CRITICAL ILLNESS AND PALLIATIVE CARE

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KEY OBJECTIVES

• Definitions / Role and Benefit of PC in the ICU
• Obstacles to Palliative Care in the ICU
• Integrating Palliative Care into YOUR ICU
TRUE OR FALSE?

- Palliative care is the same as hospice
- You call palliative medicine and supportive care when there is nothing left to do
- It is best to call for palliative care when you expect a complex recovery process
- Palliative care has been shown to extend quality of life AND quantity of life
- The ‘conversation’ is the ‘procedure’ of the palliative care team and services
CURATIVE – RESTORATIVE CARE

NONCURATIVE – PALLIATIVE CARE

DEATH

Hospice

BEREAVEMENT

TIME

INTENSITY OF CARE
1

2

3 CHF, CANCER, COPD, etc

4 DEBILITY, DEMENTIA, DIABETES
WHO DEFINES PALLIATIVE CARE:

• “an approach that improves the quality of life . . .
• patients and their families facing life-threatening illness . . .
• prevention and relief of suffering . . .
• early identification and impeccable assessment and treatment . . .
• pain and other problems, physical, psychosocial, and spiritual.”

• Requires a multidisciplinary team
PALLIATIVE CARE

• Specialized medical care
• People with serious illness
• Relief from the symptoms, pain and stress
• Whatever the diagnosis
• Improve the quality (and quantity) of life
• At any stage of illness
• Provided by a team (extra layer of support)
• Together with curative or life prolonging treatments
7/10 AMERICANS “NOT AT ALL KNOWLEDGEABLE”
Consumer research study 2011 (CAPC, AAHPM, ACS)

DEFINITION:

• Provides the best possible quality of life for patients and families
• Helps to manage the pain, symptoms, and stress of a serious illness
• Partnership of patient, medical specialists and family
• Any age, any stage of illness, along with curative treatment

92% Want for themselves
Everywhere accessible
WHY PALLIATIVE CARE?

• Public demand
• Healthcare Reform
• Emphasis on QUALITY as a value
• Holistic & Personalized Care
• Quantity ≠ Quality

Some End-of-Life Treatments can be Done, but Shouldn’t

The New York Times

We Need a Role Reversal in the Conversation on Dying

VJ Periyakoil: April 22, 2015
Institute of Medicine Sept 2014

*Improving Quality and Honoring Individual Preferences Near the End of Life*

**5 Major Recommendations**

- Person-centered, family-oriented care
- Communication and advance care planning
- Professional education and development
- Policies / payment systems
- Public education and engagement
Domains of Palliative Care

**Disease Management**
- Goals of Care
- Prognostication
- Management

**Physical**
- Pain, dyspnea & other symptoms
- Function, fluids, nutrition

**Psychological**
- Anxiety
- Depression
- Distress

**Loss, grief**
- Emotional responses
- Bereavement

**Social**
- Family dynamics
- Financial
- Legal

**End of life / death management**
- Last hours of life
- When death occurs

**Culture / Ethnicity**
- Language
- “Truth-telling”
- Rituals

**Spiritual / Religious**
- Hope
- Transcendence
- Meaning, Value
WHY PALLIATIVE CARE + ICU?

• “trial of life”
  • 20% deaths occur in or around the ICU admission
  • >50% of patients who die in an acute care admission will spend time in the ICU

• High symptom burden
  • 40 – 80% patients report uncontrolled symptoms
  • Psychosocial and spiritual distress (> 30% families experience anxiety, PTSD and complicated grief)

• Conflict and misunderstandings are commonly reported
  (70% clinicians, 40% family members)

• Post ICU Syndromes (cognitive dysfunction, sleep disorders, PTSD)

• Higher morbidity and mortality

Angus CCM 2004 (RWJF)
Nelson CCM 2010
Pandharipande, NEJM 2013
BUSINESS CASE; IMPORTANT PRINCIPLES


• Persons with serious illness, and their families are at risk for pain and suffering from multiple sources, PC helps

• Persons with progressive life-limiting disease often have heavy use of expensive health care services (ED, critical care, etc) some of which is avoidable

• Hospitalizations toward the end of life are lengthy and costly, with negative fiscal outcomes

• Inpatient PC improves symptoms, coordinates care and reduces the cost of hospitalizations
INTENSITY OF CARE

Curative / Restorative therapy

Palliative care

TIME
The single biggest problem in communication is the illusion that it has taken place.

George Bernard Shaw (1856 – 1950)
DONE WELL

Trust
Partnership
Satisfaction
Less anxiety . . . .
  • Better listening
  • Less distraction
  • Lower demand burden
  • Better compliance
  • Improved health outcomes

DONE LESS WELL

Anger / litigation
Confusion / dissatisfaction
Overtreatment
Fear and mistrust
Escalating demands
Complicated grief / Guilt
PTSD / Post-ICU syndrome
THE CHALLENGES . . .

• Patient and family want:
  • To live, to be ‘fixed’
  • “Personhood”
  • To be in control
  • To ‘know’, to ‘cope’
  • To be free of pain
  • Practical realities/impact on family
  • Hope, Honesty, Sensitivity

• Hospital Realities:
  • “Trial of life”
  • Uncertainty
  • Little control
  • Little time, much stress
  • Little trust
  • Dynamic ( ! )
  • Suboptimal holistic care systems / education
BARRIERS AND CHALLENGES TO COMMUNICATION

- Little training in communication skills (pathophysiology lectures)
- Ignoring context of communication encounter
- Not finding out what information the family needs
- Fear that honest communication will lead to anger or premature death
- Fear of malpractice
- No policies / standards that guide best practice
- Prognosis based on “intuitive knowing” vs empirical evidence
  - Negative prognostic information from critical care physicians is often delayed
PATIENT CRITICALLY ILL
OR WITH NEW ‘BAD’ DIAGNOSIS . . . .

- Complex communication task
- Verbal component
- Emotional reactions
- Decision-making tasks
- Balancing expectations
- Multiple perspectives
- Embracing cultural differences
- Providing hope and realism
WHAT HELPS PATIENTS AND FAMILIES?

• Let them talk early (increases confidence to speak)
• Encourage them to speak more rather than less (more family airtime increases satisfaction)
• Don’t miss the opportunities to:
  • Acknowledge emotion
  • Listen and respond to questions - “how’s my mom?”
  • Affirm non-abandonment, support, non-suffering
“HOW TO BREAK BAD NEWS: A GUIDE FOR HEALTHCARE PROFESSIONALS” (ROBERT BUCKMAN, 1992)

6-Step SPIKES Protocol

• **S**: Setting: Getting started
• **P**: Perception: What do patients know?
• **I**: Inquiry: What do they **want** to know?
• **K**: Knowledge: Telling them the news
• **E**: Emotion/Empathy:
• **S**: Summarize / strategize – planning & next steps
COMMUNICATION TIPS

• “Connect before Content “
  • BODY LANGUAGE  (7% words / 38% tone / 58% body language)
  • Timing, management and delivery is key
  • Perceived attitude of practitioners →“first impression” and the rest of the hospitalization
• Sit down
  • Not rushing, more relaxed
  • “How are you feeling right now?”
• Sharing the information

0 – 2 intimate zone
2 – 4 personal zone
> 4 – announcement zone
SHARING THE INFORMATION . . .

• Warning shot across the bow
  • “I wish I had better news for you…..”
  • “your mom is 86 and is critically ill . . . . “

Small ‘bite-size’ piece of information
Say it, then STOP

• Avoid monologue
• Use silence
• Promote dialogue
• Pause frequently
• Check for understanding (any questions?)
• Watch body language (anxiety earmuffs)
SHARING THE INFORMATION

- Don’t minimize severity
  - Avoid vagueness, confusion and euphemisms
  - Avoid jargon, medical terms
  - Trust in the patient / family’s ability to cope

- Don’t ‘rescue’
  - Don’t rush in with: You have X-bad disease BUT ........
  - Let them have time (anxiety earmuffs)
  - Only 10% retention, repeat
FOUNDATIONAL: “TELL ME MORE”

• Every conversation has 3 levels at same time:
  • Facts
    • “Tell me more about what you need at this point?”
  • Feelings
    • “Could you share how you are feeling about what we discussed?”
  • Meanings
    • “Could you tell what this means for you and your life?”

HARVARD NEGOTIATION PROJECT, 1980
FOUNDATIONAL: ASK – TELL – ASK

• Ask
  • ‘just to be sure we are on the same page, . . . “
  • “What’s most important for you right now?”
  • “what have the other doctors told you?”

• Tell
  • Straightforward language (9th grade or less)
  • Short chunks (<3 pieces of information)

• Ask
  • What have you heard me say?
  • What will you tell your sister when you talk with her?
FOUNDATIONAL : EMPATHY PHRASES

early concerns

• “I’m worried about your mom. I want you to understand what we are seeing.”
• “the results were not what we were hoping for”

loss, futility, unrealistic expectations

• “I wish things were different”
• I’m hoping he will get better too, but I’m worried that . . . .
FOUNDATIONAL: “NURSE”  
(RESPONDING AND ACCEPTING PATIENT EMOTIONS)

- **Naming** – “sounds that you might be worried . . .” “some people in this situation . . .” Name the emotion but in non declarative mode

- **Understanding** – active listening, silence (NO PREMATURE REASSURANCE)

- **Respecting** – stay present. Non-verbal or verbal. “I am impressed with how well you’ve held things together . . . .”

- **Supporting** – express understanding, willingness to help, partnership, non-abandonment

- **Exploring** – link the ‘I’ with the ‘you’ “I sense how upset you are feeling about . . .”

Smith RC *Patient-centered Interviewing: An Evidence-based Method*. Lippincott 2002
MULTI-CULTURALISM - INFORMATION IS ABSORBED DIFFERENTLY

- Ethnicity, culture, religion, socioeconomic status, education level, age
- 1 in 2 Americans can’t read above 5 – 9th grade level
- Only 1 in 10 can benefit from health care information from internet, media, etc

   Respect and minimize negative consequences of cultural differences

- Chaplains and Social Workers are cultural ‘experts’ – ask for help
- ‘Us’ and ‘Them’
  - Culture, history, policies, processes of care and attitudes
  - “how is my son doing?”

Source: Institute for Healthcare Advancement, La Habra
WHEN THINGS DON’T GO WELL, OPTIMIZING THE CONVERSATION

• **Emphasize their ‘rights’** – “it is your right to know what we know and see what we see”

• **Be very honest** - “I know this is so hard to hear, and I want to talk to you as though you are my brother ... (insert truth here).”

• **Demonstrate your moral ethic** - “I want to do my best to do what is best for your loved one,” or, “It is morally important for me to tell you the truth about your medical situation.”

• **Trust first** – Trust them, help them trust you

• **Be vulnerable** - Tell your own story
PALLIATIVE CARE + ICU

“Trial of Life”

- Emphasis on quality of life; patient centered
- Communication; family meetings early and often
- Hope and compassion

Best Outcomes:

Full recovery +/- palliative medicine
Good End-of-Life Care / palliative care
Whole-person care > > Organ-based care
TRUE OR FALSE?

• Most people want to die the “default American death” (ICU, tubes, etc)
• All critical care specialists have good training in and enjoy delivery of bad news
• In a sudden traumatic death scenario, there is no need for palliative care
• The culture of cure / rescue can make transition to pall care and goals difficult
• All ICUs should have early psychosocial support for families, early and consistent communication about likely outcomes, and alignment of patient wishes and therapeutic choices
WHAT CAN YOU DO IN YOUR ICU?

- Brochure describing the ICU experience
- Family Meeting Brochure:
  - Goals
  - Who should come / when the meeting will happen
  - What questions are important
  - What to expect during the meeting
- Meetings with the family – plan and execute
- Communication Workshops (practice)
- PC Skills Education for Nursing (pain management, etc)
- “Death Rounds”

5 Major Recommendations

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Near the End of Life
ON-LINE AND SELF-STUDY RESOURCES

- CSU Institute for Palliative Care [https://csupalliativecare.org](https://csupalliativecare.org)
- Education in Palliative and End of Life Care (EPEC) [www.epec.net](http://www.epec.net)
  EPEC (O, EM, LTC, PED, VET, CGVRS, GERI, RC, AA)
- End of Life Nursing Education Consortium (ELNEC) core and trainers
- Center to Advance Palliative Care (CAPC) [www.capc.org](http://www.capc.org)
  IPAL – ICU, IPAL – EM, IPAL - OP
- Fast Facts (Palliative Care Network of Wisconsin) [www.mypcnow.org](http://www.mypcnow.org)
- American Academy of Hospice and Palliative Medicine (AAHPM) [www.aahpm.org](http://www.aahpm.org)