Objectives

- Describe palliative care in the ICU
- Identify why intensivists must master palliative care skills
- Explore practical tips to improve delivery of high quality palliative care
Life is pleasant. Death is peaceful. It’s the transition that’s troublesome. 

*Isaac Asimov*

Palliative care = prevention and relief of suffering --improvement in quality of life
End of life care = --when curative care stops --final hours days/weeks/months

Critical care = --at / near transition between life & death --closest to death they have ever been --may live or die, really struggling
Palliative care in the ICU

Patient and family support
- Symptom management
- Decision making (patient and family centered)
- Communication (timely, clear, compassionate)
- Dignity (the patient is a person)
- High quality death
- Emotional and spiritual support
- Continuity of care (versus fragmented)

ICU team member support
- Emotional support
- Organizational support
Palliative care relives suffering and improves quality of life

What does it do to the length of life?


Among patients with metastatic non–small-cell lung cancer, early palliative care led to significant improvements in both quality of life and mood. As compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life but longer survival. (Funded by an American...
What about the ICU?

Palliative care interventions in the ICU

Mortality

- Higher mortality = 1 study
- Lower mortality = 1 study
- No change = 14 studies

Hospital length of stay

- Shorter LOS = 8 studies
Palliative care interventions in the ICU

- Improve quality of life
- Improve quality of death
- Decrease treatment intensity
- Shorter hospital length of stay
- No change or lower mortality

Palliative care implementation

- Integrative model
  - ICU team provides palliative care
- Consultative model
  - Palliative consult team provides palliative care
- Mixed model
  - Integrative + consultative as needed
  - Similar to other ICU consult models
- Other
  - Trigger system for consultation
  - Pre-rounds with palliative care team
Shortage of palliative care specialists

- Currently employed: 4,400
- Estimated shortage: 6,000-18,000
- Newly trained annually: 180

“Rather than expect thousands of newly trained palliative care doctors to meet this need, the reality is that ICU physicians will and should provide this care. Conversations about end of life care goals and options are key interventions that all intensivists should become experts in, as important as understanding our patients’ physiology and offering procedural expertise.”

Palliative care in the ICU

**Patient and family support**

- Symptom management
- Decision making (patient and family centered)
- Communication (timely, clear, compassionate)
- Dignity (the patient is a person)
- High quality death
- Emotional and spiritual support
- Continuity of care (versus fragmented)

**ICU team member support**

- Emotional support
- Organizational support
Decisions to limit life support

- >70% of deaths in the ICU are negotiated (decision to withhold/withdraw 1 or more forms of life support)
- Decision making is hard and messy
- The default is to continue life support
- Consequences of a bad decision making
  - Premature death
  - Prolonged suffering
  - Patient distress
  - Family distress
  - ICU team member distress

Prendergast TJ. AJRCCM. 1997;155(1):15-20
How do we know that a “good” decision was made?

• Identifies:
  • Which option best achieves the patient’s goals
  • Which option is most authentic to the patient “True to Sally”
  • People who are in the final phases of life who do not wish to have a burdensome rescue

• Like buying a shirt. Help people “try on the options” and see which option they feel more comfortable in.

• Based on accurate diagnosis, treatment options, prognosis
  • Acknowledges uncertainty

How do we know that a “good” decision was made?

• Shared decision
  • Clinicians need to know something about the patient
  • Patient needs to know something about their medical facts

• Sensitive to the patient (culturally, spiritually, etc.)

• A good process was followed

• Less treatment intensity does not always equal a good decision
Shared decision making

- Share information
- Share the decision
- Share the burden

Preferred decision making role

<table>
<thead>
<tr>
<th>Role</th>
<th>USA</th>
<th>Canada</th>
<th>France</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family decides alone (autonomy)</td>
<td>10%</td>
<td>1%</td>
<td>0%</td>
</tr>
<tr>
<td>Family decides after considering MD opinion</td>
<td>44%</td>
<td>21%</td>
<td>&lt;5%</td>
</tr>
<tr>
<td>Shared decision</td>
<td>40%</td>
<td>39%</td>
<td>47%</td>
</tr>
<tr>
<td>MD decides after considering family opinion</td>
<td>4%</td>
<td>24%</td>
<td>30%</td>
</tr>
<tr>
<td>MD decides alone (parentalism)</td>
<td>2%</td>
<td>15%</td>
<td>10-15%</td>
</tr>
</tbody>
</table>
How do decisions go bad?

• Decision making is delayed, avoided
• Misinformation about diagnosis, prognosis, options
  • Uncertainty is not acknowledged
  • Mixed messages from different team members
• Goals/values/preferences are misconstructed
  • Pseudoempathy (inaccurate belief that patients see the world the way clinicians do)
• Involve the family, but not the patient
• Place whole burden on the family. “You decide”
• Don’t involve the nurses, chaplains, etc.
• Don’t consider cultural, spiritual mindset of patient

100 DNR/DNI patients in the hospital

How many want a trial of intubation for certain circumstances?
  • 3 out of 5

How many want a trial of CPR?
  • 1 out of 5

Most DNI patients are not really DNI.
  • They really want to be DNLMIFARLT.
  • Do-not-leave-me-intubated-for-a-really-long-time
  • I am okay with a trial of intubation with the ability to stop if that trial becomes protracted

DNR ≠ automatic DNI
  • Survival and recovery are vastly different
100 MICU patients

How many recalled discussing code status or goals of care?
• **50%**

How many identify the three main components of CPR (compressions, shock, breathing support)?
• **4%**

How many wanted a different code status than what was in the chart?
• **16%**

For how many patients did the physicians disagree with patients about the primary goal of care?
• **68%**

---

Variability between different ICUs in the US

[Image of a graph comparing different ICUs]
Variability between physicians in a single ICU

Physician characteristics associated with more decisions to limit life support

- Younger
- Attending (versus fellow)
- More experienced
- ICU specialty (versus subspecialty)
- More EOL training, reads more EOL papers
- Less likely to prefer life support for self
- Less risk adverse
- Judging personality
- Less religious (versus more religious)
- Protestant > Catholic > Muslim > Jewish
- “Quality of life” attitude


Decision Making Tips
Goals of hospitalized patients

1. Be cured of disease
2. Live longer
3. Improve or maintain quality of life or function or independence
4. Be comfortable
5. Achieve a particular life goal:
   -- Live at home (versus a skilled nursing facility)
   -- Strengthen a relationship
   -- Special occasion or accomplishment (graduation of a child)
   -- Spiritual goal
   -- Good death
6. Provide support for family/caregiver
7. Further understand diagnosis or prognosis
**Serious Illness Conversation Guide**

1. **Set up the conversation**
   - Introduce purpose
   - Prepare for future decisions
   - Ask permission

2. **Assess understanding and preferences**

3. **Share prognosis**
   - Share prognosis
   - Frame as a "wish...worry", "hope...worry" statement
   - Allow silence, explore emotion

4. **Explore key topics**
   - Goals
   - Fears and worries
   - Sources of strength
   - Critical abilities
   - Tradeoffs
   - Family

5. **Close the conversation**
   - Summarize
   - Make a recommendation
   - Check in with patient
   - Affirm commitment

6. **Document your conversation**

7. **Communicate with key clinicians**

---

"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — is this okay?"

What is your understanding now of where you are with your illness?"

"How much information about what is likely to be ahead with your illness would you like from me?"

"I want to share with you my understanding of where things are with your illness..."

*Uncertain:* “It can be difficult to predict what will happen with your illness. I hope you will continue to live well for a long time but I’m worried that you could get sick quickly, and I think it is important to prepare for that possibility.”

OR

*Time:* “I wish we were not in this situation, but I am worried that time may be as short as [express as a range, e.g. days to weeks, weeks to months, months to a year].”

OR

*Function:* “I hope that this is not the case, but I’m worried that this may be as strong as you will feel, and things are likely to get more difficult.”

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https://www.ariadnelabs.org/areas-of-work/serious-illness-care/
Serious Illness Conversation Guide

“What are your most important **goals** if your health situation worsens?”

“What are your biggest **fears and worries** about the future with your health?”

“What gives you **strength** as you think about the future with your illness?”

“What **abilities** are so critical to your life that you can’t imagine living without them?”

“If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?”

“How much does your **family** know about your priorities and wishes?”

“I’ve heard you say that ____ is really important to you. Keeping that in mind, and what we know about your illness, I **recommend** that we ____. This will help us make sure that your treatment plans reflect what’s important to you.”

“How does this plan seem to you?”

“I will do everything I can to help you through this.”

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**Serious Illness Conversation Guide**

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---

https://www.ariadnelabs.org/areas-of-work/serious-illness-care/
Facilitated Values History

- Attend to surrogate’s emotions: NURSE
  - N-ame the emotion: You seem upset
  - U-nderstand the emotion: This is such a hard thing to go through
  - R-espect the family: You are doing a wonderful job advocating for your Mom
  - S-upport the family: How are you and your family doing?
  - E-xplore the emotion: Tell me more about why you feel that way
- Help surrogates understand their contribution to decision making
- Understand the patient as a person
- Explore specific values and value conflicts
- Summarize the values relevant to the decision
- Bridge between values and treatments
- Give permission to follow the patient’s wishes (express empathy, address moral concerns, share social norms).

Best Case / Worst Case
Best Case / Worst Case

- Good way to talk about diversity of outcomes
- Good way to acknowledge uncertainty
- Good way to ensure you actually discuss two options

Caution:
- “best” and “worst” may not be the same for all patients

Option 1
Surgery

Option 2
Supportive care
Don’t demand a decision be made now

- What I hear is that you are leaning towards the following decision ____________.
- I am going to leave. I am going to give you time to talk amongst yourselves. See how you feel about this decision. Does this decision feel right for you and for the patient.
- I will be back in ____________ minutes.
Don’t forget about a “time limited trial”

• Option 1. Full medical support (indefinitely)
• Option 2. Comfort measures only
• Option 1. Full medical support for a few days
  • Assurance we will revisit with you and family in 3-5 days

Decision to intubate ≠ decision to forever ventilate

Patient centered care ≠ family centered care

• The patient may wish to focus on comfort.
• The family wants the patient to keep living.
• Ultimate goal: honor patient wishes

• “Sometimes it is really hard to separate what you might want for your Mother from what she might choose for herself, but it is really important to try.”
• “Let’s say your Mother were sitting here with us and could hear all of this information.”
The problem with previously stated wishes

• Advance care planning
  • Decisions before acute illness
  • Hypothetical scenarios
  • Made days or months or years in advance
  • Written in advance directives
  • Assessing (previously determined) preferences

• Current care planning
  • Decisions during acute illness
  • Current goals, phase of life, diagnosis, prognosis
  • Constructing preferences

What people imagine when they fill out advance directives
What facing death is actually like

“The bull looks different once you enter the ring.”

No matter how well you plan beforehand . . .
(advance care planning)

- Your current illness is not the scenario you imagined
- Your goals, values, preferences are likely to change when your health changes
- Your current illness is “unexpected” and therefore has not been “planned for”
- Many people do not want unnecessary treatment in a “terminal” or “irreversible” state
  - (This is really hard to determine)
- Pathways are highly contextual and nuanced
Mike and family on vacation

Can’t entirely plan for:

• What’s going to happen
• When it’s going to happen
• Where you will be
• Where your family will be
• Who’s going to care for you
• How you are going to feel
• What the treatments will be
• What your recovery will be
Look for previously stated wishes

- Interpret with caution
  - When were these wishes stated?
  - Under what conditions were these wishes stated?
  - What has changed now?

- Your goal: help patient construct preferences (not just assess their existing preferences)
Communication matters

“The nurse and doctors kept saying mom was really sick. I wish I knew that meant mom was dying because then I could have been there when she died.”

*ICU family member*

ICU words are powerful

“I can convince a family to choose any decision I want just based on how I communicate with them. I can nudge them down any path I want.”

*ICU physician*
ICU communication is suboptimal

- 50% ICU families do not understand diagnosis or prognosis
- 30% ICU families not happy with communication
- 15% ICU families report receiving "conflicting information"
- Physicians speak 75% of time, listen 25% of time

Consequences of poor communication

- Devastation
- Confusion
- Bad decision making
- Conflict
- Mistrust
- Burnout
- Anxiety, depression, PTSD, sleeplessness
- Other . . .
The healing power of listening

Family satisfaction with family conferences about end-of-life care in the intensive care unit: Increased proportion of family speech is associated with increased satisfaction

Jonathan R. McDonagh, MD; Tricia B. Elliott; Ruth A. Engelberg, PhD; Patey D. Treece, RN, MN; Sarah E. Shannon, PhD, RN; Gordon D. Rubenfeld, MD, MSc; Donald L. Patrick, PhD, MSPH; J. Randall Curtis, MD, MPH

Missed opportunities in family conferences

<table>
<thead>
<tr>
<th>TABLE 2. DESCRIPTION OF THE MISSED OPPORTUNITIES DURING INTENSIVE CARE UNIT FAMILY CONFERENCES CONCERNING END-OF-LIFE CARE OR DELIVERY OF BAD NEWS</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. Passages</td>
</tr>
<tr>
<td>Overall missed opportunities</td>
</tr>
<tr>
<td>Listen and respond</td>
</tr>
<tr>
<td>Opportunity to answer family member questions</td>
</tr>
<tr>
<td>Opportunity to clarify meaning or follow up on important statement by family member</td>
</tr>
<tr>
<td>Acknowledge or address emotion</td>
</tr>
<tr>
<td>Opportunity to acknowledge emotions or support family grief</td>
</tr>
<tr>
<td>Opportunity to address or attempt to alleviate family guilt</td>
</tr>
<tr>
<td>Address important tenet of palliative care</td>
</tr>
<tr>
<td>Opportunity to explore family statements of patient preferences</td>
</tr>
<tr>
<td>Opportunity to explain basis for surrogate decision making</td>
</tr>
<tr>
<td>Opportunity to affirm medical team nonabandonment</td>
</tr>
</tbody>
</table>
## Errors of communication vs Good communication

<table>
<thead>
<tr>
<th>Errors of communication</th>
<th>Good communication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don’t have the conversation</td>
<td>Early family conference (day 3)</td>
</tr>
<tr>
<td>Wrong word choice “withdrawal of care”</td>
<td>Careful word choice</td>
</tr>
<tr>
<td>Medical jargon</td>
<td>Simple language</td>
</tr>
<tr>
<td>Don’t listen</td>
<td>Shut up and listen “Ask, tell, ask”</td>
</tr>
<tr>
<td>Don’t respond</td>
<td>Respond</td>
</tr>
<tr>
<td>Give mixed messages</td>
<td>Whole team has unified message</td>
</tr>
<tr>
<td>Avoid conflict</td>
<td>Manage conflict</td>
</tr>
<tr>
<td>Avoid uncertainty</td>
<td>Acknowledge uncertainty</td>
</tr>
</tbody>
</table>

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**Dignity**

*(The patient is a person)*
Dehumanization in the ICU
(patients is an object)

**Not so subtle**
- Publicly shaming/mocking patients
- Exploitation for research purposes

**Subtle**
- Take away everything that identifies them as a person
  - No clothes, wedding ring, glasses, dentures, hair style, cell phones, wallets
- Take away their family
- Personal information attached to a tag on wrist
- Tubes everywhere
- Don’t ask permission to enter personal space or to touch
- Don’t call people by their preferred names
- No privacy
- No control over anything (get out of bed, even breathe)
- Speak another language (medical jargon)
- Vulnerable: distress, pain, dyspnea

People are reduced to a bunch of numbers
“Room 512 who was intubated for COPD exacerbation”

“Cindy not Cynthia”
Find out something non-medical about your patient

Behave as if you were a dinner guest
Behave as if you were a dinner guest

Common courtesy

- Introduce yourself
- Ask permission to enter living space (room)
- Ask permission to touch
- Explain what you are doing
- Explain what is happening

- Easy to avoid this:
  - comatose, delirious, altered, ventilated

Let them in (the family members)
“Audrey did not leave Gillian’s side”

“It’s just another day for you. But for me, it’s the worst day of my life.”

MICU family member
In the ICU: patient care = family care

- Family members are **not** visitors
- The patient and family are a single entity
- Big emergency: you hold your family close
- This is the closest to death they have ever been

---

**We still lack patient centered visitation in intensive care units**

Samuel M Brown director, Center for Humanizing Critical Care, Intermountain Medical Center, 5121 South Cottonwood Street, Murray, UT 84107, USA, and assistant professor, pulmonary and critical care medicine, University of Utah School of Medicine

I couldn’t find words for my anger when my friend called to explain that hospital policy barred Tom’s wife and children from his bedside as he lay, comatose, in hospital. No more than two visitors for 20 minutes at two hour intervals for a maximum of five times a day, the dehumanizing policy stipulated. My friend explained how desperately they wanted to be at Tom’s side and how mystified they were by the restrictions. As life drained from Tom the clinicians forced his family to abandon him for most of each day.

- 80% of ICUs in US have restrictive visiting hours
- Restrictions are based on tradition and a lot of “reasons”
- Pediatric ICUs have had open visitation for years
- We should be able to make it work too
- Requires a culture change, coordination
- Open visitation should be rule not exception
- “You are important to the patient. You are welcome to stay, but you don’t have to. We will take care of your loved one as if they were our own family member. We will call you if anything changes.”

Brown SJ. BMJ. 2015;350:h792.
Let them in (family presence)

- What about family watching CPR?
  - Family member PTSD, anxiety, depression = ↓
  - Medical team distress = no change
  - Assign someone to be the family “guide”

- What about family watching brain death evaluations?
- What about family being present for procedures?
  - central line, thoracentesis, intubation, etc.

Central line placement “comfort tent”
Dignity
(The patient is a person)

Why do we treat patients as objects?
How can we prescribe compassion?
The Epidemic of Disillusioned Doctors

It's much harder for disillusioned doctors to muster empathy for their patients.

Doctor has lower empathy score → patient has worse clinical outcomes OR 1.7 (95% CI, 1.2 – 1.4)

High Quality Death
64 year old woman

- Metastatic colon cancer, refractory
  - Acute colonic obstruction → colonic stent
  - 6 months good QOL at home
- Admitted to ICU with sepsis, abdominal pain, respiratory failure
- Patient: “Do anything to help me live longer. I am not ready to die.”
- Doctor: “We can try colonoscopy, try to relieve obstruction.”
- Colonoscopy
  - Intubated prior to colonoscopy for procedure
  - Stent obstructed with cancer → severe ischemic colitis
  - Worsening respiratory failure
  - Worsening shock

64 year old woman

- 10pm family meeting (surgeon, intensivist, nurse, daughter)
  - We cannot treat this problem
  - If we extubate, she will be in extraordinary pain and dyspnea
  - Shared decision: transition to comfort measures only
  - Patient died peacefully a few hours later, never woke up

What went right?
What went wrong?

“I didn’t expect her to die today.”
“I never got to say goodbye.”
“Going off to war” talk

Words of love, support, encouragement

Best case: soldier returns home alive

Worst case: last words together

Hope for the best
Prepare for the worst

Intubation in the ICU

• Cannot communicate (at least temporarily)
• Outcomes can be bad (unexpected)
• “Going off to war talk”
  • Hope for the best, prepare for the worst
• Avoid stealing last words
• 2 minutes can “save a death”
• Include it with my intubation checklist
High quality death

- Be kept clean
- Name a decision maker
- Have a nurse with whom one feels comfortable
- Know what to expect about one’s physical condition
- Have someone who will listen
- Maintain one’s dignity
- Trust one’s physician
- Have financial affairs in order
- Be free of pain
- Maintain sense of humor
- Say goodbye to important people
- Be free of shortness of breath
- Be free of anxiety
- Have physician with whom one can discuss fears
- Have physician who knows one as a whole person

- Resolve unfinished business with family or friends
- Have physical touch
- Know that one’s physician is comfortable talking about death and dying
- Share time with close friends
- Believe family is prepared for one’s death
- Feel prepared to die
- Presence of family
- Treatment preferences in writing
- Not die alone
- Remember personal accomplishments
- Receive care from personal physician

Quality of death

- Attributes rated as important by >70% of patients but not physicians
  - Be mentally aware
  - Be at peace with God
  - Not be a burden to family
  - Pray
  - Have funeral arrangements planned
  - Not be a burden to society
  - Feel one’s life is complete
Three wishes project

Identify 3 ways to honor dying patients

Humanizing the environment
- Soliciting personal mementos for the patient’s room
- Playing the patient’s favorite television channel 24 h/d
- Using the patient’s preferred nickname
- Recruiting date night in the ICU
- A rock and roll sing along with the patient’s friends
- Playing Scottish bagpipe music at the time of death
- Obtaining flowers for the patient’s bedside

Personal tributes
- Holding a breakfast tribute by the staff for the patient’s partner
- Planting a tree in the patient’s honor
- Proposing a trend to the patient at the patient’s bedside
- Creating a framed word cloud
- Holding a tea party at the patient’s bedside
- Naming a park bench for the patient
- Providing a final supper for the family in the ICU conference room

Family connections
- Encouraging visitation by a beloved pet
- Locating an estranged relative
- Facilitating a Skype reunion
- Resolving residual family discord about the patient’s burial place
- Tasting the patient’s favorite pasta sauce before the patient dies
- Allowing a mother to lie in bed with her son as he dies
- Dying with all family members present in the room

Rituals and observances
- Birthday celebration for the family in the ICU conference room
- Renewal of wedding vows at the patient’s bedside
- Fireworks display
- Wedding ceremony at the patient’s bedside
- Deter-switching life support until after a religious holiday
- Release of a helium balloon with a message to the patient
- Memorial service at the patient’s bedside

Paying it forward
- Family member securing a hospital volunteer position
- Ceremonial donation
- Unsolicited family gift to future families
- Project’s donation to a charity significant to the patient
- Family’s donation of a stuffed “happy pill” for other grieving families
- Lunch gift certificate for a family gathering after the funeral
- Project’s donation to an infant’s personal education fund

http://3wishesproject.com/

Alison and Amy
Top 10 recommendations:

• Open the doors to the ICU
• Formal family meeting on day 3-5
• Listen more, talk less. It is healing.
• Find out something non medical about your patient. Find photos. It is healing.
• DNI often means do-not-leave-me-intubated-for-a-really-long-time
• “Going off to war” talk as part of intubation checklist
• 3 wishes to honor dying patients
• “Serious illness conversation guide” “Facilitated values history”
• Dinner guest rules: talk to patients who are altered/sedated.
• Don’t demand a decision be made now. Let them “try on the decision.” Come back in 5 minutes.

Thank you!

Michael E. Wilson MD
wilson.michael1@mayo.edu