

Integrating Palliative Care into the Critical Care

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The Landscape



Objectives

- Review the concepts of Palliative Care and how it impacts the care provided to critically ill patients and their families
- Explore strategies for leading a culture change in the critical care with goal-oriented thinking for specific disease processes
- Describe how approaching critical care from a palliative care perspective can improve critical care outcomes and patient quality of life after discharge
- Explain how palliative care in critical care supports the AACN expectation of critical care nurses in advocacy and moral/ethical concerns

What is Palliative Care?

(Palliare: “To Cloak”)

- Palliative care is an interdisciplinary specialty that aims to relieve suffering and improve quality of life for patients with advanced illness, and their families. It is provided simultaneously with all other appropriate medical treatment.
- Palliative Care can occur at the same time as curative or disease modifying therapy.

Desired Image of Palliative Care



Barrier Image of Palliative Care

Palliare??
“To Cloak”?



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Changing the image will take compassionate, educated providers

- The cliché tells us that what can't be cured must be endured. This conceptualized medical mantra must change.
- Palliative Care reminds us that, even for someone with an incurable disease, life is not something to be endured, but enjoyed.
- It is not about defying or defeating death, it is about living life on your terms with the time you have left.

What is does Palliative Care Provide?

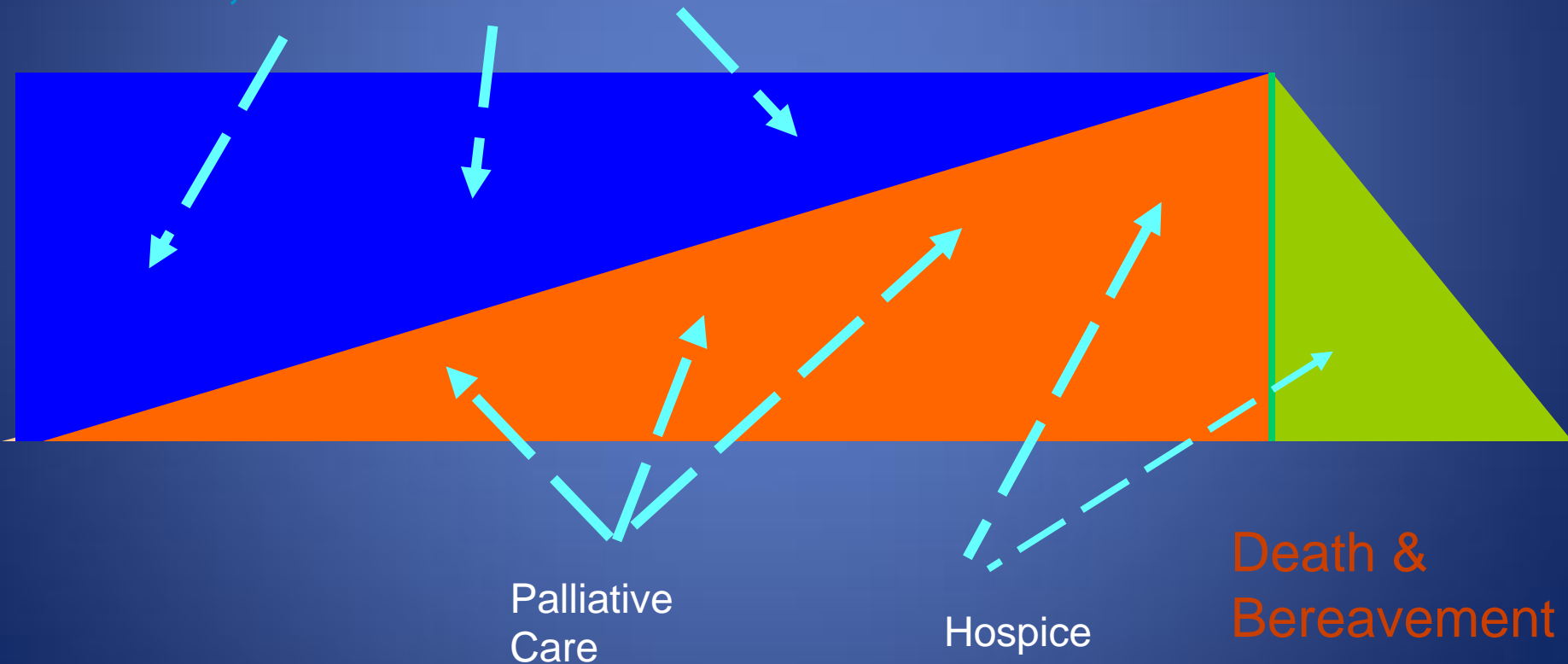
- Palliative Care is a patient-centered model of medicine that:
 - Recognizes that the patient and the family (whoever the patient defines that to be) is the unit of care
 - Reduces the level of *suffering* among patients with serious illness
 - Improves the ability of patients' families to cope and care for their loved one
 - Improves patient and family satisfaction with care
 - Provides grief and bereavement support to health providers who care for the ill and dying
 - Enhances communication among patients, families, and care providers to ensure the dignity and wishes of the patient are honored

What ISN'T Palliative Care

- Palliative Care IS NOT only for actively/imminently dying patients
- Palliative Care IS NOT doing nothing
- Palliative is never futile
- Palliative Care DOES NOT start when curative treatment stops; it is simultaneous along the continuum of care
- Palliative Care DOES NOT convince patients to stop treatment
- Palliative Care DOES NOT take the place of care by the patient's personal physician
- Palliative Care IS NOT Hospice Care

PALLIATIVE CARE ACROSS THE DISEASE CONTINUUM

Disease Modifying Therapy
Curative, or restorative intent



So what is Hospice Care?

“Hospice recognizes that the dying process is a part of the normal process of living and focuses on enhancing the quality of remaining life.”



Hospice Admission Criteria

- The patient is certified as being terminal with a life expectancy of 6 or fewer months if the illness runs its course
- The patient wants hospice care
- A physician is available and willing to provide medical care and consultation

Responsibilities of the Hospice Team

- Managing pain and symptoms
- Providing necessary medication, supplies, and equipment
- Coaching and education family caregivers
- Delivering special services as needed (volunteers, counselors, chaplains, etc.)
- Making short-term inpatient care available for symptom management or respite
- Providing grief/bereavement support for loved ones and friends

What is Suffering?

- **Suffering:** The bearing of pain, inconvenience, or loss; as pain endured; as distress or loss; or as pain or sorrow. Suffering in palliative care and hospice is usually physical suffering as a result of symptoms of the terminal illness or process of actively dying. Suffering can also be emotional or psychosocial as a patient or family struggles with the actuality of death and loss.
- **The word “patient” actually means “to tolerate suffering”**
 - Bearing or enduring pain, difficulty, provocation, or annoyance with calmness.
 - **2.** Marked by or exhibiting calm endurance of pain, difficulty, provocation, or annoyance.
 - **3.** Tolerant; understanding
 - **4.** Persevering; constant
 - **5.** Capable of calmly awaiting an outcome or result; not hasty or impulsive.
 - **6.** Capable of bearing or enduring pain, difficulty, provocation, or annoyance

Terms surrounding End of Life

- **Terminal Illness:**
 - A debilitating condition which is medically progressive, incurable and can be expected to cause death
- **Imminent death:**
 - Phase of dying in which death is expected within 14 days
- **Bereavement :**
 - “the process of adaptation to a loss through death of someone representing a close and significant relationship.” Bereavement is a shared journey traveled while grieving.
- **Anticipatory grief:**
 - Pain experienced before a loss which may begin at the time of a life-limiting illness.
- **Complicated grief:**
 - A disorder that occurs after the death of a loved one that leaves survivors feeling devastated or traumatized for greater than 6 months after the death. Complicated grief interferes with the individual's ability to carry on a normal life and many times results in symptoms of severe depression, isolation, or unusual or destructive behaviors.

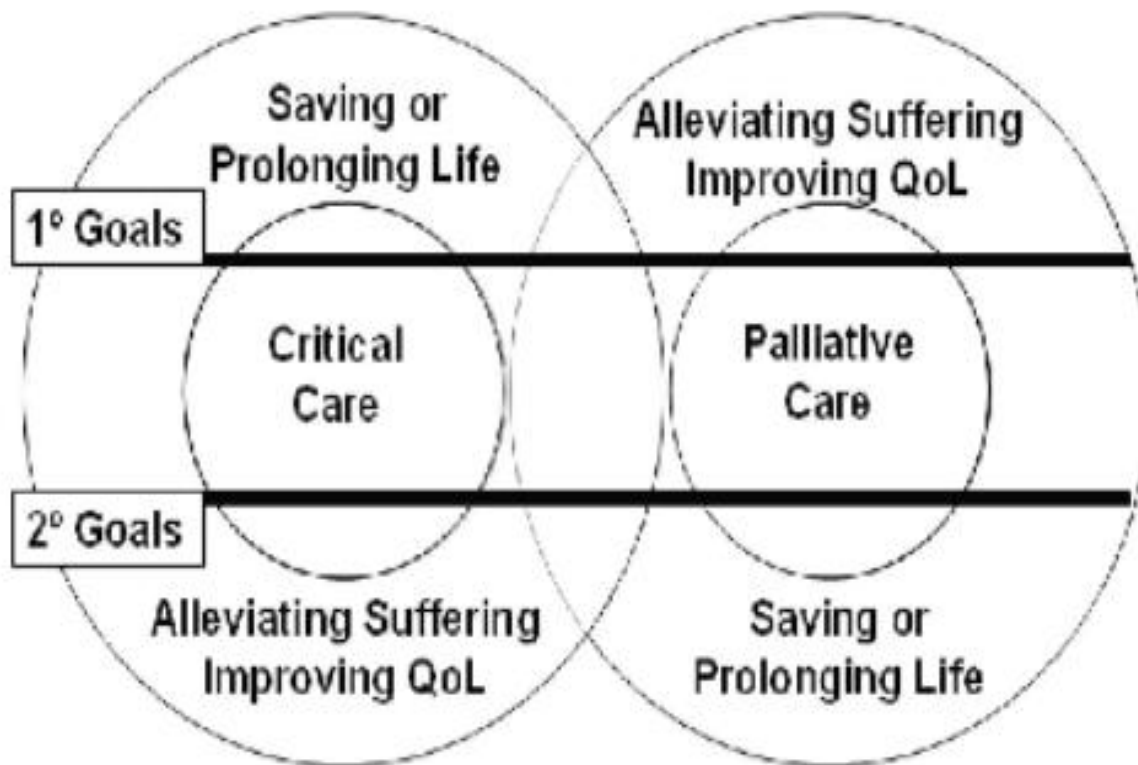
Where are Critical Care Providers failing?

- “We sure spend a lot of time telling people how to be cured and how to die, but we spend very little time discussing how a person can take care of themselves while they are living with a disease.”
- *Our patients and their families have the right to define quality of life.* Health providers need to ask that question, EVERY time there is a new interaction with that patient.
- We tend to present every option, even those that may be inappropriate, rather than discuss living well with a disease and preparing for death. Does the risk outweigh the burden?

Where are “we” failing?

- We all know that to get into medicine does not happen by failing everything. But dying is not getting an “F” on an exam.
- The goal of medicine cannot always be cure....at some point death must be recognized as a spiritual problem to be faced as part of life. It asks us to confront the unknown for all of us.
- Running from death through technology can make it come quicker....technology can be toxic and burdensome and induce suffering
- When is it time to let go and let God (or whatever you call peace) come in?
- When is it about vital healing not vital signs?

Concordance of Values and Goals



Concordance of values and goals in critical care and palliative care. *QoL*, quality of life.

Why do we need Hospital Palliative Care?

- Patients and families deserve better end of life care (that does not mean death care)
- The hospital is usually the first place patients and families confront the fact that their illness may be terminal
- 53% of all patients die in the hospital, most of whom are in pain and distress
- The majority of patients who are made a “No Code” die within 2-3 days of this decision—what happened to their Quality of Life?
- Sometimes the focus needs to change to comfort and living life to the fullest, and for many patients that is not in a hospital. *Someone needs to help patients and families communicate their goals.*
- Appropriate use of palliative care and plans for discharge will reduce 911 calls, emergency room visits, and unnecessary procedures—it is easier to manage things you expect and are prepared for
- We educate and prepare people for birth, why not death?

What can Palliative Care offer to patients and families?

- Management of symptoms in order to decrease the burden of illness on patients and families
- Focuses on the physical, psychosocial, existential and spiritual needs of the patient and family
- Provides continuity of care between outpatient and inpatient settings
- There is a collaboration between experts in specialized disease process (cardiology, pulmonary, critical care, oncology, etc) and experts in dealing with terminal illness
- Reduction of readmissions and visits to the ER

What Patient Populations Benefit from Palliative Care

- ALL patients benefit from palliative care as it means “to alleviate symptoms of a disease without curing it.”
- Patients have improved quality of life because they are more compliant with a treatment regimen they can understand and accept
- Family systems benefit from palliative care as indicated in the evidence by increased satisfaction with care as well as decreased incidence of PTSD after discharge or death
- Cognitive impairment accompanies many chronic disease processes. Unfortunately many of these patients are undiagnosed as lacking capacity, but they are labeled as noncompliant with therapy. Cognitive impairment can be a source of suffering and impact QOL for patients after discharge
- There are many chronic diseases, such as diabetes and heart failure, that medicine cannot cure, but the symptoms can be alleviated and living with the disease can be improved. We can plan for symptom burden in many diseases.

When is Palliative Care appropriate?

- It is most appropriate at the onset of the disease process so transitional planning can occur and maximal benefits can be ascertained
- PALLIATIVE CARE IS AN EARLY INTERVENTION, NOT WHEN DEATH IS IMMINENT!!
- When treatment becomes based on symptom relief and QOL rather than pure survival
- If your answer to the following question is “no” the patient should be referred to Palliative Care—
 - “Would you be surprised if this patient died in the next 6 months?”

Barriers to appropriate referral to Palliative Care and Hospice

- Difficulty in prognostication
 - Nurses predict death better than any prognostication model
- Communication difficulties with patients
 - Many patients know they have a chronic disease but do not understand that it is a fatal condition due to the waxing and waning nature of the disease
- Curative focus and many technological advances to offer
- Specialists sometimes believe that if the patient consents to procedure, they have to go the full course
- Providers lack the skills in discussing palliation and EOL
- Providers want to convey hope
- There is a general lack of knowledge about Palliative Care
- There is a lack of time to communicate with patients and families

“EOL Rhetoric Undermines Good Palliative Care”

- “EOL is often translated to near death” and this causes palliative consults to happen at discharge rather than early in disease process or on admission.
- Death panel language is deeply perverse and makes the process of dying urgent and portrays that the hospital needs to move things along
- Stop the rhetoric and demagoguery by:
 - “Good doctoring and good nursing that uses bedside chairs, willing butts to sit in them, and skill in guided conversation about goals, not 5th rounds of chemo for widely metastatic disease and invasive tests/monitoring for late phases multi-system organ failure
 - Reframe the rhetoric of choices to one of making decisions, some of them hard. Choice implies that there is right and wrong, decisions reflect a review of information. Living and dying is not a commodity.
 - Prevent damaged doctor-patient-family communication or interpersonal communication by providing sound judgments that balance COMFORT, FUNCTION, AND SURVIVAL.” Robert Martensen, 2011

Why Physicians Do Not Have Discussions About Poor Prognosis (60% of oncologists prefer not to)

- Study on misconceptions about divulging prognostic information:
 - “It makes people depressed.” **Incorrect**
 - More aggressive medical care in the intensive care at the end of life was associated with higher depression in patients and bereaved caregivers
 - “Involvement of Hospice or Palliative Care will reduce survival.” **Incorrect**
 - Multiple studies suggest survival is equal or better with hospice or palliative care
 - “We don’t really know a patient’s prognosis.” **True, with qualifications**
 - This is not an excuse, reasonable formulations can be done
 - Then check the patient’s understanding
- “Talking about prognosis is not culturally appropriate.” **Incorrect**
 - Ask your patient
- “It will take away hope.” **Incorrect**
 - Evidence shows hope is maintained even in truthful discussions that teach the patient there is no chance of cure.”
 - “It is striking that physician honesty, even about difficult news, may actually help patients feel more hopeful.” It allows for decision making and alleviates fear of the worst.
- “We don’t like to have these discussions, and they are hard on us.” **True**
 - It should be difficult if you are a human being in relationship with another living thing. If it is not hard, then you need to find a new job.

Getting Started

- Why?

- Informed consumers of health care are demanding it
- Patient epidemiology
 - Patients are living longer with chronic disease (we cannot cure) due to advancements in technology and pharmaceuticals
 - Patients may be living longer, but that does not translate to functionality
 - Patients are living with burdensome symptoms while seeking curative interventions, palliative care could help

Why?

– Legislation is mandating it in many areas (Health Care Reform)

- Evidence suggests that palliative care “improves care, gives people more realistic choices and reduces the cost of care.” (NEJM, 2011)
- On average, patients who received palliative care incurred \$6900 less in hospital costs during hospital admission compared to those who receive usual care. (Health Affairs, March 2011)
- Estimated reductions in Medicaid hospital spending in New York State could range from \$84 million to \$252 million annually (assuming 2% and 6% of Medicaid patients discharged received palliative care, respectively) if every hospital with 150 or more beds had a fully operational palliative care consultation team. (Sean Morrison et al., Health Affairs, March 2011)
- Patients report greater satisfaction with their care experience and provider communication, had fewer ICU admissions on readmission, and lower total health care costs following discharge (\$4,855 per patient) when inpatient palliative care team was used (Gade, Journal of Pall Med, 2008).

Why Palliative Care in Critical Care?

Informed Consent (AMA statement)

- “Informed consent is more than simply getting a patient to sign a written consent form. It is a process of communication between a patient and physician that results in the patient's authorization or agreement to undergo a specific medical intervention. In the communications process, you, as the physician providing or performing the treatment and/or procedure (not a delegated representative), should disclose and discuss with your patient:
 - The patient's diagnosis, if known;
 - The nature and purpose of a proposed treatment or procedure;
 - The risks and benefits of a proposed treatment or procedure;
 - Alternatives (regardless of their cost or the extent to which the treatment options are covered by health insurance);
 - The risks and benefits of the alternative treatment or procedure; and
 - The risks and benefits of not receiving or undergoing a treatment or procedure.
- In turn, your patient should have an opportunity to ask questions to elicit a better understanding of the treatment or procedure, so that he or she can make an informed decision to proceed or to refuse a particular course of medical intervention. This communications process, or a variation thereof, is both an ethical obligation and a legal requirement spelled out in statutes and case law in all 50 states.”

“Informed Consent?”

- Research studies demonstrate it must be looked at:
 - 69% of patients with Stage IV lung cancer and 81% of patients with Stage IV colon cancer (n=1193) did not understand chemotherapy would not likely cure their cancer. Educational level, functional status, and patient role in decision making were not associated with belief about chemotherapy. (NEJM, 2012)
 - “The optimism of surrogate decision makers for patients requiring long term ventilation with tracheostomy should be balanced by discussions of outcomes in 1 year when considering prolonged life support.” (Unroe, Ann of Int. Med, 2010)
 - At 1 year, only 9% of the study patients were alive with no functional dependency
 - 26% were alive with moderate dependency
 - 21% were alive with complete functional dependency
 - 44% were dead
 - The estimated cost per independently functioning survivor was \$3.5 million at the end of 1 year

Regret

- “Although our patient has continued to consent for ongoing medical and surgical procedures to treat the complication of her heart surgery, she also now looks back on her decision to undergo surgery with regret, telling her family and doctors that if only she had known what to expect, she might have chosen differently.

On the most basic, personal level, such regret is tragic. Yet, considered more broadly, it points to shortcomings inherent in perspectives on medical decision making that are widely held by physicians.

For patients like ours, explicit examination of such distinctions represents an important step toward confronting and understanding the regret that can occur in ICU, and toward achieving a practice of medicine that can offer both hope and compassion.” *Dr J. Raiten and Dr. M. Neuman, NEJM, Nov 8, 2012*

Why?

- Nursing Moral Distress
 - One of the responsibilities of a critical care nurse is to act as an advocate
 - “Advocacy is defined as working on another’s behalf and representing the concerns of the patient, family, and community; moral agency is serving as a moral agent in identifying and helping to resolve ethical and clinical concerns within the clinical setting.” (AACN 2005)

Nurse as Advocate

- “Advocacy (AACN 2005) refers to respecting and supporting the basic values, rights, and beliefs of the critically ill patient. The critical care nurse is expected to do the following:
- Respect and support the right of the patient or the patient’s designated surrogate to autonomous informed decision making
- Intervene when the best interest of the patient is in question
- Help the patient obtain necessary care
- Respect the values, beliefs and rights of the patient
- Provide education and support to help the patient or the patient’s designated surrogate make decisions
- Represent the patient in accordance with the patient’s choices
- Support the decisions of the patient or the patient’s designated surrogate or transfer care to an equally qualified critical care nurse
- Intercede for patients who cannot speak for themselves in situations that require immediate action
- Monitor and safeguard the quality of care a patient receives
- Act as a liaison between the patient, the patient’s family and health care professionals.”

Why?

- Suffering

- First due no harm?
 - Is death in an ICU really *natural*?
 - Does more “stuff” make it hurt less?
 - Is “DOING SOMETHING” better than just “BEING”?
 - What if your patient defines harm different than you?
 - Is palliation meeting the goals of benefit better than the reality of technological burden?
 - By not addressing prognosis, suffering is induced:
 - Patients lose good time with their family and spend more time in ICU
 - Patients and families cannot make sound decisions without information (PTSD and existential suffering)
- Suffering can be physical, emotional, spiritual, psychological or existential
- It can occur in families long after a patient dies and contributes to complicated grief and PTSD
- It contributes to burn out by repeatedly asking bedside providers to betray their own integrity

So.....

Isn't the question really

WHY NOT?

What is the Evidence?

- “As the US health care system undergoes restructuring and pressure to reduce cost intensifies, patients worry that they will receive less compassionate care. So do health care providers. In a survey of 800 patients and 510 physicians, it was found that compassionate care is ‘very important’ to successful medical treatment. *However, only 53% of patients and 58% of physicians said that the health care system generally provides compassionate care.* Given strong evidence that such care improves health outcomes and patients’ care experiences, we recommend that national quality standards include measures of compassionate care; that such care be a priority for comparative effectiveness research to determine which aspects have the most influence on patients’ care experiences, health outcomes, and perceptions of health-related quality of life; and that payers reward the provision of such care. We also recommend the development of systematic approaches to help health care professionals improve the skills required for compassionate care.” *Health Affairs, Sept 2011, Schwartz Center for Compassionate Healthcare, Harvard Medical School*

SCCM: Surviving Sepsis Guidelines

- 2013
 - Section W. Setting Goals of Care
 - “We recommend that goals of care and prognosis be discussed with patients and families (Grade 1B)”
 - “We recommend that goals of care be incorporated into treatment and end-of-life care planning, utilizing palliative care principles where appropriate (Grade 1B)”
 - We suggest goals of care be addressed as early as feasible, but no later than within 72 hours of ICU admission (Grade 2C).”

Oncology Statement

- “It is the Panel’s (ASCO) expert consensus that combined standard oncology care and palliative care should be considered early in the course of illness for any patient with metastatic cancer and/or high symptom burden. Strategies to optimize concurrent palliative care and standard oncology care, with evaluation of its impact on important patient and caregiver outcomes (QOL, survival, health care services utilization, and costs) and on society, should be an area of intense research.” (ASCO 2012)

CHEST Statement

- “The American College of Chest Physicians strongly supports the position that palliative and end of life care of the patient with an acute devastating or chronically progressive pulmonary or cardiac disease and his/her family should be an integral part of cardiopulmonary medicine. This care is best provided through an interdisciplinary effort by competent and experienced professionals under the leadership of a knowledgeable and compassionate physician.” CHEST 2005

ACC/AHA Guideline Update (2005) for Heart Failure and Decision Making

- Added recommendations for EOL considerations:
 - Patient and family needs to be educated regarding prognosis for functionality and survival at the onset of disease
 - Options provided for advance directives and resuscitation
 - Discussion of the option to inactivate the ICD
 - Only 25% of HF patients receive this discussion
 - 22% of the time this discussion occurs within a few days of death
 - Recommendation is that this discussion should happen with informed consent upon implantation of device
 - Shocks during the dying process only contributes to poor QOL and suffering for the patient and family
 - Provide continuity of care between inpatient and outpatient settings
 - Provide the option for the components of Hospice care including the use of opiates to relieve suffering
 - Improve the approaches to palliation at the initial diagnosis and with each subsequent follow-up

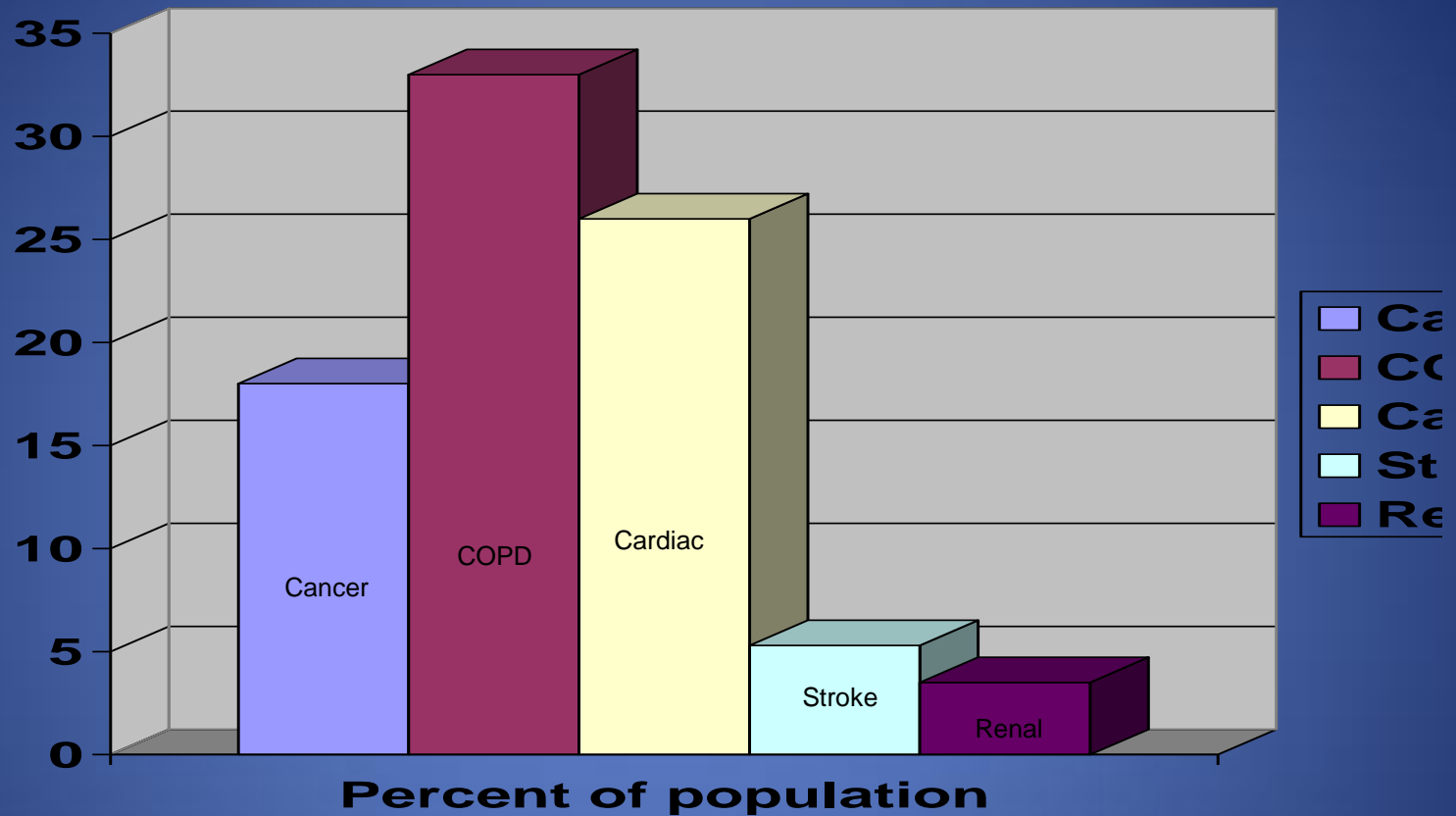
Nephrology Statements

- ANNA Standard of Care (page 128)
 - “The patient and family will receive guidance with advance care planning. The patient will receive appropriate pain and symptom management, and psychological and spiritual support throughout the chronic kidney disease and dying experience.”
- “Care of ESRD patients on dialysis requires expertise not only in the medical maintenance of patients on dialysis but also in the palliative care that focuses on management of pain and other symptoms, advance care planning and attention to ethical, psychosocial and spiritual issues related to starting, continuing, withholding and withdrawing dialysis.”

American Stroke Association Statement

- 2013 Guidelines: *Early Management of Ischemic Stroke*
 - “Many (especially elderly) patients who survive massive hemispheric or brain stem strokes may be candidates for palliative care.....Early discussion with the patient and family can ensure any prior do-not-resuscitate or limitations-of-care orders are respected. Additionally, it is critical to conduct discussions with patients and families regarding poststroke prognosis to allow them to make informed decisions regarding any new do-not-resuscitate or limitations-of-care orders.” (p. 51)

OMC Population in Critical Care



Of the total patients (n=114) screened in CCU for Palliative Care from January 1, 2010, to March 31, 2010:

- 21/114 were recurrent or metastatic cancer patients
- 38/114 were severe COPD patients
- 30/114 were advanced cardiac disease patients
- 6/114 were stroke patients with 50% reduction in functional status
- 4/114 were end stage renal patients

Base Camp



How?

- Create a culture change:
 - Educate your nursing staff with the evidence not only for palliative care and quality end of life care, but in the care and complications of chronic disease
 - Teach your nursing staff what the difference is between a DO NOT RESUSCITATE and an Advanced Directive
 - Ask your colleagues if the procedure(s) will prolong life or prolong the dying process
 - Screen every single patient with a valid and reliable palliative tool (see next slide) and have a daily report run
 - Attend rounds every single morning in CCU and report each patients palliative score BOLDLY and put a sticker on the chart for all to see
 - Ask the Critical Care Medical Director to mandate family meetings for every patient on Days 3-7 of CCU stay to open COMMUNICATION. This is the most critical tool of a palliative care team---the family meeting.
 - Empower the nurses at the bedside to be advocates for the person they are serving first: THE PATIENT. The nurse is where change begins and takes hold.
 - Lead by integrity, knowledge, advocacy and passion
 - Find champions from every discipline and meet weekly

**PALLIATIVE CARE
SCREENING TOOL**

(Not a permanent part of the medical record)

Criteria – Please consider the following criteria when determining the palliative care score of this patient			
1. Basic Disease Process a. Cancer (Metastatic/Recurrent) b. Advanced COPD c. Stroke (with decreased function by at least 50%)			SCORING d. End stage renal disease e. Advanced cardiac disease – i.e. CHF, severe CAD, CM (LVEF < 25%) f. Other life-limiting illness <i>Score 2 points EACH</i> _____
2. Concomitant Disease Processes a. Liver disease b. Moderate renal disease c. Moderate COPD			d. Moderate congestive heart failure e. Other condition complicating cure <i>Score 1 point overall</i> _____
3. Functional status of patient Using ECOG Performance Status (Eastern Cooperative Oncology Group)			<i>Score as specified below</i> _____
ECOG	<u>Grade</u>	<u>Scale</u>	
	0	Fully Active, able to carry on all pre-disease activities without restriction.	Score 0
	1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light housework, office work.	Score 0
	2	Ambulatory and capable of all self-care but unable to carry out any work activities. Up and about more than 50% of waking hours.	Score 1
	3	Capable of only limited self-care; confined to bed or chair more than 50% of waking hours.	Score 2
	4	Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair.	Score 3
4. Other criteria to consider in screening The patient:			<i>Score 1 point EACH</i>
a. is not a candidate for curative therapy			_____
b. has a life-limiting illness and chosen not to have life prolonging therapy			_____
c. has unacceptable level of pain >24 hours			_____
d. has uncontrolled symptoms (i.e. nausea, vomiting)			_____
e. has uncontrolled psychosocial or spiritual issues			_____
f. has frequent visits to the Emergency Department (>1 x mo for same diagnosis)			_____
g. has more than one hospital admission for the same diagnosis in last 30 days			_____
h. has prolonged length of stay without evidence of progress			_____
i. has prolonged stay in ICU or frequent readmissions to ICU without evidence of progress			_____
j. Is in an ICU setting with documented poor or futile prognosis			_____
<u>TOTAL SCORE</u>			_____
SCORING GUIDELINES: TOTAL SCORE = 1-3, No intervention needed TOTAL SCORE = 3-5, Consider Palliative Care Consult TOTAL SCORE = 6 or above, Palliative Care Consult Recommended			

PALLIATIVE PERFORMANCE STATUS SCALE

*This scale is a modification of the Karnofsky Performance Scale. It takes into account ambulation, activity, self-care, intake and consciousness level.

COMMENTS:

%	AMBULATION	ACTIVITY AND EVIDENCE OF DISEASE	SELF-CARE	INTAKE	CONSCIOUSNESS LEVEL
100	Full	Normal Activity No evidence of Disease	Full		Full
90	Full	Normal Activity Some Evidence of Disease	Full		Full
80	Full	Normal Activity with Effort Some Evidence of Disease	Full	Normal or Reduced	Full
70	Reduced	Unable Job/Work Some Evidence of Disease	Full	Normal or Reduced	Full
60	Reduced	Unable Hobby/House Work Significant Disease	Occasional Assistance Necessary	Normal or Reduced	Full or Confusion
50	Mainly Sit/Lie	Unable to Do Any Work Extensive Disease	Considerable Assistance Required	Normal or Reduced	Full or Confusion
40	Mainly in Bed	Unable to Do Any Work Extensive Disease	Mainly Assistance	Normal or Reduced	Full or Drowsy Or Confusion
30	Totally Bed Bound	Unable to Do Any Work Extensive Disease	Total Care	Reduced	Full or Drowsy Or Confusion
20	Totally Bed Bound	Unable to Do Any Work Extensive Disease	Total Care	Minimal Sips	Full or Drowsy Or Confusion
10	Totally Bed Bound	Unable to Do Any Work Extensive Disease	Total Care	Mouth Care Only	Drowsy or Coma
0	Death	-	-	-	-

ATTENTION Dr. _____					Palliative Screen Score: _____		
					ECOG Performance Status Grade _____		
					Palliative Performance Score: _____%		
Your patient has qualified for a Palliative Care Team Consultation. If you wish to utilize this service, please write an order for the Palliative Care Physician and Team consult. If you have any questions, please contact Dr. Everett Murphy, Jana Whitton (791-3520), or Joey Barton (791-4350).							

How?

- Choose NOT to see the glass ceiling because suffering does not have one
- When you look at your “PATIENT”, remember that term is also a definition of “ENDURING SUFFERING”---look for the ways they are suffering in every single interaction
- Remind providers of the ways the patient is suffering and that they have the power to do something about it
- Publish a Palliative Newsletter every quarter
- Read the Art of War and apply the strategies: as a palliative team in Critical Care, you will always be in the valley between a mountain and river, but you will need to figure out how to advance and not retreat
- Collect and interpret data and know how to present it and to whom

Building a Team

- Recommend the development of an Advisory Committee that includes lay people, multiple disciplines, and outpatient providers
- Critical Care Providers do this well because they understand disease process, they critically think, they communicate in difficult situations, they partner with other specialists
- A team of health care providers and specialists provide Palliative Care. This team may include:
 - Physician (always)
 - Nurse Practitioner (usually)
 - Nurses (always)
 - Social Workers (always)
 - Rehabilitation Services (always)
 - Clergy (always)
 - Volunteers (usually)
 - Always invite others involved in care (CHF clinic, Hospice/Home Health, Primary MD, oncology) to participate in family meetings

Goals of Palliative Care from Critical Care Providers

- Impeccable symptom management by acknowledging suffering objectively
- Education to families, patients and staff regarding, disease processes, palliative care with curative therapies and end of life care
- Continuity of care and seamless follow-up throughout the hospital stay
- Communication about goals of care: Are providers and family/patient goals aligned
- Early discussions and preparation so patients and families can make informed decisions about end of life wishes
- Psychological care
- Spiritual care and partnership with clergy
- Grief and Bereavement Care (recommended for 13 months for loved ones following death)
- Human presence at time of death
- Incorporates cultural preferences into plan of care
- Recognition of Ethical considerations surrounding care/death
- Adherence to Advance Directives/DNR wishes
- Palliative Care is the expectation no the exception

What are we have done.....

- Trialed first in CCU with screening, stickers and consults, 2009
- Screening of all admitted patients to the hospital, with repeated screens at Day 5 (2011)....Arghhhhh!
- Family meetings for all patients in CCU on days 3-7
- Code status verification on every patient and with change in condition
- Vigorous education with all staff about DNR vs Advanced Directive and NO MORE PARTIAL DNRs
- Consults with recommendations for palliative interventions on floors, palliative concept is now integrated in our CCU
- ELNEC training for nursing staff
- EOL training for MDs
- Bereavement follow-up at 6 weeks by Hospice volunteers
- Order sets, policies, and interventions
 - Palliative Care, Peaceful Death, Palliative Sedation, Delirium, Sedation and Analgesia, EOL guidelines and care, cognitive evaluations on severe sepsis and CHF patients

The Most Important Tool: A Palliative Meeting

- The Palliative Family Meeting (and a chair) is considered the clinical tool of the Palliative Care Team
- The meeting is about listening to the patient and family and ascertaining their understanding of the disease process, prognosis, and treatment options
- The meeting is about setting goals around how the patient defines quality of life and exploring the interventions that can meet those goals
- The initial meeting is usually not a decision making meeting

The Family Meeting

- Critical Care leaders agree that one of the most essential responsibilities of clinicians in ICU is communication with patients and their families.
- This core responsibility is as important as hemodynamic instability, respiratory failure, or life-threatening hemorrhage
- Palliative care consultation should be used to assist with family meetings in ICU to formulate the agenda and to integrate information from multiple providers as well as plans for symptom management.
- The role of palliative care in ICU family meetings is “undoubtedly an important explanation for favorable ICU outcomes, earlier identification of goals of care and shorter stays in the ICU and the hospital.”
- “ICUs should reach out to palliative care services for assistance in optimizing family meetings. The most effective strategy will be shaped by the integrative palliative care model in which palliative care is integrated early in the course of critical illness rather than only when patients are obviously or imminently dying.” *Journal of Critical Care, 2009*

Palliative Meeting (cont.)

- Each team member will prepare for the meeting from their own discipline:
 - Physician: Disease, *prognostication (PPS with screening)*, trajectory, possible technological interventions, burdensome symptoms
 - ARNP/RN: Functional status, ADLs, general care in the hospital, holistic care, decision makers identified, code status, burdensome symptoms, grief and bereavement
 - Social Services: Financial concerns, discharge plans, qualification for hospice or other placement, psychosocial issues, grief and bereavement, cultural assessment
 - Chaplain: Spiritual (not religious rituals) assessment, grief and bereavement, support systems, contact for spiritual care or funeral arrangements, cultural assessment
 - Pharmacist: Medication for symptom relief, dose conversions
 - Rehabilitation: PT/OT/ST daily assessments and recommendations for rehabilitation potential at discharge

How and when do we talk to patients and families?

- My conviction: “Courage is the resistance to fear, the mastery of fear—not the absence of fear.” — Mark Twain
- How do help our patients to live with their disease with courage? How do we help our patients to become warriors of their disease and not victims?
- Build a milieu of collaborative trust through communication, diligence, and all efforts to improve the patient’s QOL
- Communicate that there is no agenda, only the patient’s goals and concerns; we simply come along side where ever the are at

Talking (cont.)

- Give them the choices by informing them
 - Listen to their fears, hopes, burdens and acknowledge uncertainty both for them and for you
 - Discuss their EOL options to prepare for an event that they are unable to speak for themselves
 - Discuss the life limiting nature of their disease and the risk of death at the time of diagnosis to avoid the “surprise” later when the patient is deteriorating. Helps them fight the disease with compliance to treatment
 - Talk about dying when the patient inquires about it, when it is required for decision making about interventions, or with a decline in status
 - Make a PLAN, however hard that is and however many times it has to be discussed
 - Use decision aids to help when appropriate (see next slide)



Patient Decision Aids

- For specific conditions
- For any decision

Development Toolkit

Implementation Toolkit

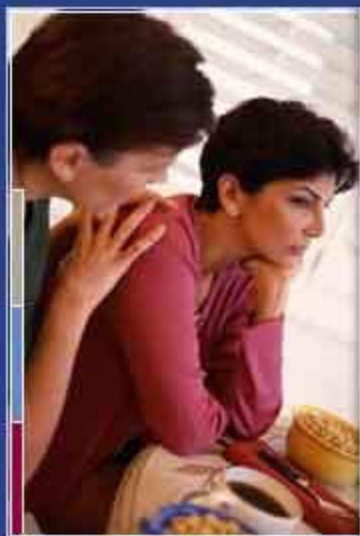
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Welcome

What are patient decision aids?

Patient decision aids are tools that help people become involved in decision making by providing information about the options and outcomes and by clarifying personal values. They are designed to complement, rather than replace, counseling from a health practitioner.

How can I find decision aids and learn about their quality?

[A to Z Inventory](#): allows you to search for decision aids on particular health topics.

[Ottawa Personal Decision Guide](#): a general decision guide that can be used for any health or social decision.

New! [iShould](#) an easy to use decision application on Facebook.

How do I develop a decision aid?

[Development Toolkit](#): provides information for developers and researchers interested in producing decision aids.

How can I implement decision aids in clinical practice?

[Implementation Toolkit](#): provides tools and training for incorporating decision support in practice centres.

[Cochrane Decision Aid Registry](#)

Developers can login to the [Decision Aid Library Inventory \(DALI\) system](#) to enter and manage the information about their decision aids for inclusion in the [Cochrane Inventory](#) (69 KB Excel file) and the [A to Z Inventory](#).

[Ottawa Decision Support Tutorial \(ODST\)](#)

An online auto-tutorial available to help practitioners develop skills in providing decision support.

Talking (cont.)

- In general:
 - **The estimated chance of death should reflect the amount of time dedicated to planning palliative and EOL care. For example, if a patient has a 50% chance of dying in the following year, 50% of the health provider effort for care should be directed toward palliation or EOL options/plans.*

Bereavement Programming

- The Preferred Practices for Palliative and Hospice Care Quality recommend
 - Facilitation of grieving by implementation of a bereavement care plan after the patient's death, when the family remains the focus of care
 - Bereavement Bags when goals of care changed to comfort
 - Follow up with family by phone, letter correspondence and support group referrals for a period of 13 months after the death
 - Follow up with grief support for staff who cared for the patient and family
 - Educational activities for staff and community on grief

“No One Dies Alone”

- Volunteer program developed in Oregon that is focused on providing a human presence and comfort to dying patients and their families
- Nursing staff can call on trained volunteers to sit with patients who do not have family or friends to be with them during the active phase of dying
- Provides quiet support, reading, music, massage, etc.
- Allow nurses comfort knowing the patient is not alone while they complete care for their other patients

The Reality

[HTTP://IMG.EU/](http://img.eu/) HOSTS THIS IMAGE SINCE 2012-08-13

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What are our options when considering palliation in Critical Care?

- Maximize treatment options while being alert to suffering
- Remember Palliative and EOL discussions are a procedure and take just as much skill as a cardiac catheterization
- Balance treatment with symptom management
- Always, always move in the direction of the patient's goals
- Listen and then talk when asked (within reason):
ASK—TALK—ASK model
- The patient and/or family should be talking more than you (70/30 rule). Silence is ok---count to 7.

Options (cont.)

- Communicate goals of care with all providers of the team, even the difficult conversations surrounding EOL
- Recognize that death is a part of life and it is not optional. *It is an option to plan and accomplish a good death.*
- We have the chance to make this a good memory for loved ones, one that they will carry the rest of their lives
- If we look at death as the enemy, we will set ourselves and our patients up to fail. Because in the end, death always wins.

In conclusion.....

- The results that make me most proud:
 - Nurses are advocating for their patients and focus on the relief of suffering based on patient and family goals
 - Long standing problems in ICU like pain and delirium are seen as suffering and the focus is to alleviate this so QOL is improved
 - Patients are being seen as whole persons, not as disease entities that require treatments
 - Providers are asking, “Am I treating a disease or prolonging dying?” to guide treatment decisions and documenting their EXPERT opinions
 - The time we spend with patients and families gives us insight into the best ways to provide critical care (pain, sedation, delirium, mobility, cognitive testing, discharge setting)
 - The team became inter-disciplinary rather than patriarchal
 - Movement into disease specific advanced care planning
 - The goals of health care standards for improved patient satisfaction, reduced LOS and reduced readmissions come along side an output of mission: “providing compassionate, quality health care in an environment of trust and collaboration”.

The Math is Easy



- **A**=Critical Care Nurse as **A**dvocate
- **B** = **B**e alert to suffering in patient or family
- **C** = **C**onsult Palliative Care

$$A+B=C$$

*“To cure sometimes, relieve often,
and comfort always....”* --16th Century physician