubmed.ncbi.nlm.nih.gov/23094723/>
- 28 Liu PH, Landrum MB, Weeks JC, et al. Physicians' propensity to discuss prognosis is associated with patients' awareness of prognosis for metastatic cancers. *J Palliat Med*. 2014;17(6):673-682. doi:10.1089/jpm.2013.0460 <https://pubmed.ncbi.nlm.nih.gov/24742212/>
- 29 Schlick CJR, Bentrem DJ. Timing of palliative care: When to call for a palliative care consult. *J Surg Oncol*. 2019;120(1):30-34. doi:10.1002/jso.25499 <https://pubmed.ncbi.nlm.nih.gov/31102469/>
- 30 &star; Lowrance WT, Breau RH, Chou R et al: Advanced Prostate Cancer: AUA/ASTRO/SUO Guideline PART I. *J Urol* 2021; 205: 14 ; DOI: 10.1097/JU.0000000000001375
- 31 Institute of Medicine. 2015. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. Washington, DC: The National Academies Press ; DOI: 10.17226/18748
- 32 Betty R. Ferrell, Jennifer S. Temel, Sarah Temin, Erin R. Alesi, Tracy A. Balboni, Ethan M. Basch, Janice I. Firn, Judith A. Paice, Jeffrey M. Peppercorn, Tanyanika Phillips, Ellen L. Stovall†, Camilla Zimmermann, and Thomas J. Smith
- 33 World Health Organization . Strengthening of palliative care as a component of comprehensive care throughout the life course [Internet]. Geneva : WHO ; 2014 May 24 [cited 2017 May 17 ]. Available from: [http://apps.who.int/gb/ebwha/pdf\\_files/WHA67/A67\\_R19-en.pdf](http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf)
- 34 Dans et al. NCCN Clinical Practice Guidelines in Oncology. Palliative Care. Version 2.2021 - February 12 2021.
- 35 Taylor DH Jr, Kaufman BG, Olson A, et al. Paying for Palliative Care in Medicare: Evidence From the Four Seasons/Duke CMMI Demonstration. *J Pain Symptom Manage*. 2019;58(4):654-661.e2. doi:10.1016/j.jpainsymman.2019.06.019 <https://pubmed.ncbi.nlm.nih.gov/31254641/>
- 36 &star; Loughlin KR: The Confluence of the Aging of the American Population and the Aging of the Urological Workforce: The Parmenides Fallacy. *Urology Practice* 2019; 6:3:198. doi: 10.1016/j.urpr.2018.07.004 <https://www.auajournals.org/doi/full/10.1016/j.urpr.2018.07.004> US Census
- 37 Lautenbacher S. Experimental approaches in the study of pain in the elderly. *Pain Med*. 2012;13 Suppl 2:S44-S50. doi:10.1111/j.1526-4637.2012.01326.x <https://pubmed.ncbi.nlm.nih.gov/22497747/>

- 38 Taylor WD. Clinical practice. Depression in the elderly. *N Engl J Med*. 2014;371(13):1228-1236. doi:10.1056/NEJMcp1402180 <https://pubmed.ncbi.nlm.nih.gov/25251617/>
- 39 Alexopoulos GS. Depression in the elderly. *Lancet*. 2005;365(9475):1961-1970. doi:10.1016/S0140-6736(05)66665-2 <https://pubmed.ncbi.nlm.nih.gov/15936426/>
- 40 Ng TP, Broekman BF, Niti M, Gwee X, Kua EH. Determinants of successful aging using a multidimensional definition among Chinese elderly in Singapore. *Am J Geriatr Psychiatry*. 2009;17(5):407-416. doi:10.1097/JGP.0b013e31819a808e <https://pubmed.ncbi.nlm.nih.gov/19390298/>
- 41 Hugar, L.A., Lopa, S.H., Yabes, J.G., Yu, J.A., Turner, R.M., II, Fam, M.M., MacLeod, L.C., Davies, B.J., Smith, A.B. and Jacobs, B.L. (2019), Palliative care use amongst patients with bladder cancer. *BJU Int*, 123: 968-975. <https://doi.org/10.1111/bju.14708>
- 42 Hugar LA, Yabes JG, Filippou P, et al. High-intensity end-of-life care among Medicare beneficiaries with bladder cancer. *Urol Oncol*. 2021;39(10):731.e17-731.e24. doi:10.1016/j.urolonc.2021.02.008 <https://pubmed.ncbi.nlm.nih.gov/33676849/>
- 43 Bergman J, Saigal CS, Lorenz KA, et al. Hospice use and high-intensity care in men dying of prostate cancer. *Arch Intern Med*. 2011;171(3):204-210. doi:10.1001/archinternmed.2010.394 <https://pubmed.ncbi.nlm.nih.gov/20937914/>
- 44 Huen K, Huang C, Liu H, et al. Outcomes of an Integrated Urology-Palliative Care Clinic for Patients With Advanced Urological Cancers: Maintenance of Quality of Life and Satisfaction and High Rate of Hospice Utilization Through End of Life. *Am J Hosp Palliat Care*. 2019;36(9):801-806. doi:10.1177/1049909119833663 <https://pubmed.ncbi.nlm.nih.gov/30808193/>
- 45 Bergman J, Ballon-Landa E, Lorenz KA, et al. Community-Partnered Collaboration to Build an Integrated Palliative Care Clinic: The View From Urology. *Am J Hosp Palliat Care*. 2016;33(2):164-170. doi:10.1177/1049909114555156 <https://pubmed.ncbi.nlm.nih.gov/25326489/>
- 46 Bergman J, Lorenz KA, Acquah-Asare S, et al: Urologist Attitudes Toward End-of-life Care. *Urology*, 82, 1, 2013, 48-52. <https://doi.org/10.1016/j.urology.2013.01.040>. <https://www.sciencedirect.com/science/article/abs/pii/S0090429513001477>
- 47 Rabow MW, Benner C, Shepard N, Et al: Concurrent urologic and palliative care after cystectomy for treatment of muscle-invasive bladder cancer. *Urologic Oncology: Seminars and Original Investigations*, 33, 6, 2015, 267. <https://doi.org/10.1016/j.urolonc.2015.02.012>. <https://www.sciencedirect.com/science/article/abs/pii/S1078143915000757>

- 48 Kamal AH, Wolf SP, Troy J, et al. Policy Changes Key To Promoting Sustainability And Growth Of The Specialty Palliative Care Workforce. *Health Aff (Millwood)*. 2019;38(6):910-918. doi:10.1377/hlthaff.2019.00018 <https://pubmed.ncbi.nlm.nih.gov/31158018/>
- 49 Lally KM, Ducharme CM, Roach RL, Towey C, Filinson R, Tuya Fulton A. Interprofessional training: Geriatrics and palliative care principles for primary care teams in an ACO. *Gerontol Geriatr Educ*. 2019;40(1):121-131. doi:10.1080/02701960.2018.1459595 <https://pubmed.ncbi.nlm.nih.gov/29630470/>
- 50 Rangachari D, Smith TJ. Integrating palliative care in oncology: the oncologist as a primary palliative care provider. *Cancer J*. 2013;19(5):373-378. doi:10.1097/PPO.0b013e3182a76b9c <https://pubmed.ncbi.nlm.nih.gov/24051609/>
- 51 Gelfman LP, Kavalieratos D, Teuteberg WG, Lala A, Goldstein NE. Primary palliative care for heart failure: what is it? How do we implement it?. *Heart Fail Rev*. 2017;22(5):611-620. doi:10.1007/s10741-017-9604-9 <https://pubmed.ncbi.nlm.nih.gov/28281018/>
- 52 Bergman J, Lorenz KA, Ballon-Landa E, et al. A Scalable Web-Based Module for Improving Surgical and Medical Practitioner Knowledge and Attitudes about Palliative and End-of-Life Care. *J Palliat Med*. 2015;18(5):415-420. doi:10.1089/jpm.2014.0349 <https://pubmed.ncbi.nlm.nih.gov/25748832/>
- 53 Taylor LJ, Nabozny MJ, Steffens NM, et al. A Framework to Improve Surgeon Communication in High-Stakes Surgical Decisions: Best Case/Worst Case. *JAMA Surg*. 2017;152(6):531-538. doi:10.1001/jamasurg.2016.5674 <https://pubmed.ncbi.nlm.nih.gov/28146230/>
- 54 Zimmermann CJ, Zelenski AB, Buffington A, et al. Best case/worst case for the trauma ICU: Development and pilot testing of a communication tool for older adults with traumatic injury. *J Trauma Acute Care Surg*. 2021;91(3):542-551. doi:10.1097/TA.0000000000003281 <https://pubmed.ncbi.nlm.nih.gov/34039930/>
- 55 Christakis NA, Lamont EB. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. *BMJ*. 2000;320(7233):469-472. doi:10.1136/bmj.320.7233.469 <https://pubmed.ncbi.nlm.nih.gov/10678857/>
- 56 Enzinger AC, Zhang B, Schrag D, Prigerson HG. Outcomes of Prognostic Disclosure: Associations With Prognostic Understanding, Distress, and Relationship With Physician Among Patients With Advanced Cancer. *J Clin Oncol*. 2015;33(32):3809-3816. doi:10.1200/JCO.2015.61.9239 <https://pubmed.ncbi.nlm.nih.gov/26438121/>
- 57 White N, Kupeli N, Vickerstaff V, Stone P. How accurate is the 'Surprise Question' at identifying patients at the end of life? A systematic review and meta-analysis. *BMC Med*. 2017;15(1):139. Published 2017 Aug 2. doi:10.1186/s12916-017-0907-4 <https://pubmed.ncbi.nlm.nih.gov/28764757/>

