Palliative care

Clinical year in review 2016

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American Thoracic Society

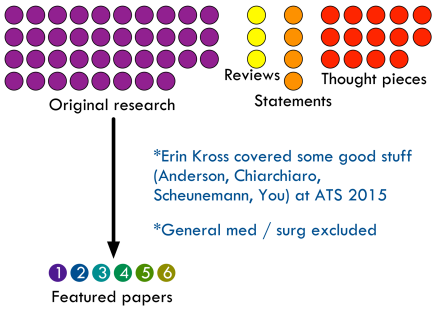
Session Faculty Disclosure

Christopher Cox

1. **Relevant financial relationships with a commercial interest:**
   No relevant commercial interests. NIH, PCORI.

We help the world breathe

Highly scientific general strategy for CYIR manuscripts



Palliative medicine	Palliative care	Hospice care
Subspecialty focused on improving QOL	Care focused on improving QOL Any age, diagnosis, or stage of illness	Care focused on improving QOL <6 month survival

…the right care
to the right people
at the right time

What does the field **need now** to deliver on its mantra?

ORIGINAL RESEARCH

Medical Record Quality Assessments of Palliative Care for Intensive Care Unit Patients
Do They Match the Perspectives of Nurses and Families?

Richard A. Mularski[1,2], Lissi Hansen[2], Susan J. Rosenkranz[2], Michael C. Leo[1], Paula Nagy[2], and Steven M. Asch[3]

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Cultures & systems

1

Cook D, Swinton M, Toledo F, Clarke F, Rose T, Hand-Breckenridge T, Boyle A, Woods A, Zytaruk N, Heels-Ansdell D, Sheppard R.

Personalizing death in the intensive care unit: The 3 Wishes Project.

Annals of Internal Medicine 163:271-279.

1 Background

Problem

End of life care in the technology-centered ICU environment

- dehumanizing for patients
- stressful for families
- induces clinician burnout

Question

How can we re-humanize the situation—including all stakeholders in the process?

1 Methods: design & population

Design

Uncontrolled, prospective intervention study in a single ICU.

Population

40 Patients	**50 Family members**	**120 Clinicians**
Prob. death >95%	56 yo (mean)	37 yo (mean)
W/d planned	58% female	65% female
	generally Catholic/ protestant	generally Catholic/ protestant

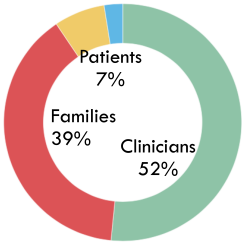
1 Methods: intervention

'3 wishes' designed to honor the patient…

Elicited by team or clinician

…documented

…and then implemented.



1 Methods: outcomes

Semi-structured interviews / thematic analysis

Families *[112d from patient death; 73% in-person]*

Clinicians *[15d from patient death; 99% in-person]*

Quality of End of Life-10 scale

Families

1 Results: examples and implementation

1 Humanizing the environment
-recreating date night in ICU
-using nicknames

2 Personal tributes
-planting tree in honor
-providing family supper in ICU

3 Family reconnections
-locating estranged family
-mom in bed with son as he dies

4 Rituals /observances
-renewal of wedding vows
-ballon release with message

5 Paying it forward
-family volunteers
-organ donation
-family gift to future families

Success
-98% of wishes were implemented
-50% before death
-most with little expense

arginated from:

1 Results: impact on personalizing care

Quality of End-of-Life Care-10 scale identified three central domains reflecting how the 3 Wishes intervention personalized care:

1 Dignifying the patient

The simplicity of the whole project, yet the depth of it. . . . This project does force everyone to really look deep inside at . . . how they . . . might feel about end-of-life . . . this is putting the absolute human side [into] the whole experience. I think this project is so pow-erful. [nurse]

1 Cook: comments

1. 3 Wishes intervention for dying ICU patients resulted in a **more humanistic experience** for patients, families, and clinicians alike.
2. Relatively simple (though creative) interventions and study designs can be incredibly **powerful and persuasive**.
3. Describing the impact using **narrative** rather than with multivariate statistical analyses is highly effective.
4. Great example of PC intervention led by **generalists** (ICU team).
5. **Limitations:** uncontrolled, diversion of care, sustainability?
6. **Few logistical barriers** to broader implementation.

*Hansen-Flaaschen editorial: 'ICUs must balance resuscitation, rehab, and palliation'

2

Curtis JR, Treece PD, Nielsen EL, Gold J, Ciechanowski PS, Shannon SE, Khandelwal N, Young JP, Engelberg RA.

Randomized trial of communication facilitators to reduce family distress and intensity of end-of-life care.

Am J Resp Crit Care Med. 2016 193:154-162

2 Curtis: background

Problem

Poor communication quality in ICUs is common and has a negative impact on family outcomes.

Question

Improve family outcomes by using a communication facilitator to enhance the clinician-family interaction?

2 Curtis: design & outcomes

Design

Two-center **RCT** comparing intervention vs. usual care among 306 family members of adult ICU patients w/ 30% predicted mortality

Primary outcome

Adjusted depression symptoms (PHQ-9) at 3 *and* 6 months

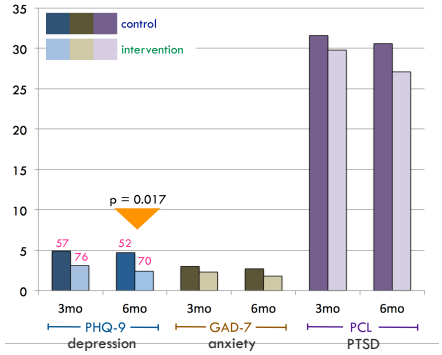
Hospital	3 months	6 months
PHQ-9	PHQ-9	PHQ-9
GAD-7	GAD-7	GAD-7
PCL	PCL	PCL
LOS		
Costs		

2 Curtis: intervention

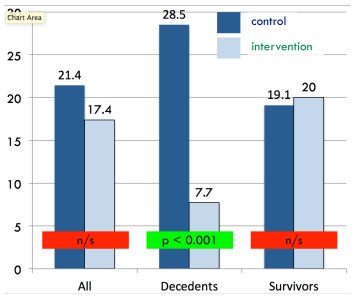
Communication facilitators:
- highly trained nurse and a social worker
- aimed to increase self-efficacy expectations using 5 strategies:

family interviews to understand needs, concerns, and communication characteristics	clinician meetings to summarize family concerns, needs, and communication styles	providing communication and emotional support aligned with family attachment style	family conference participation	follow up with family 24 hrs after patient discharge

2 Curtis: results—psychological distress symptoms



2 Curtis: results—LOS & costs lower for decedents



2 Curtis: comments

1 **View A:** Communication facilitator reduced 6-month (not 3-month?) depression symptoms as well as LOS and costs among decedents.

2 **View B:** Non-physician providers reduced EOL care intensity without worsening family members' distress.

3 Focuses on a **3rd party** rather directly on clinician communication

4 **Limitations** include a high dropout rate (>40%) and the potential difficulties of intervention scaling.

5 Note the challenging **emotional / grief context** that investigators navigated to conduct this 6-month study.

The Kentish-Barnes & Azoulay editorial is a great companion piece.

3

Braus N, Campbell TC, Kwekkeboom KL, Ferguson S, Harvey C, Krupp AE, Lohmeier T, Repplinger MD, Westergaard RP, Jacobs EA, Roberts KF, Ehlenbach WJ.

Prospective study of a proactive palliative care rounding intervention in a medical ICU.

Intensive Care Medicine. 42:54-62.

3 Braus: background

Problem
Guidelines recommend integrating palliative care in the ICU. However, there are few examples of feasible collaborative (i.e., generalist-specialist) models.

Question
Can the presence of a palliative care clinician on daily ICU rounds improve patient and family outcomes?

3 Braus: design & outcomes

Design
Before / after (6mo each) in single medical ICU

Primary outcome
% of patients with documented ICU family meeting

Secondary outcomes
LOS & mortality
family satisfaction (3mo)
family depression and PTSD symptoms (3mo)
family QODD summary item (3mo)

3 Braus: intervention

Intervention intent: 'to prompt the ICU team to consider patients' and families' palliative care needs'

Triggers* to identify patients at high risk of unmet palliative care needs

What **was** done in intervention:
- Palliative care specialist (nurse) would participate in rounds
- Specialist would make suggestions about addressing needs
- Specialist would recommend timely family meetings

What **was NOT** done in the intervention:
- Formal palliative care consultation was not routinely provided
- Specialist didn't routinely interact with families or participate in meetings

*adapted from Norton SA et al.

3 Braus: results—before & after groups similar

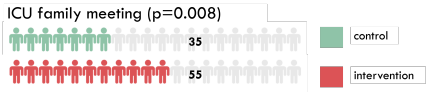
100 (before) and 103 (after) patients were similar:

General characteristics p>0.05
- age ~60
- white
- trigger criteria:
  - cardiac arrest
  - ward >10 days before ICU
  - ventilator >7 days
  - age >80 + comorbidities

Mortality ~28% p>0.05

Palliative care consultation ~20% p>0.05

3 Braus: results—more family mtgs w/ intervention



56% of all patients had no family meeting documented.

3 Braus: results—secondary outcomes

Length of stay
- No difference overall (p=0.22)
- Among decedents:
  - intervention w/19% ICU LOS reduction (p=0.04)
  - intervention w/26% hospital LOS reduction (p<0.001)

Questionnaire-based outcomes (40% dropout)
- No difference by group
  - PTSD and depression symptoms
  - satisfaction
  - quality of dying and death

3 Braus: comments

1. Non-physician, collaborative palliative care intervention was associated with **more timely family meetings.**
2. Lower LOS among intervention decedents with this less intensive intervention is **comparable to more complex** interventions.
3. Shows the importance of crafting interventions that **complement hospital culture** and clinician workflow.
4. **Limitations** include relatively small sample size (likely the *p* value problem), single center design, before/after methodology, and potential difficulty scaling.

4

Hart JL, Harhay MO, Gabler NB, Ratcliffe SJ, Quill CM, Halpern SD.

Variability among US intensive care units in managing the care of patients admitted with preexisting limits on life-sustaining therapies.

JAMA Internal Medicine. 175:1019-1026.

4 Hart: background

Context & problem
Variability in EOL / ICU care exists generally. Yet little is known about those with similar preferences for EOL care.

Question
How much hospital variability exists in the care of patients with previously expressed treatment limitations (TLs) who are admitted to ICUs?

4 Hart: methods

Design
- Retrospective cohort study in Project IMPACT database
- 277,693 ICU patient visits between 2001 - 2008

Outcomes
Proportion of TL patients…
among all ICU admissions
who received CPR and life support
who had reversals of TL in ICU

4 Hart: results

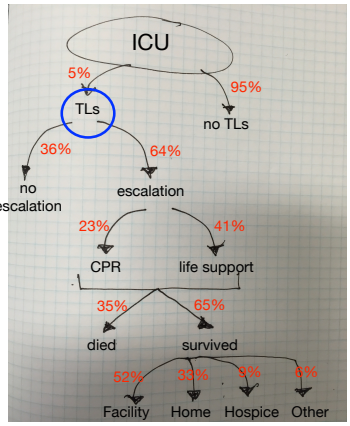
Patients with treatment limitations
- 78 years old, median
- 60% had ADL dependencies
- 77% were DNR

Setting
- 141 ICUs in 105 hospitals
- ICUs with 1% to 21% (4% median) patients w/ TLs

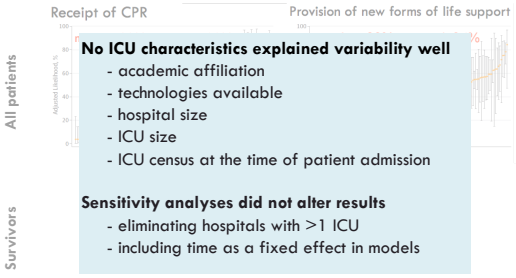
4 Hart: results

Glass half full:
- Most survived
- Some went home

Glass half empty:
- 50% needed SNF
- 23% received CPR
- Many with DNRs died after CPR



4 Hart: results—wide variability across >100 ICUs



No ICU characteristics explained variability well
- academic affiliation
- technologies available
- hospital size
- ICU size
- ICU census at the time of patient admission

Sensitivity analyses did not alter results
- eliminating hospitals with >1 ICU
- including time as a fixed effect in models

4 Hart: comments

1 There is **substantial variability** among ICUs in how often aggressive measures are provided to patients with treatment limitations (TLs).

2 Treatment limitation status shouldn't drive **ICU triage decisions**…rather a discussion about values & goals.

3 Opportunities exist to **improve care quality** based on (a) high rates of discordant care, (b) frequent reversals of TLs, and (c) unexplained variability among ICUs.

4 A few **grains of interpretional salt**:
- What are appropriate frequencies of TL reversal?
- Reversals informed by shared decision making?
- Proportions don't reflect changes in illness, preferences, etc during admission
- Is 2016 practice the same as the study period (2001-2008)?
- Does **institutional culture** drive these ICU behaviors? Let's dig deeper…

Editorial by Barnato & Dzeng is really great.

5

Dzeng E, Colaianni A, Roland M, Chander G, Smith TJ, Kelly MP, Barclay S, Levine D.

Influence of institutional culture and policies on do-not-resuscitate (DNR) decision making at the end of life.

JAMA Internal Medicine. 175:812-819.

5 Dzeng: background

Context
Patient **autonomy** vs. best interest (**beneficence**) matters in DNR decision making because:

- Autonomy emphasis: oversimplification, unsupportive?
- Beneficence emphasis: physician-centered, biased?

Question
Does institutional culture (i.e. autonomy vs. best-interest priority) shape:

- physicians' approaches to DNR decision making at the end of life
- development of trainees' approach to EOL communication

5 Dzeng: design & methods

Autonomy (n=29)

Physicians were purposively sampled by age, experience, and specialty.

Authors conducted qualitative analysis of semi-structured, in-depth, open-ended **interviews**.

5 Dzeng: key interview content

1. **Institutional policies and culture:**
   - Understanding of hospitals official policy re: DNR / conflict?
   - What do people usually do at your hospital re: DNR decisions?
2. **Attitudes and beliefs:**
   - How do you feel about the current approach you take to DNR orders?
   - Recommend when treatment is unlikely to work?

5 Dzeng: results—culture reflected by responses

Autonomy (n=29)

Hospital **A:** US Northeast

'…it's not our job to dictate what exactly you should do…it's their decision.'

Hospital **B:** US Mid-Atlantic

'I often see [housestaff] taking overwhelmed families and giving them a long list of therapies to approve or disapprove.'

Best-interest (n=29)

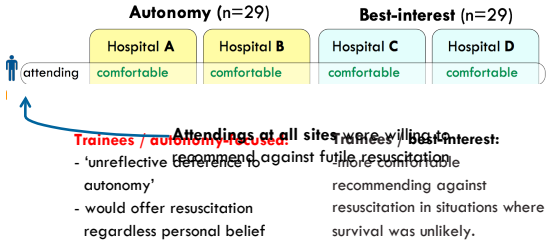
Hospital **C:** US Northwest

'If it's not in the patient's best interest, we shouldn't be offering it.'

Hospital **D:** UK East

'I feel a responsibility not to offer…treatments for which [patients] are unlikely to benefit.'

5 Dzeng: results—respondents views on discussing treatment that is unlikely to work



Trainees / autonomy-focused:
- 'unreflective deference to autonomy'
- would offer resuscitation regardless personal belief

Trainees / best-interest:
more comfortable recommending against resuscitation in situations where survival was unlikely.

5 Dzeng: comments

1 **Hospital culture** influences approaches in DNR decision making:
- **Attending physicians'** approach did not differ by culture
- **Trainees'** approach differed from their own supervising physicians' in autonomy-dominated cultures

2 Important because **DNR more frequently chosen** when framed as the norm as could be the case in autonomy-focused cultures.

3 Given how commonly trainees conduct DNR discussions, a new **intervention target** has now been defined.

Excellent editorial by Mills and Anderson.

6

Choi PJ, Curlin FA, et al.

"The patient is dying, please call the chaplain": The activities of chaplains in one medical center's intensive care units.

J Pain and Symptom Management. 50:501-506.

6 Choi: background

Problem

Spiritual support is a palliative care quality metric and can be provided by hospital chaplains.

Critical illness is often associated with spiritual distress.

Questions

What are the prevalence, timing, and nature of hospital chaplain encounters in adult ICUs?

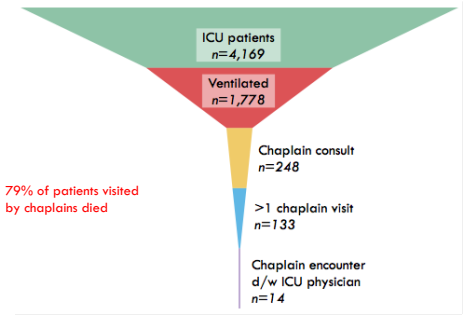
Choi: methods

Setting
Retrospective cohort study at a single academic medical center.

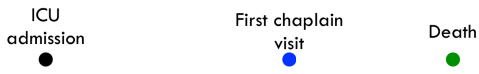
Data source and search strategy
Hospital electronic health record (EHR) was used to identify:
- all adult ICU patients admitted
- during a 6-month period with
- at least 1 note from hospital chaplain

[Search strategy validated using randomly pulled charts and cross-checking with chaplaincy records.]

Choi: results—the spiritual desert of ICU care



Choi: results—chaplain visits happen late in course



Choi: comments

1 Spiritual needs may be **poorly addressed** at some centers:
- Clinicians **incorrectly conceptualize** chaplains' role as 'peri-death providers'—rather than proactive spiritual supporters.
- Chaplain encounters **uncommon**…and too late to give adequate spiritual support…even in a resourced center (divinity school,etc)

2 **Limitations:** retrospective single center design, unclear frequency of spiritual support from a faith leader familiar to the family.

3 Note also the topically-related work of **Ernecoff *et al.*** in the Additional Articles section.

No editorial, had to read it myself…

Intervention studies

Campbell ML, et al. A Two-Group Trial of a Terminal Ventilator Withdrawal Algorithm: Pilot Testing. *J Palliat Med.* 2015;18:781-785.

El-Jawahri A, et al. A Randomized Controlled Trial of a CPR and Intubation Video Decision Support Tool for Hospitalized Patients. *J Gen Intern Med.* 2015;30:1071-1080.

Jenko M, et al. Facilitating Palliative Care Referrals in the Intensive Care Unit: A Pilot Project. *Dimens Crit Care Nurs.* 2015;34:329-339.

Observational studies, 1

Creutzfeldt CJ, et al. Palliative care needs in the neuro-ICU. *Crit Care Med.* 2015;43:1677-1684.

Ernecoff NC, et al. Responses to Religious or Spiritual Statements by SDMs. *JAMA Intern Med.* 2015;175:1662-1669.

Kentish-Barnes N, et al. Complicated grief after the intensive care unit. *Eur Respir J.* 2015;45:1341-1352.

Lautrette A, et al. Impact of no escalation of treatment. *Int Care Med* 2015;41:1763.

Lee JJ, et al. The Influence of Race/Ethnicity and Education on QODD in the ICU. *J Pain Symptom Manage.* 2016;51:9-16.

McKenzie MS, et al. An Observational Study of Decision Making… *Crit Care Med.* 2015;43:1660-1668.

Stotts NA, et al. Predictors of thirst in intensive care unit patients. *J Pain Symptom Manage.* 2015;49:530-538.

Wright AA, et al. Family perspectives on aggressive cancer care near EOL. *JAMA.* 2016;315:284-292.

Observational studies, 2

Chiarchiaro J, et al. Developing a simulation to study conflict in ICUs. *Ann Am Thorac Soc.* 2015;12:526-532.

Colman R, et al. Outcomes of lung transplant candidates referred for palliative care. *Palliat Med.* 2015;29:429-435.

Ganzini L, et al. Family members' views on the benefits of harp music vigils. *Palliat Support Care.* 2015;13:41-44.

Heyland DK, et al. The prevalence of medical error related to end-of-life communication. *BMJ Qual Saf.* 2015.

Long AC, et al. Time to Death after Terminal W/D of Mechanical Ventilation. *J Palliat Med.* 2015;18:1040-1047.

Mitchell IA, et al. Why don't end-of-life conversations go viral? *BMJ supportive & palliative care.* 2015.

Miller SJ, et al. Quality of transition to EOLC care for cancer patients in the ICU. *Ann Int Care.* 2015;5:59.

Nunez ER, et al. Surrogates' Stories About the Decision to Limit Life Support. *Crit Care Med.* 2015;43:2387-2393.

Systematic reviews

Hinkle LJ, et al. Factors Associated With Family Satisfaction With End-of-Life Care in the ICU. *Chest.* 2015;147:82-93.

Khandelwal N, et al. Estimating the effect of palliative care interventions and advance care planning on ICU utilization. *Crit Care Med.* 2015;43:1102-1111.

Mark NM, et al. Global variability in withholding and withdrawal of life-sustaining treatment in the intensive care unit. *Intensive Care Med.* 2015;41:1572-1585.

Notable thought pieces and commentaries

Angus DC, Truog RD. Toward better ICU use at the end of life. *JAMA*. 2016;315:255-256.

Cox CE, Curtis JR. Using Technology to Create a More Humanistic Approach to Integrating Palliative Care into the Intensive Care Unit. *Am J Respir Crit Care Med*. 2016;193:242-250.

Halpern SD. Toward Evidence-Based End-of-Life Care. *N Engl J Med*. 2015;373:2001-2003.

Hansen-Flaschen J. A Practical Approach to Humanizing Care for Patients Who Are Expected to Die in an Intensive Care Unit. *Annals of Internal Medicine*. 2015;163:318-319.

Summary comments: 2016 palliative care CYIR

1 New palliative care-themed research during 2015-2016:
- defined **innovative interventions**
- demonstrated important **future targets** for intervention
- explored new collaborative **care delivery models**

2 A **little closer** to delivering the right treatment, right person, right time [mantra preserved!]

thanks so much

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