

Palliative Care and the ICU

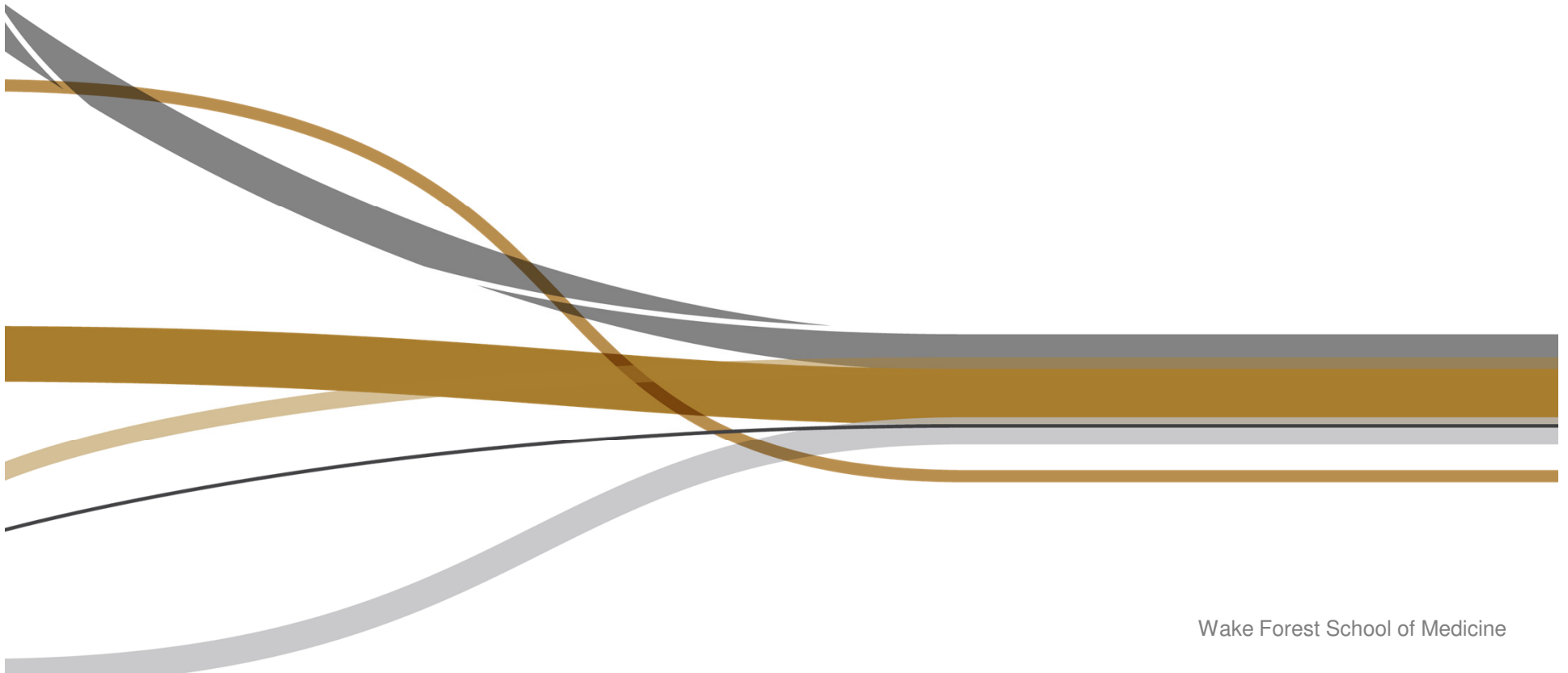
Marie Caldwell MSIV - March 9, 2012



Objectives

- Present the history of palliative care in the ICU
- Discuss current approaches to palliative care in the ICU
- Describe how to apply certain palliative care approaches to withholding/withdrawing treatment in the ICU

History of Palliative Care in the ICU



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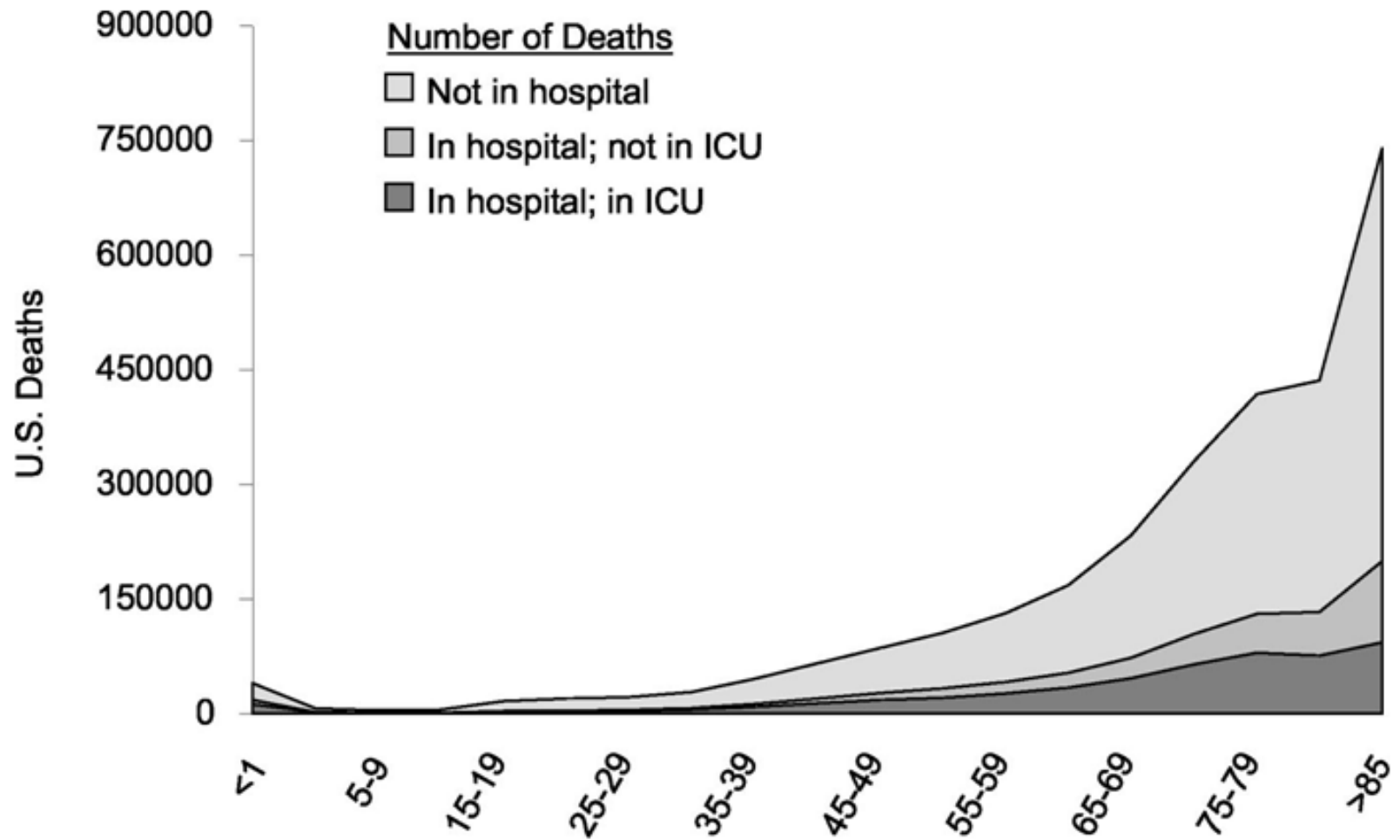


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"The old fool's dead."

Dying in the ICU

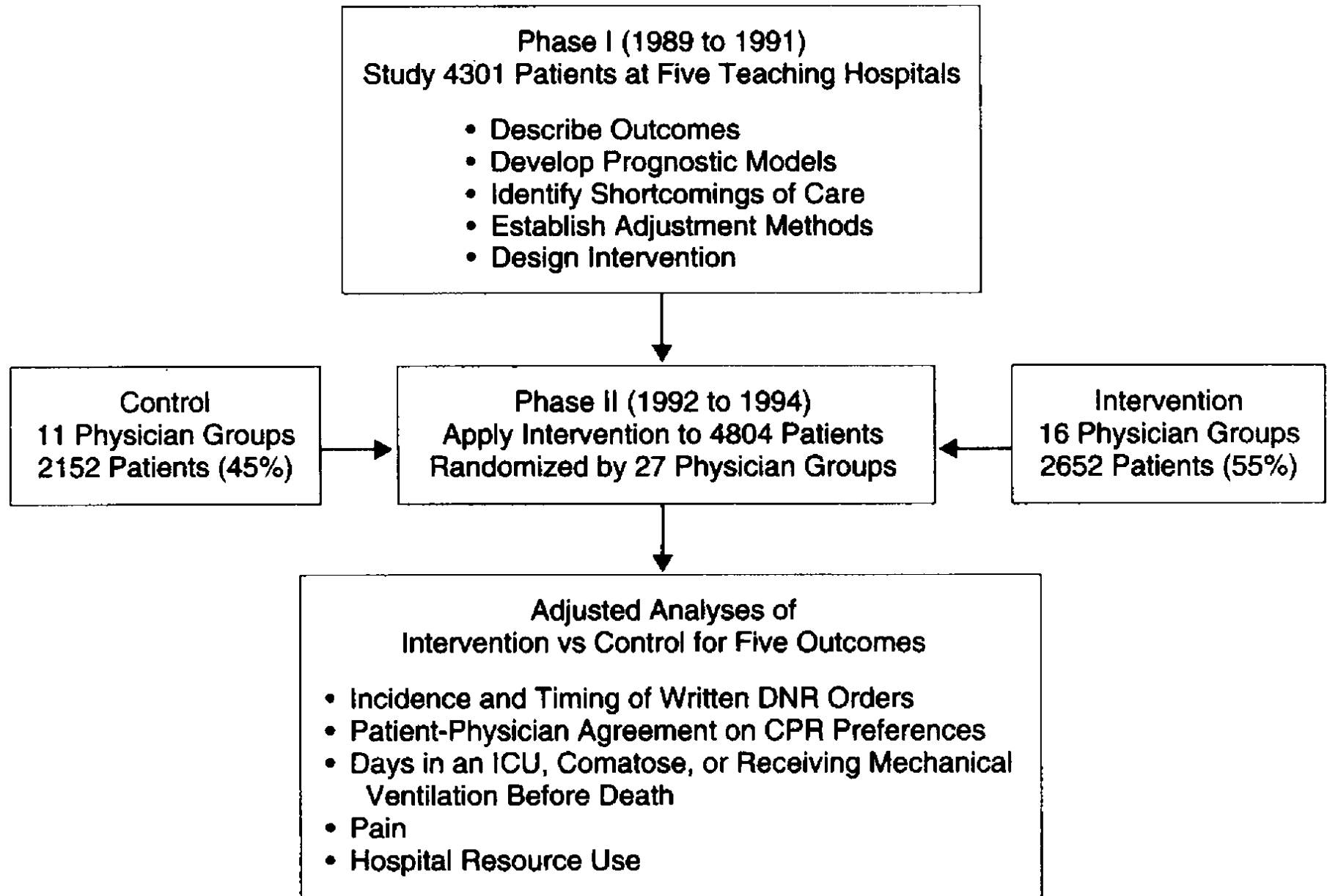
- The goal of the ICU is to save the lives of those patients with reversible medical conditions and to provide the dying with a dignified death
- A 2004 study (Angus et al.) estimated that 540,000 people, or 20% of Americans, die in ICUs every year
- The NHPCO reported 41.6% of deaths in the United States served by hospice in 2009



Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) -1996

- Included patients with life-threatening diagnoses of: acute respiratory failure, multiple organ system failure with sepsis, MOSF with malignancy, coma, COPD, CHF, cirrhosis, metastatic colon cancer, NSCLC
- Excluded patients under 18, discharge/died within 48 hours, HIV/AIDS, pregnant, trauma

Objectives and Organization of SUPPORT



SUPPORT Study - 1996

- Phase I results:
 - 31% of patients preferred that CPR be withheld, only 47% of physicians knew this during their first interview
 - 49% of those who preferred DNR status did not have a DNR order written during that hospitalization
 - After death surrogates reported that 50% of patients were in moderate to severe pain for the last three days of life

SUPPORT Study - 1996

- Phase II results:
 - No change in any of the 5 outcomes
 - Incidence and timing of DNR orders
 - Knowledge of patient DNR preference
 - Days spent in the ICU
 - Days on mechanical ventilation in a coma
 - Pain level
 - 41% of patients who did not discuss DNR status reported that they would have liked to

Palliative Care and the ICU



- As of 1994, palliative care in the form of treating pain, finding out patient's wishes and having discussions with families was very poor.

National Survey of End-of-Life Care for Critically Ill Patients - 1998

- Prendergast et al. 1998
- At UCSF between 1987-1988, 51% of patients who died in an ICU had life support withheld or withdrawn
- Between 1992-1993 this increased to 90%
- UCSF trend, or a national trend?
- Looked at every postgraduate program with critical care and performed prospective observational study

National Survey of EOL Care - 1998

TABLE 2
SUMMARY BY PATIENT

Total ICU admissions	74,502
Total ICU deaths	6,303 (8.5% mortality)
Brain deaths	393 (6.2% of deaths)
Patients facing end-of-life decisions	5,910
Full resuscitation	1,544 (26%)
Withholding of resuscitation	1,430 (24%)
Withholding of life support	797 (14%)
Withdrawal of life support	2,139 (36%)

National Survey of EOL Care - 1998

- Studied 131 ICUs in the US
- Death preceded by failed CPR 4-79%
- DNR status 0-83%
- Withholding of life support 0-67%
- Withdrawal of life support 0-79%
- No correlation with hospital type, ICU type, number of admissions

Palliative Care and the ICU



- From the 1998 Prendergast study, physician practices in end of life decision making vary greatly and cannot be correlated with any one factor
- In order to know with which patients to have end-of-life discussions, physicians need to be able to predict outcomes
- Can more experienced physicians better predict the patients who will do well?

Does Experience Matter?

- Vicente et al. 2004
- 2003 study of 233 patients in Medical-Surgical ICUs
- Interviewed physicians about length of stay and outcome
- Graded experience
 - Junior = <1 year experience in critical care
 - Middle = fellow
 - Senior = staff physician

Does Experience Matter?

- Senior physicians were good at predicting length of stays ≤ 4 days, moderate for 5-6 days and fair > 6 days
- Junior physicians' predictions were fair or poor for all lengths of stay
- Use of mechanical ventilation or diagnosis of shock at presentation was associated with longer stay
- All physicians underestimated mortality, with no statistical significance with experience

Palliative Care and the ICU



- Physicians cannot always predict which patients will live and which will die, so an open honest discussion is needed with frequent updates
- What do the patients perceive as opportunities for palliative care in the ICU?

Patient Perception in the ICU - 2004

- Van de Leur et al. 2004
- 125 patients over 18 who stayed >24 hours in an ICU, and were intubated with mechanical ventilation
- Questionnaire administered 3 days after discharge from the ICU
- Patient identified sources of discomfort included: *presence of an ET tube, hallucinations and medical activities*

Patient Perception in the ICU - 2004

Table 2

Sources of discomfort in intensive care unit patients (n = 66)

Source of discomfort	
Endotracheal tube	42
Hallucinations	32
Medical activities	29
Noise and bustle	14
Pain	12
Thirst	9
Inability to talk	9
Shortness of breath	6
Being afraid	6

(Because patients could list more than one source of discomfort, the summation of percentages exceeds 100%)

Patient Perception in the ICU - 2004

- Hallucinations reported more with increasing patient age
- Pain more reported among younger patients
- Patients also tested for factual recollection during their ICU stay
- The more patients remembered, the more discomfort they reported on the questionnaire

Palliative Care and the ICU



- Patients have many sources of discomfort in the ICU, the most frequently reported being an ET, hallucinations and medical activities
- What do caregivers identify as potential areas for palliative care?

Family Perception in the ICU

- Mularski et al. 2005
- 94 family members of 38 decedents
- Retrospective study using the Quality of Death and Dying Questionnaire (QODD)
 - Rate 0-10
 - 0 = terrible experience, 10 = perfect

QODD

- Symptoms and personal care
- Preparation for death
- Family concerns
- Discuss EOL care wishes
- Whole person concerns
- Moment of death

Family Perception in the ICU

- Higher QODD scores associated with pain and event control and ability to prepare for death
- Quality of moment of death 67/100
- ICU as place of death 61/100
- Quality of life last 7 days 32/100
- 47% reported family member's pain under control most or all of the time
- 3% felt their family member was breathing comfortably most or all of the time
- Only 8% felt they had control of events

What Factors do Families Identify as Important for a Quality Death?

- Glavan et al. 2008
- Chart review and survey of 340 family members of patients who died in the ICU at 10 Northwest hospitals
- Higher QODD scores associated with
 - documentation of a living will, documentation of patient's wishes
 - presence of family member at death
 - withdrawal of tube feeding or life support

Family Satisfaction with Decision Making

- Gries et al. 2008
- Survey of 356 families of patients from 10 medical center ICUs in the Seattle area
- Family satisfaction associated with
 - withdrawal of life support
 - documentation of physician recommendations to withdraw life support
 - discussions of patient's wishes
 - discussing spiritual needs

PTSD Among Family Members

- Kross et al. 2011
- Previous studies had looked at family member characteristics that put them at risk for psychological stress after death
 - Being involved in decision making, female, lower educational level, knowing patient for shorter amount of time
- Kross et al. looked at patient characteristics and patient care characteristics
- Cohort study of 15 hospitals in WA

PTSD Among Family Members

- 226 family members mailed surveys 6 months after death
- Family members were assessed using a PTSD symptom questionnaire and Patient Health Questionnaire 8
- Prevalence of PTSD was 14%
- Prevalence of depression 18.4%
- Older patient's family members had lower PTSD scores

PTSD Among Family Members

- Family members present at time of death and who had a conference within 72 hours of ICU admission had higher PTSD scores
- Family members of patients with withdrawal orders for mechanical ventilation had lower depression scores

Palliative Care and the ICU



- Family members report symptoms of PTSD and depression from the experience of having a family member die in the ICU
- Caregivers also identify pain control, dyspnea and communication as areas for improvement
- Higher satisfaction associated with living will, documentation of patient's wishes, family member presence, discussion of spiritual needs

Conclusions

- Palliative care plays an important role in improving the quality of life of patients and their family members in the ICU
- The nature of ICU work makes it difficult to predict which patients will have good outcomes
- Because of this clinicians must continually be in communication with the families and patients, reassessing their wishes at regular intervals

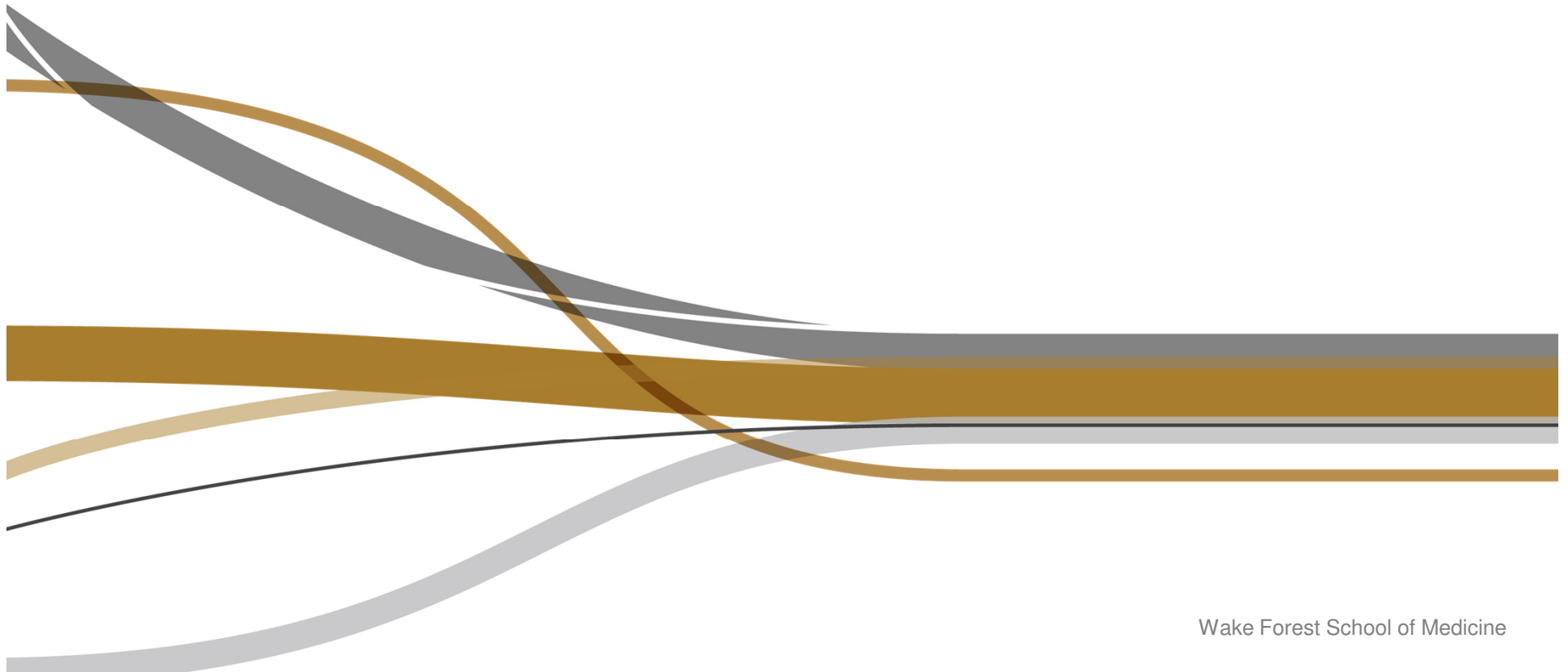
Conclusions

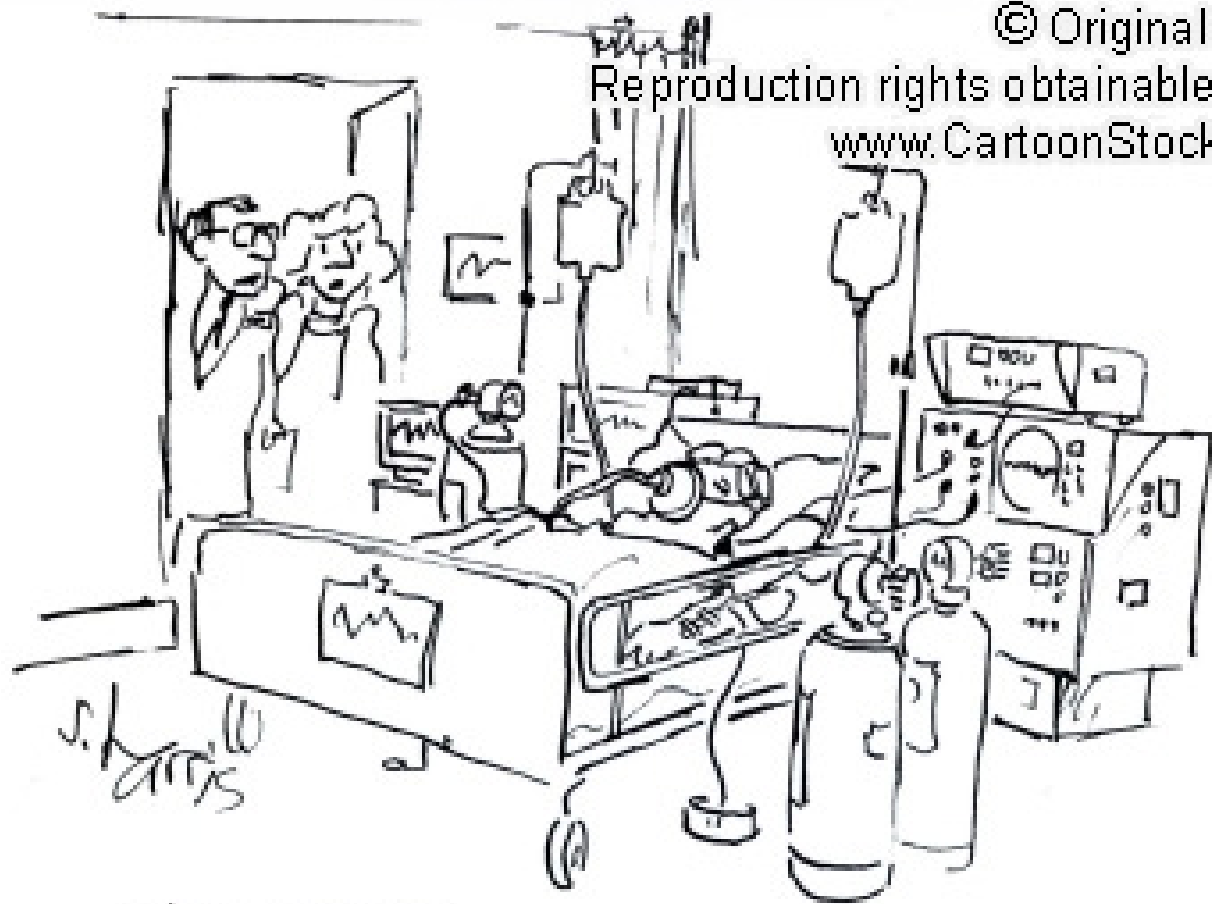
- Clinicians must try to modify their practices to create a better environment for patients and their families
- Patients and families identify pain and dyspnea as symptoms that need to be assessed every day
- Trying to minimize medical activities, preparing for death, discussing a living will, and spiritual needs help families and patients cope

Conclusions

- Families report less PTSD symptoms and more satisfaction with death when withdrawal of life support has occurred
- Family members are more satisfied when present at time of death, but this does not apply to everyone as some family members have increased PTSD symptoms if present at death
- As always, a continuous reassessment of the patient's wishes is very important

Approaches to Palliative Care in the ICU





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"HE'S RESTING
COMFORTABLY."

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After SUPPORT (1996)...

- 1998 End-of-Life Care in the ICU Working Group established to develop a national agenda for improving care of patients dying in the ICU
- Ethics committee of Society of Critical Care Medicine published recommendations for EOL care in the ICU
- American Academy of Critical Care Medicine published a consensus document for improving EOL care in the ICU

IPAL-ICU Project

- NIH and Center to Advance Palliative Care (CAPC) combined to start the IPAL-ICU project
- Portfolio with improvement tools for integrating palliative care into the ICU, quality improvement of palliative care in the ICU
- Improvement tools include progress notes for family discussions, QA nurse surveys, physician surveys

THE IPAL PROJECT

IMPROVING PALLIATIVE CARE

JUMP TO ANOTHER IPAL PROJECT:

IPAL-EM

Improving Palliative Care
in Emergency Medicine

IPAL-ICU

Improving Palliative Care in the ICU

IPAL-ICU Portfolio

Improvement Tools

Patient & Family Resources

Reference Library

Professional Education

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Welcome

Little more than a decade ago intensive care and palliative care were thought to be mutually exclusive; they were seen as sequential approaches to critical illness. Today we recognize that from the time of admission to the ICU, all critically ill patients and their families should benefit from palliative care. Palliative care should therefore be provided concurrently with intensive care therapies.

IPAL-ICU was designed to provide a central venue for sharing expertise, evidence and tools, along with links to colleagues, organizations and informational materials. The goal is to assist ICU and hospital leaders, as well as clinicians across disciplines, to integrate palliative care and intensive care successfully.

Implementing this integrated paradigm in day-to-day practice is an important, ongoing challenge. With support from the National Institutes of Health (NIH) and the Center to Advance Palliative Care (CAPC), we have created IPAL-ICU to help.

Take advantage of [guidance](#) from our experts and explore our website. If you have innovative resources you would like to share, please contact us at ipalicu@mssm.edu.

Join the Discussion

Share information, get advice and exchange

ideas through our faculty-moderated forum at [CAPCconnect™](#).

THE IPAL PROJECT

IMPROVING PALLIATIVE CARE

IPAL-ICU

Improving Palliative Care in the ICU

[IPAL-ICU Portfolio](#)

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JUMP TO ANOTHER IPAL PROJECT:

IPAL-EM Improving Palliative Care
in Emergency Medicine

Improvement Tools

Clinicians and administrators at the front lines of patient and family care have come up with creative ways to facilitate ICU palliative care improvement. IPAL-ICU shares (with permission) a representative group of tools developed by colleagues at a range of institutions across the country, as well as some by our Project Team.

Templates/Forms

 [Critical Care Progress Note Template \(NSLIJ\)](#)

 [Family Conference Progress Note for EMR \(VA VISN 3\)](#)

 [Family Conference Progress Note \(Froedert Hospital\)](#)

 [Family Conference Progress Note \(Central Baptist\)](#)

Quality Monitoring Tools

 [VHA, Inc. Care and Communication Bundle of ICU Palliative Quality Measures](#)

 [Data Collection Tool for Use with the VHA Care and Communication Bundle](#)

 [ICU Palliative Care Quality Assessment - Nurse Survey](#)

 [ICU Palliative Care Quality Assessment - Physician Survey](#)

 [Clinician Satisfaction Survey \(Ann Arbor VA\)](#)

THE IPAL PROJECT

IMPROVING PALLIATIVE CARE

IPAL-ICU

Improving Palliative Care in the ICU

IPAL-ICU Portfolio

Improvement Tools

[PATIENT & FAMILY RESOURCES]

Reference Library

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JUMP TO ANOTHER IPAL PROJECT:



Improving Palliative Care
in Emergency Medicine

Patient & Family Resources

In study after study, ICU patients and families have stressed the need for information about their clinical care and the decisions they face. Here are a variety of valuable materials that clinicians can provide, along with direct communication, to help meet this important need.

Your Healthcare Team Meeting (Information for ICU Families)-Clarian Health

This leaflet was prepared for families of patients receiving ICU care in Clarian Health Partners hospitals in Indiana. Clarian participated in the Transformation of the ICU Project of the Voluntary Hospital Association, Inc., including the ICU palliative care improvement initiative. The leaflet is intended to prompt families to request and to prepare for a meeting with the healthcare team.

Meeting with the ICU Team: a Guide for Families

The ICU Palliative Care Initiative by Veterans Integrated Service Network 3 sponsored development of this guide to help families prepare for a meeting with the ICU team. The guide encourages families to gather relevant information and materials, focus on specific topics (examples provided), and write down questions for clinicians. The intent is to make ICU family meetings more effective and efficient.

Mount Sinai Medical ICU Family Information Brochure

In 2002, Azoulay et al. reported results of a randomized controlled trial showing that a family information leaflet was associated with greater comprehension and satisfaction among ICU families in France (Am J Respir Crit Care Med. 2002; 165:438-42). Based on the leaflet used in that trial, this brochure was designed for a U.S. medical ICU.

Frequently Asked Questions in the ICU

This booklet is for ICU families "who are facing a stressful situation with a loved one." It can be purchased from the American College of Chest Physicians, with bulk discounts.

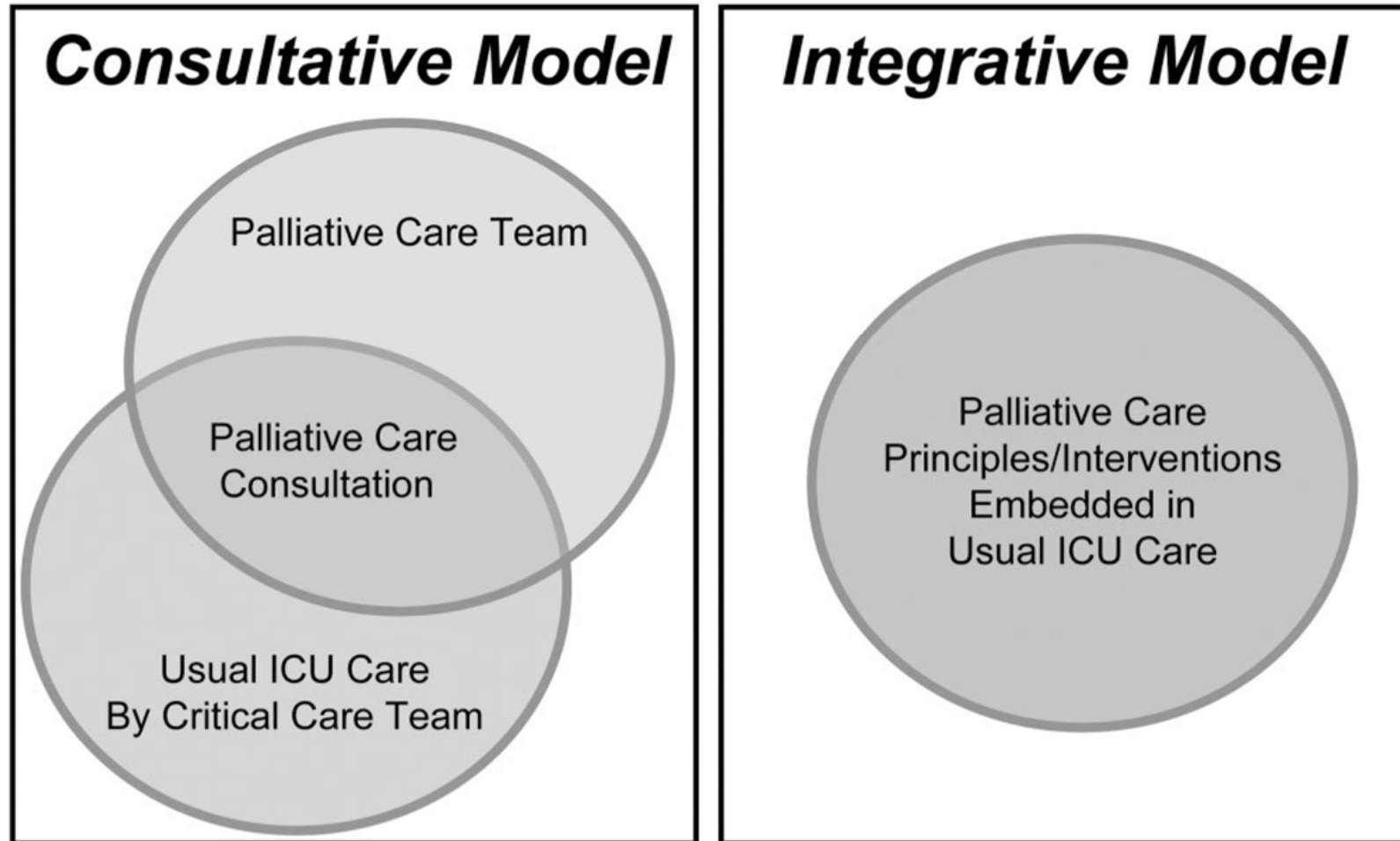
Stories at the End of Life

Palliative Care and the ICU



- In the past 10 years, many initiatives have been started for incorporating palliative care into the ICU
- How do these initiatives see palliative care being implemented into the ICU?

Models for Structuring An ICU-Palliative Care Initiative



Consultative Model Nelson et al. 2010

- Available at >75% of hospitals in the US
- Staffed by hospice and palliative care doctors and nurses
- Applied to a subset of patients in the ICU at risk for worse outcomes
- Many ICUs use triggers for palliative care consultation
- Some ICUs have a palliative care physician who rounds with the ICU team

Consultative Model

- Robert Wood Johnson Foundation Critical Care End-of-Life Peer Workgroup identified key domains for palliative care consults
 - Patient and family centered decision making
 - Communication
 - Continuity of care
 - Support, emotional, spiritual for families, patients and ICU clinicians
 - Symptom management

Integrative Model

- Because of the high rates of mortality and morbidity in the ICU, many believe ICU clinicians should integrate palliative care principles into daily practice
- Critical competencies identified by Society of Critical Care Medicine, ATS, ABIM
- Integrative model requires increased education and new systems of care (tools, order sets, guidelines)

Integrative Model

- American College of Critical Care Medicine provides recommendations for end-of-life care in the ICU
 - Focus on family centered care
 - Asking families how they prefer to make decisions
 - Identifying goals and resolving conflict
 - Communication with families

Care and Communication Bundle

By ICU day 1

- Identify medical decision maker
- Address advance directive status
- Address resuscitation status
- Distribute family information leaflet
- Assess pain regularly
- Manage pain optimally

By ICU day 3

- Offer social work (emotional/practical) support
- Offer spiritual support

By ICU day 5

- Conduct interdisciplinary family meeting

Consultative vs. Integrative

- Consultative model
 - Pros - expertise, continuity of care
 - Cons - need extra staff, conflicts can arise between teams, ICU team has less incentive for knowledge
- Integrative model
 - Pros - availability, systematization promotes reliability
 - Cons - additional education, depends on commitment of ICU team, requires hand-offs

Palliative Care and the ICU



- The consultative and integrative models are examples of how to incorporate the process of palliative care into the ICU
- What specific actions can clinicians perform to fully incorporate palliative care into the ICU?

What Families Need

Prendergast et al. 2002

Box 3. A Dozen Needs of the Family in the Setting of Critical Illness

- To have questions answered honestly
- To know specific facts about what is wrong with the patient
- To know the prognosis for recovery
- To be called at home about changes in the patient's status
- To receive information from the physician (at least) once daily
- To receive information in understandable language
- To believe that hospital personnel care about the patient
- To be assured of the patient's comfort
- To be comforted
- To express emotions
- To find meaning in the death of their loved one
- To have the opportunity to eat, drink, and sleep

Ways for Clinicians to Improve

- Personalize the patient's environment (pictures, blankets, etc)
- Visit and communicate with patient
- Encourage sharing of the patient's story
- Ensure privacy for the patient and family
- Make sure tissues and chairs are available
- Be available for support
- Have family members participate in various aspects of care (eg, bathing, hair combing)

Ways for Clinicians to Improve

- Listen, use clear language, explain everything in lay terms
- Explain prognosis and implications
- Anticipate emotion
- Help with the transition from aggressive goals to end-of-life, palliative care goals
- Work with clinical nurse specialists, social workers, pharmacists, clergy
- Allow family to be present

Palliative Care and the ICU



- Many resources recommend ways for clinicians to interact with families to promote palliative care in the ICU
- What systems make a difference in the lives of families of patients who die in the ICU?
- How do ICU clinicians assess their palliative care competencies?

Communication Strategy and Brochure for Relatives of ICU Patients

- Lautrette et al. 2007
- 2007 prospective RCT of 126 patients dying in ICUs in France
- Family members interviewed 90 days after death and used the Impact of Event Scale (IES) and Hospital Anxiety and Depression Scale
- Experimental group received a brochure and end-of-life conference

Communication Strategy and Brochure for Relatives of ICU Patients

- Experimental group had lower IES score and lower rate of PTSD symptoms (45% vs 69%)
- Family conference length increased from 20 to 30 minutes
- Amount of time family members talked increased from 5 to 14 minutes

Communication Strategy and Brochure for Relatives of ICU Patients

- End-of-life conference mnemonic
 - V- value and appreciate family member input
 - A- acknowledge emotions
 - L- listen
 - U- ask questions to allow caregiver to understand who the patient was as a person
 - E- elicit questions from family members

Assessment of Self-Perceived EOL Competencies of ICU Providers

- Montagnini et al. 2012
- 185 ICU staff members in Milwaukee received a Scale of End-of-Life Care questionnaire
- Sample size included 40% nurses, 27% physicians
- Physicians: 52% IM, Pulm/ICU 28%, GenSurg 20%
- 70% of ICU staff had previous education on EOL care

Assessment of Self-Perceived EOL Competencies of ICU Providers

- Questionnaire included:
 - Demographic information
 - Self perceived knowledge, attitudes and behaviors
 - Family and patient decision making, communication, continuity of care, emotional and practical support, symptom management, spiritual support, emotional and organizational support for ICU clinicians

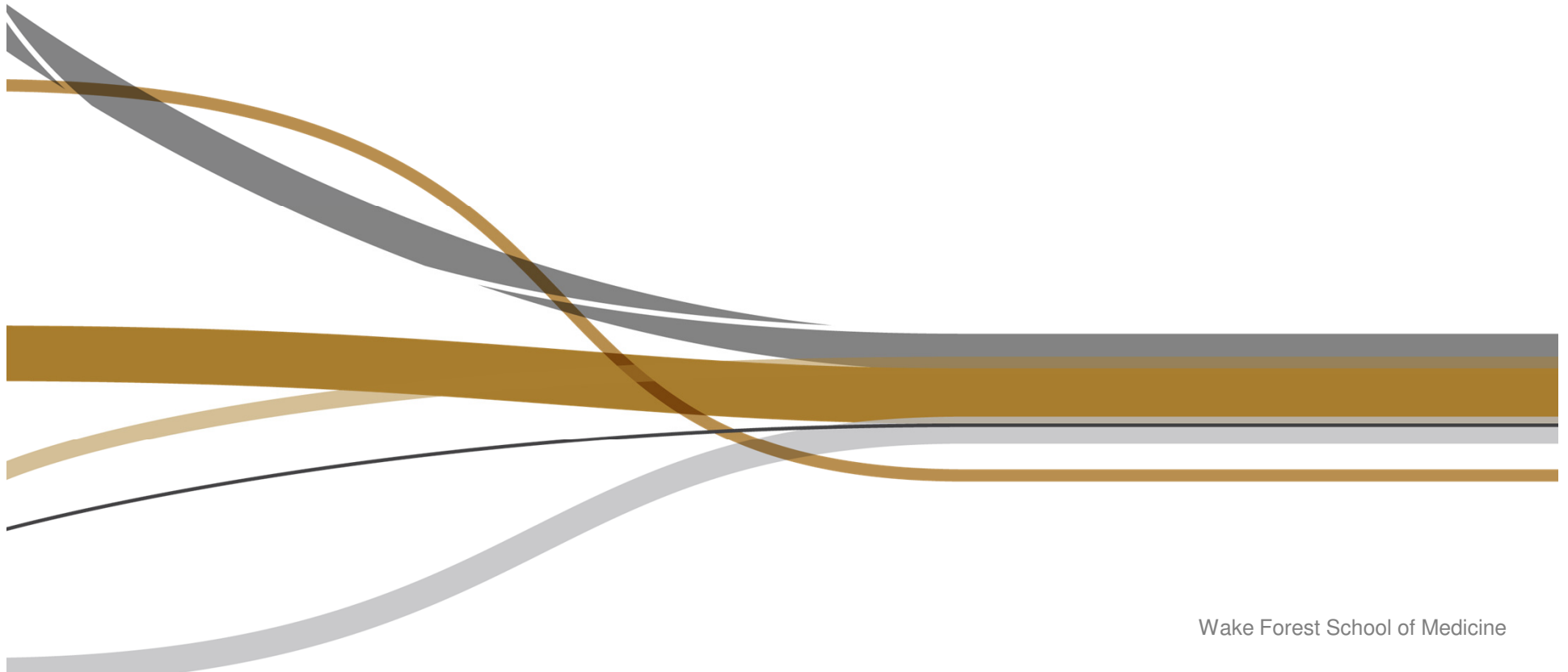
Assessment of Self-Perceived EOL Competencies of ICU Providers

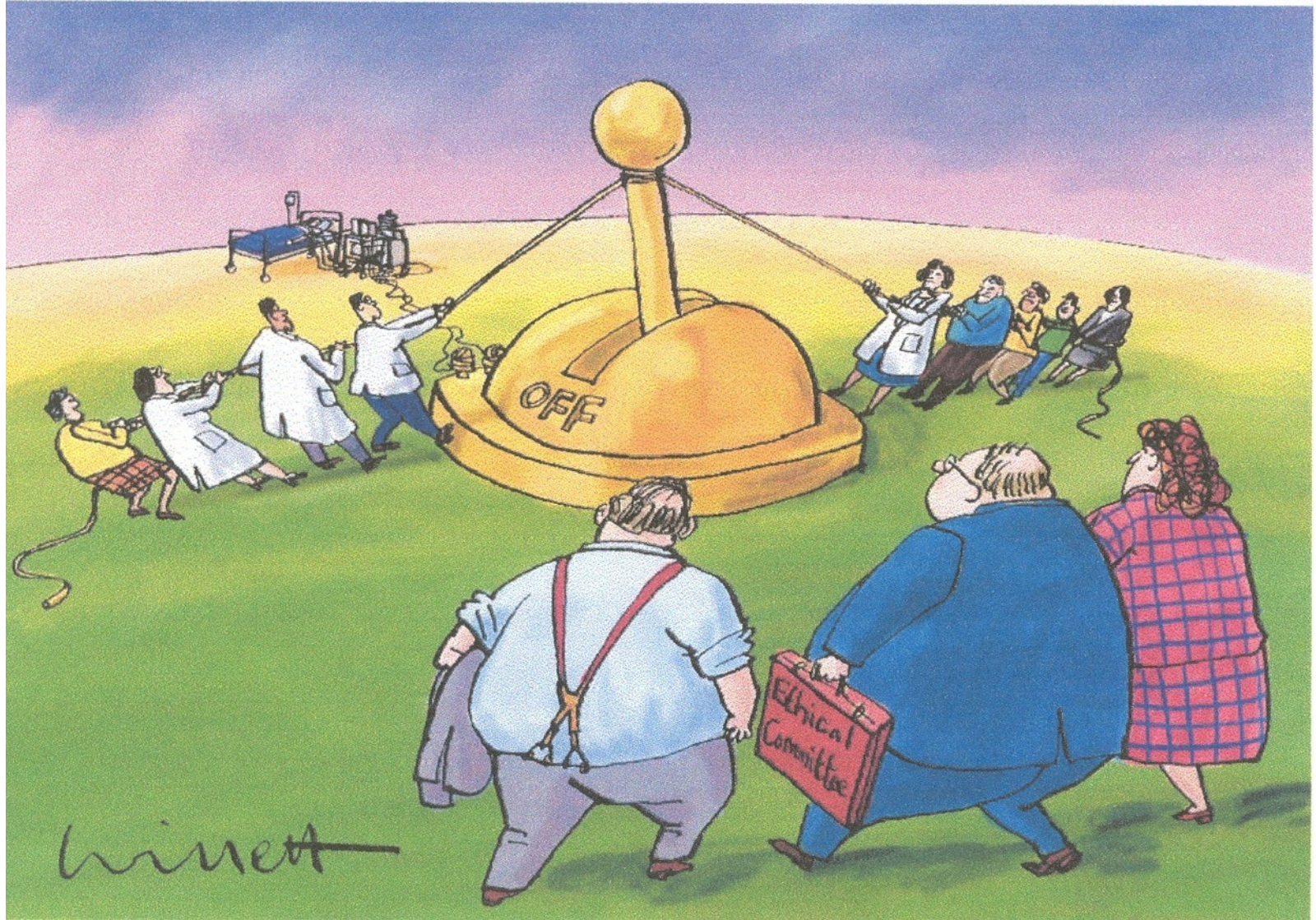
- Greatest self-perceived competence in patient and family support
- Least competence in continuity of care, staff support, communication
- Positive correlation between years in practice and family/patient support competency
- Surgeons reported less knowledge of EOL care, less confidence in EOL decision making, and less confidence with spiritual support than IM physicians

Conclusions

- There are many resources and initiatives for improving palliative care in the ICU
- The integrative and consultative models provide two different examples of integrating palliative care into the ICU
- Although there are guidelines and recommendations for clinicians, there are still many areas for educational improvement
- Adding 10-20 minutes a day to spend with the family of those dying can make a big difference

Withholding and Withdrawing Treatments in the ICU





Language Matters

- Language Matters: *“Sometimes We Withdraw Treatment but We Never Withdraw Care”*
- 2007 editorial in J Palliat Med
- Be careful of word choice in communicating with families

Consensus Statement from Am Col Crit Care Med

- Three ethical principles shape the current consensus
 - Withholding and withdrawing life support are equivalent
 - There is a difference between killing and allowing to die
 - “Double effect” doctrine: relief of pain and symptoms with sedatives that may have the foreseen but not intended consequence of hastening death

Families Reasons to Refuse Withdrawal of Life Support

- Prendergast et al. 2002
- Mistrust of medical professionals
- Poor communication
- Guilt
- Cultural, religious, scientific views

Practical Aspects of Withdrawing Life Support

- IPAL-ICU report
- Communication with families and preparing them for the withdrawal process
 - normal respiratory patterns
- Assist families in the dying process, provide quiet environment
- Remove and turn off all monitors
 - Discuss with family

Practical Aspects of Withdrawing Life Support

- Reevaluate therapies such as antibiotics, dialysis, pressors, etc
- Abrupt discontinuation of life sustaining treatments (except mechanical ventilation) does not cause discomfort, so do not wean
- Mechanical ventilation can be gradually reduced to allow for titration of medications for dyspnea

Practical Aspects of Withdrawing Life Support: Mechanical Ventilation

- ET tube: proven source of discomfort, so remove after discontinuation of ventilator
- Decide timing based on family/patient/clinician preferences
- Noninvasive ventilation may be used for dyspnea, but discontinue if no longer providing relief

Practical Aspect of Withdrawing Life Support: Mechanical Ventilation

- Do not use neuromuscular blockers (NMBs) to hide symptoms from family
- If patient has been on paralytics
 - Can allow time for reversal
 - If long duration of action or renal/hepatic failure, balance benefits vs risks and adjust medications, knowing that signs of discomfort will be hard to see

Practical Aspect of Withdrawing Life Support: IPAL-ICU Resources

- Provides withdrawal of life support orders
- Helps to prompt documentation, along with removal of all monitors, analgesia, sedation

IPAL-ICU Withdrawal Orders

1. Initial ventilator setting: IMV rate ___, PS level ___, (choose IMV or PS, not both), FiO₂ ___, PEEP ___.
2. Reduce apnea, heater, and other ventilator alarms to minimum setting.
3. Reduce FiO₂ to room air and PEEP to zero over <5 minutes and titrate sedation as indicated for discomfort.

IPAL-ICU Withdrawal Orders

4. As indicated by level of comfort, wean IMV to 4 or PS to 5 over 5-20 minutes; titrate sedation for comfort.
5. When patient is comfortable on IMV rate 4 or PS of 5, select one:
 - Extubate patient to air
 - T-piece with air (not CPAP on ventilator)

Palliative Care and the ICU



- There are guidelines and many examples of order sets, progress notes, and checklists for withdrawal of life support
- How do practices differ based on the facility and what do families say about their experience after withdrawal of life support?

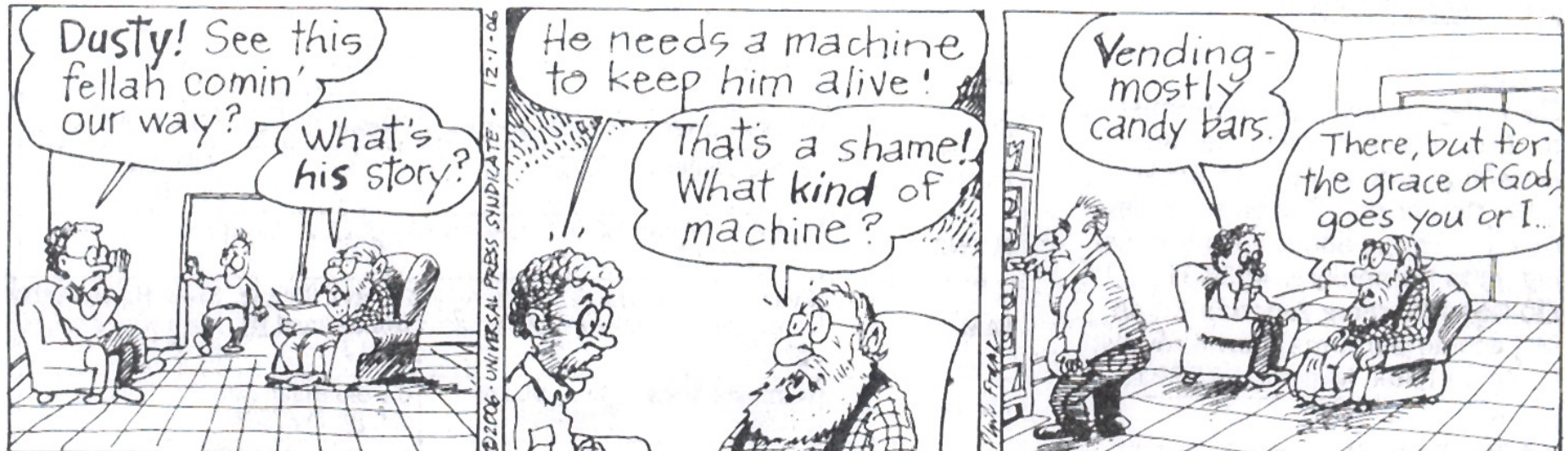
Comparison of LTACH vs MICU Withdrawal of Mechanical Ventilation

- White et al. 2009
- LTACH patients more likely to have health care proxy than ICU patients
- Decision for withdrawal more likely to be initiated by patient/family in LTACH, staff in ICU
- LTACH had more involvement of social work and pastoral care in the decision making process
- Doses of benzodiazepines greater in ICU in final 24 hours of life

Families Looking Back: One Year After Withdrawal or Withholding

- Abbott et al. 2001 study of 98 family members of ICU patients at Duke hospitals
- 46% reported conflict (DNR decision in front of patient, other communication problems)
- Reported a need of space for conferences
- More liberal visitation policy
- Increased continuity of care: 48% named the attending, and noted the importance of communicating with the physician 'in charge'

ELDERBERRIES



Conclusions

- Many families have reasons for not choosing to withhold/withdraw life support
- Communication can help alleviate conflict
- During the process of withdrawing life support ICUs must modify the environment for the patient and the family
 - Turn off machines
 - Provide a quiet and peaceful environment
 - Ensure all symptoms are managed
 - Involve social work and chaplains

Conclusions

- 20% of Americans die in the ICU every year, so palliative care should be a priority in the ICU
- The integrative and consultative care models provide a starting point for incorporating palliative care in the ICU into an institution, but an optimal ICU incorporates both models
- There are many resources for order sets, brochures and other quality improvement measures to increase palliative care in the ICU, available to clinicians



Why Doctors Die Differently

- “It's not something that we like to talk about, but doctors die, too. What's unusual about them is not how much treatment they get compared with most Americans, but how little. They know exactly what is going to happen, they know the choices, and they generally have access to any sort of medical care that they could want. But they tend to go serenely and gently.”



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