# Integrating Palliative Care into the Management of Bladder Cancer Patients Perspective from a Future Urologic Surgeon

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#### Slide 1

**pi1** Progress Indicator: Ignore this slide Progress Indicator, 4/16/2018

- What palliative care isn't
- What palliative care is
- Origins of palliative care
- Bladder cancer and palliative care research
- The surgeon's role in palliative care
- Future directions





## What palliative care isn't





# Palliative care = Hospice







Life-prolonging or curative treatment

Palliative care to manage symptoms and improve quality of life

Diagnosis







Life-prolonging or curative treatment

Palliative care to manage symptoms and improve quality of life

Diagnosis

Life-prolonging or curative treatment

Palliative care to manage symptoms and improve quality of life

Diagnosis

Death





## What palliative care is





Specialized multidisciplinary medical care for people living with serious illnesses, focusing on the relief of symptoms and stress of an illness, with the goal to improve quality of life for both the patient and their family.

#### Whole person care...

- Physical
- Intellectual
- Emotional
- Social
- Spiritual

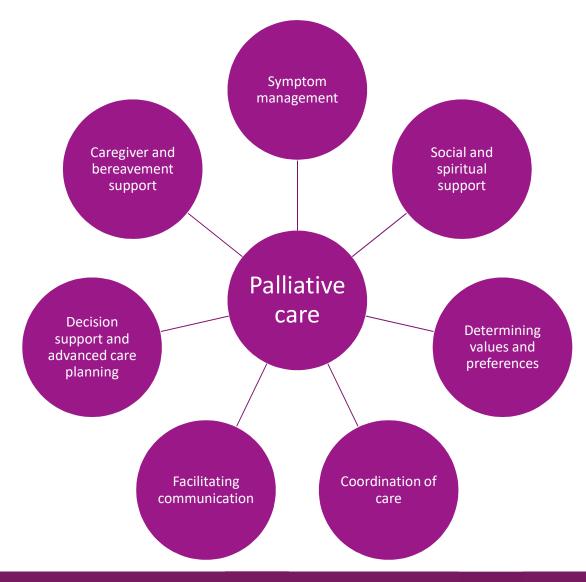
...at any stage of illness.





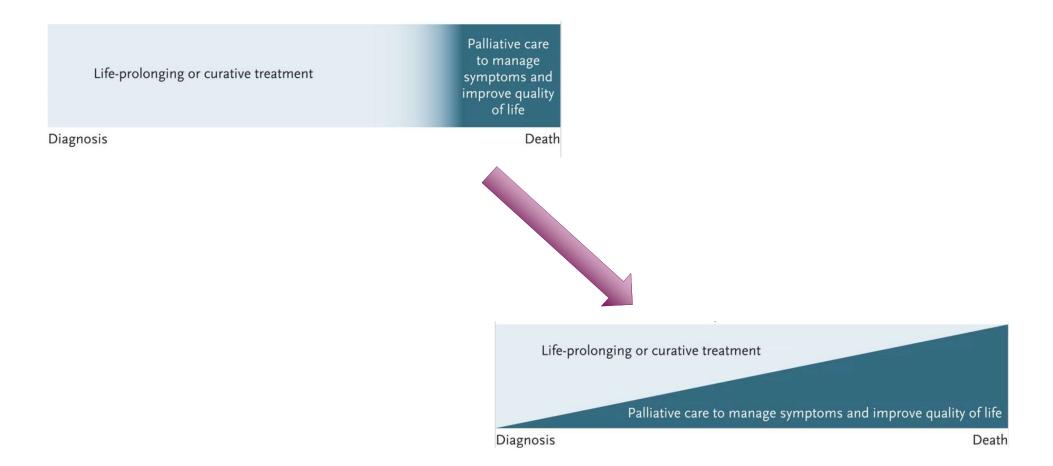


Tenets of palliative care













### Origins of palliative care











"Cure sometimes, treat often, comfort always"

Shaw, Br, J Gen Pract, 2009







Figure 1: Cicely Saunders working as a nurse in the 1940s

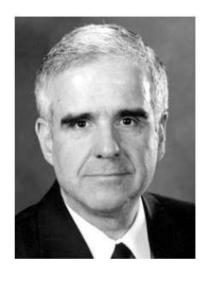


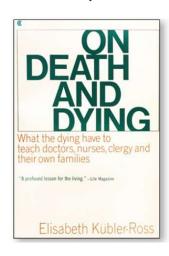












Denial
Anger
Bargaining
Depression
Acceptance

<u>Urology.</u> 1974 Dec;4(6):741-8.

Death and dying: attitudes in a teaching hospital.

Mount BM, Jones A, Patterson A.









### The problem of caring for the dying in a general hospital; the palliative care unit as a possible solution

BALFOUR M. MOUNT, FRCS[C]

Cancer. 1980 Apr 15;45(7 Suppl):1985-92.

Psychological impact of urologic cancer.

Mount BM.









# Bladder cancer and palliative care research





#### Symptom burden in bladder cancer

Palapattu et al show a high prevalence of psychologic distress prior to cystectomy with minimal significant change postoperatively (J Urol 2004)

	No. Preop (%)
High depression	26 (42)
High anxiety	34 (55)
High somatization	15 (24)
High general distress	30 (48)

Brenner and Rabow show significantly increased brief pain inventory (BPI) scores postoperatively (J Urol, 2014)

#### Outcomes with time

Survey (time point)	Av Score (95% CI)	p Value for Score Trend
BPI:		
Initial visit	4.0 (0-8.0)	0.03
2 Mos	9.2 (3.8—14.6)	
4 Mos	11.3 (1.0—18.6)	
6 Mos	9.8 (1.9—17.6)	





#### Symptom burden in bladder cancer

Klaassen and Terris show a high burden of suicide in patients with genitourinary cancer, especially in patients with bladder cancer (Cancer, 2015)

TABLE 3. Suicide in Patients With Cancer by Disease Site and Years Since Diagnosis

	Time Since Diagnosis					
Cancer Site	0 to 5 Years	5 to 10 Years	10 to 15 Years	≥15 Years		
Prostate						
Suicides, no.	953	468	144	48		
Person-y accrued	3,114,400	1,434,147	450,948	113,017		
SMR <sup>a</sup>	1.33	1.42	1.39	1.84		
95% CI	0.95-1.81	1.02-1.91	0.99-1.86	1.39-2.41		
Bladder						
Suicides, no.	312	88	29	10		
Person-y accrued	743,899	300,270	100,701	33,355		
SMR <sup>a</sup>	3.05	2.13	2.09	2.18		
95% CI	2.26-3.96	1.53-2.94	1.47-2.86	1.53-2.94		





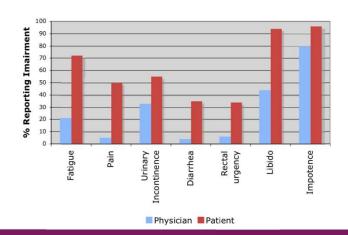
#### Symptom assessment in bladder cancer

Gilbert et al report that the Bladder Cancer Index is sensitive to differences in function and bother across treatment approaches (Cancer 2007)

Sonn et al show that physicians underestimate patient health related quality of life and that this assessment does not improve over time (J Urol, 2012)

#### **Adjusted Mean BCI Domain Scores**

BCI Score	Native bl	ladder	Cystectomy		
	No intravesical Tx n = 52	Intravesical Tx n = 75	Ileal conduit n = 66	Neobladder n = 122	
Urinary domain					
Function	$90.7^{\dagger}$	89.2‡	86.5*	49.8*‡ <sup>†</sup>	
Bother	95.4*	93.4‡	88.4	86.3*‡	
Bowel domain		- CALLESTON ■ 1			
Function	82.0	88.6*1	77.6*	76.6‡	
Bother	93.0*	92.3‡§	80.8*‡	85.7 <sup>†</sup> §	
Sexual domain			(*************************************		
Function	45.7* <sup>†</sup>	42.2‡§	20.0*‡	25.5 <sup>†</sup> §	
Bother	67.4*†	71.7‡§	50.3*‡	49.9 <sup>†</sup> §	







#### Palliative care use in bladder cancer

Rabow and colleagues found improved fatigue, depression, and anxiety in a serial cohort study of patients with muscle invasive bladder cancer undergoing cystectomy with and without concurrent palliative care.

Table 2 Control and intervention group outcomes

Survey	Time point	Average score (95% CI)		P value for score trend		P value for	Adjusted
		Control	Intervention	Control	Intervention	comparison of trends	comparison P va
Brief Pain Inventory	Initial visit	4.0 (0-8.0)	17.4 (8.2–26.7)	0.03	0.13	0.09	0.13
	2 Months	9.2 (3.8-14.6)	26.2 (14.3-38.0)				
	4 Months	11.3 (1.0-18.6)	8.9 (0.2-17.6)				
	6 Months	9.8 (1.9–17.6)	11.4 (4.0-18.8)				
Cancer Fatigue Scale	Initial Visit	18.6 (17.0-20.2)	34.3 (30.0–38.5)	0.12	0.02	0.002	0.002
	2 Months	18.0 (15.9-20.2)	34.3 (30.2-38.4)			V(2/25) // (25/25)	4540.40.5145.
	4 Months	21.8 (18.7-24.9)	28.7 (25.0-32.3)				
	6 Months	21.0 (17.2–24.8)	29.7 (25.7–33.7)				
Hospital Anxiety and	Initial visit	7.6 (5.1–10.0)	9.8 (7.6-11.9)	0.37	0.02	0.01	0.01
Depression Scale	2 Months	6.6 (4.3-8.9)	10.5 (8.1-12.8)				1,000,000,000
	4 Months	8.4 (6.0-10.7)	7.3 (4.9–9.6)				
	6 Months	8.4 (6.0–10.8)	7.2 (4.8–9.6)				
Depression Subscale	Initial visit	3.2 (2.1-4.3)	4.1 (3.0-5.3)	0.11	0.01	0.003	0.004
	2 Months	3.3 (2.2-4.5)	5.4 (4.1-6.7)				
	4 Months	4.4 (2.8-5.9)	3.6 (2.2-5.0)				
	6 Months	4.4 (2.8-6.0)	3.0 (1.8-4.2)				



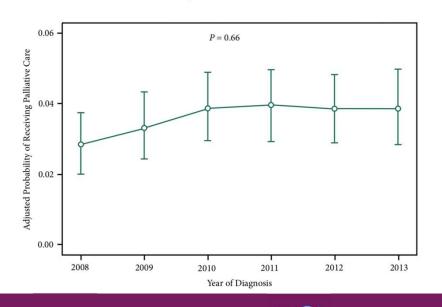


#### Trends in palliative care use

Hugar and Jacobs show poor use of palliative care in Medicare beneficiaries with bladder cancer. Age, male sex, and lower comorbidity was associated with decreased palliative care use. (BJUI, 2019)

Group	% of cohort	% receiving palliative care		
Advanced disease	34%	4.1%		
Localized disease	66%	3.3%		

p-value = 0.08







#### Co-location of palliative care

Yu and Schenker find 19x greater odds of palliative care use when co-located with oncology clinic. Travel time also impactful with 2-3x greater odds when time <60 minutes (J Oncol Pract, 2019)





Theme I. Clinicians felt that it was feasible and appropriate to address pain and comfort issues within the surgical clinic;

Theme 2. When incorporating pain and comfort issues, perceived quality of care was improved, and patients were happier;

Theme 3. Offering a palliative care consultation to patients did not require an undue amount of time;

Theme 4. Participants viewed the terminology of the "integrated" clinic to be a misnomer, and offered opportunities for improvement of the clinic organization.





# The surgeon's role in palliative care





#### Palliative care

Specialized multidisciplinary medical care for people living with serious illnesses, focusing on the relief of symptoms and stress of an illness, with the goal to improve quality of life for both the patient and their family.

#### Palliative surgery

A surgical procedure used with the primary intention of improving quality of life or relieving symptoms caused by an advanced illness, the success of which is measured by symptoms resolution.

Dunn, American College of Surgeons, 2009





# Principles of palliative surgery

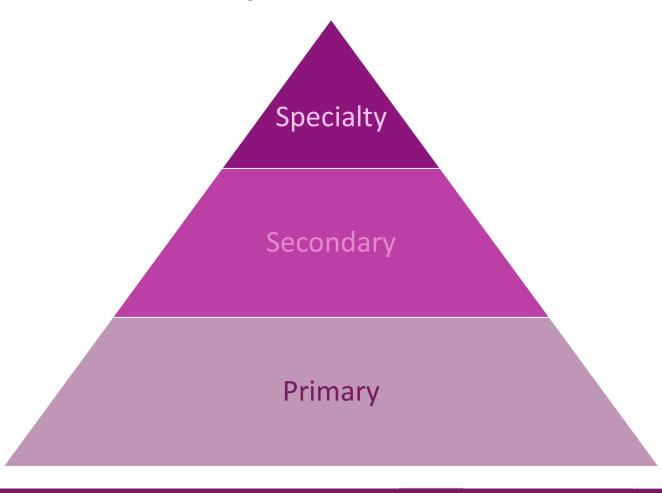
#### Principles of Palliative Surgery

- Palliation is not the opposite of cure; it has its own distinct indications and goals and should be evaluated independently
- Asymptomatic patients cannot be palliated.
- Palliative surgery is as morally and ethically legitimate as surgery for curative intent.
- Day-to-day surgical decisions are best made in the framework of ethical, scientific, and technical principles.
- The patient or surrogate must acknowledge the personal relevance of the symptom to be treated.
- Meaningful survival expectations should exist before offering surgical palliation.
- Goals must be clearly and honestly defined to patient and family, yourself, the surgical team, and other members of the health care team.





#### Hierarchy of palliative care







#### Primary palliative care

Basic management of pain
Basic symptom management
Basic discussions on:

- Prognosis
- Goals of care
- Suffering and symptom burden
- Code status

#### Specialty palliative care

Management of refractory pain

Management of complex symptoms

Assistance with conflict resolution:

- Within families
- Between families and providers
- Among treatment teams
   Addressing cases of near futility

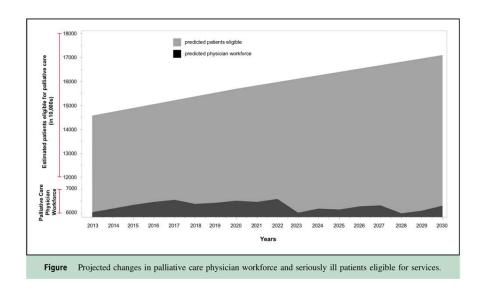
Quill, NEJM, 2009





#### The importance of primary palliative care

- Current palliative care workforce meets only 20-25% of demand
- Estimated growth of palliative care physicians over next two decades: 1%
- Estimated growth of patients eligible for palliative care: 20%



Lupu, J Pain Symptom Manage, 2010 Kamal, Am J Med, 2017



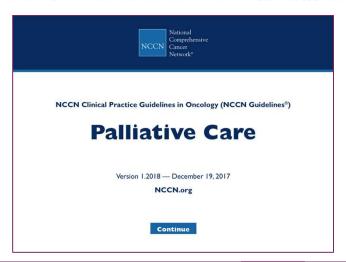


#### Screening for palliative care needs

#### TABLE 3. CRITERIA FOR A PALLIATIVE CARE ASSESSMENT AT THE TIME OF ADMISSION

A potentially life-limiting or life-threatening condition *and* . . . Primary Criteria<sup>a</sup>

- The "surprise question": You would not be surprised if the patient died within 12 months or before adulthood <sup>23–25</sup>
- Frequent admissions (e.g., more than one admission for same condition within several months)<sup>26–30</sup>
- Admission prompted by difficult-to-control physical or psychological symptoms (e.g., moderate-to-severe symptom intensity for more than 24–48 hours)<sup>6, 31</sup>
- Complex care requirements (e.g., functional dependency; complex home support for ventilator/antibiotics/feedings)<sup>6</sup>
- Decline in function, feeding intolerance, or unintended decline in weight (e.g., failure to thrive)<sup>6, 31</sup>

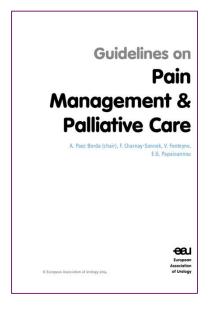


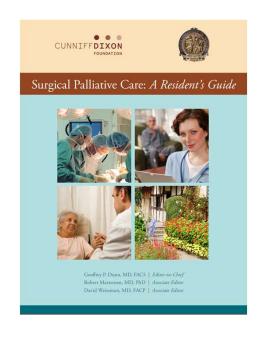
Weissman, JPM, 2011



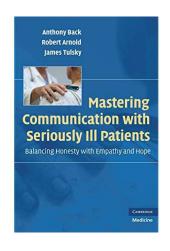


#### Surgical palliative care resources













#### **Future directions**





#### Pursue more data

- Include more surgical patients in palliative care studies
- Research the role of palliative care for patients with early-stage disease
- Identify/test triggers for palliative care
- Identify the highest impact specific elements of palliative care
- Identify and address disparities in the receipt and quality of palliative care
- Focus more research on family caregivers
- Identify end-points and outcomes which matter most to patients

Ferrell, JCO 2017 Lilley, Ann Surg, 2018





#### Reframe decision making process

Dr. Zara R. Cooper

"Embrace the uncertainty. It is because it is uncertain that we need to engage in difficult conversations."

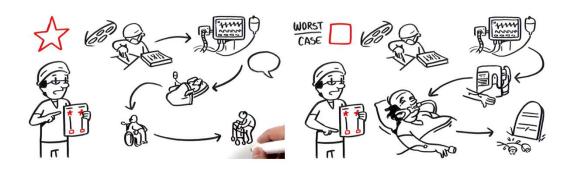
"Not doing surgery is not doing nothing."

Dr. Margaret L. Schwarze









#### BEST CASE/WORST CASE

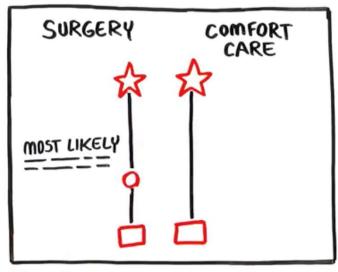
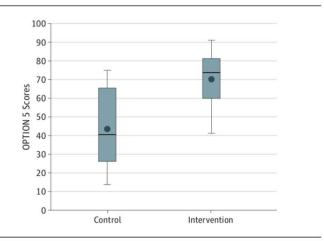


Figure 2. OPTION 5 Scores



Box plots depicting OPTION 5 scores for patients in the control and intervention arms. Dot indicates mean score within each treatment arm.

Taylor, JAMA Surgery, 2017 Best Case/Worse Case Communication Tool-Whiteboard Video





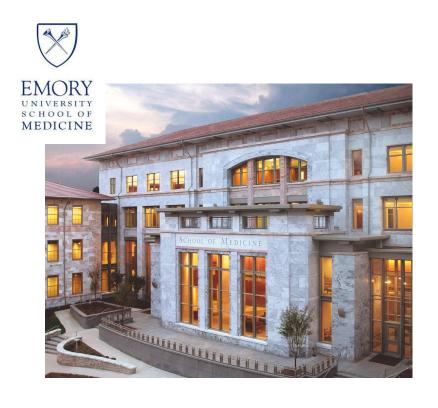
#### Find a go-to palliative care colleague

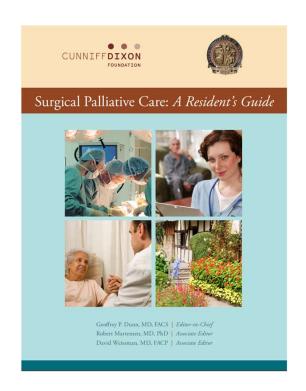






#### Early exposure to palliative care

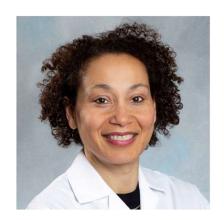








#### Continue the discourse



Dr. Zara Cooper



Dr. Balfour Mount



Dr. Margaret Schwarze



Dr. Michael Rabow



Dr. Jonathan Bergman





Palliative care is not the same as hospice

Palliative care is appropriate for any patient with a life limiting disease

Secondary palliative care skills are crucial to ease the burden on specialty palliative care providers

Research on the impact and implementation of palliative care in patients with bladder cancer is needed

Balfour Mount's legacy should inspire future Urologists (and other specialists) interested in this area of study



Sarah and Jack



Lizzie (1 year) and Jack



