A Research Agenda for End-of-Life Care in the ICU

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Famiréa Study Group
Research group on Acute Respiratory Failure in Hematology Patients.
End-of-life care in the intensive care unit: A research agenda

Gordon D. Rubenfeld, MD, MSc; J. Randall Curtis, MD, MPH; for the End-of-Life Care in the ICU Working Group

Table 1. Research agenda for end-of-life care in the intensive care unit (ICU)

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Research Agenda

1. Did we end-up with observational studies?

2. People at stake: nurses versus doctors

3. Interventions

4. Qualitative studies and mixed-methodology studies

5. My 2013-2023 research agenda
Withholding and withdrawal of life support from the critically ill

- Two ICUs, One year (1987 to 1988)
  - Withholding in 22/1719 patients (1%)
  - Withdrawing from 93/1719 patients (5 %).
  - All but 1 died = 45% of all deaths

- Thirteen (11 percent) had earlier expressed the wish that their terminal care be limited, but this affected care in only four cases.

- All but 5 of the 115 patients were incompetent.
- 100% of family participation
- 10 disagreements between clinicians and the relatives

Significant differences across countries regarding:

- Proportion of EOLD in dying patients
- Time from admission to EOLD
- Time from EOLD to discharge or death

End-of-life practices in 282 intensive care units: data from the SAPS 3 database
Family Preferences for ICU Decisions

- 1% family decides (autonomy) 0
- 21% family decides, MD input <5%
- 39% mutual (shared model) 47%
- 24% MD decides, family input 30%
- 15% MD decides (parental) 10-15%

Heyland et al, Intensive Care Med 2003
Azoulay et al, Crit Care Med 2004
Only 2% (1/51) of decisions met all 10 criteria for shared decision making.

The least frequently addressed elements were the family’s role in decision making (31%) and an assessment of the family’s understanding of the decision (25%).
Attitudes and preferences of intensivists regarding the role of family interests in medical decision making for incompetent patients*

George E. Hardart, MD, MPH; Robert D. Truog, MD

- Model 1: INTRUSIVE family interests
- Model 2: DERIVATIVE family interests
- Model 3: INTRINSIC family interests
- Model 4: PURE family interests

Importance of individual interests

Family interests not justified

Importance of family interests

Importance of role of physician as patient protector
Probability of decisions to forego life-sustaining treatments

- No birthday during ICU stay
- Birthday during ICU stay

Crude HR [95% CI] : 0.47 [0.28 - 0.78], p = 0.004

Adjusted HR [95% CI] : 0.45 [0.27 - 0.77], p = 0.003
I Don't Want to Be the One Saying 'We Should Just Let Him Die’

• Qualitative interview study in 30 surrogates actively involved in making life-sustaining treatment decisions for a loved one.

• Emotional conflicts:
  – 1) not wanting to feel responsible for a loved one's death,
  – 2) a desire to pursue any chance of recovery,
  – 3) the need to preserve family well-being.

• Coping strategies included
  – 1) recalling previous discussions with a loved one,
  – 2) sharing decisions with family members,
  – 3) delaying or deferring decision making,
  – 4) spiritual/religious practices,
  – 5) story-telling.

Risk of Post-traumatic Stress Symptoms in Family Members of Intensive Care Unit Patients

Elie Azoulay, Frédéric Pochard, Nancy Kentish-Barnes, Sylvie Chevret, Jérôme Aboab, Christophe Adrie,

Am J Respir Crit Care Med Vol 171, pp 987–994, 2005

![Box plots comparing IES scores for different groups](image)

- **P < 0.0001**
- **P = 0.01**

<table>
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<tr>
<th>Group</th>
<th>Score</th>
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<tr>
<td>All family members n=284</td>
<td></td>
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<tr>
<td>Family members of end-of-life patients n=50</td>
<td></td>
</tr>
<tr>
<td>Families informed of end-of-life status n=28</td>
<td></td>
</tr>
<tr>
<td>Families informed and involved in end-of-life decision n=20</td>
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Psychiatric illness in the next of kin of patients who die in the intensive care unit

Mark D. Siegel, MD, FCCP; Earle Hayes, DO, MS; Lauren C. Vanderwerker, PhD; Diane B. Loseth, RN, MSN, APRN, BC-PCM; Holly G. Prigerson, PhD

Table 3. Prevalence of psychiatric illness in next of kin

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Met Diagnostic Criteria for PI n = 41</th>
<th>PI, Including Subthreshold Diagnoses n = 41</th>
</tr>
</thead>
<tbody>
<tr>
<td>Major depressive disorder, n (%)</td>
<td>11 (27)</td>
<td>13 (32)</td>
</tr>
<tr>
<td>Generalized anxiety disorder, n (%)</td>
<td>4 (10)</td>
<td>4 (10)</td>
</tr>
<tr>
<td>Panic disorder, n (%)</td>
<td>4 (10)</td>
<td>4 (10)</td>
</tr>
<tr>
<td>Complicated grief disorder, n (%)</td>
<td>2 (5)</td>
<td>9 (22)</td>
</tr>
<tr>
<td>One disorder, n (%)</td>
<td>9 (22)</td>
<td>6 (15)</td>
</tr>
<tr>
<td>Two disorders, n (%)</td>
<td>3 (7)</td>
<td>8 (20)</td>
</tr>
<tr>
<td>Three disorders, n (%)</td>
<td>2 (5)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Four disorders, n (%)</td>
<td>0 (0)</td>
<td>2 (5)</td>
</tr>
<tr>
<td>Any disorder, n (%)</td>
<td>14 (34)</td>
<td>16 (39)</td>
</tr>
</tbody>
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PI, psychiatric illness. *Represents the sum of patients meeting full criteria for psychiatric illness and those meeting subthreshold criteria.
Reactions to bereavement

Affective
- Depression, despair, dejection, distress
- Anxiety, fear, dread, guilt, self-blame
- Anger, hostility, irritability, anhedonia—loss of pleasure, loneliness, yearning, longing, numbness

Cognitive
- Preoccupation with thoughts of the deceased
- Intrusive ruminations, sense of presence of deceased
- Suppression, denial, lowered self-esteem
- Self-reproach, helplessness, hopelessness
- Suicidal ideation, sense of unreality
- Memory and concentration difficulties

Behavioral
- Agitation, tenseness, restlessness, fatigue, overactivity, searching, weeping, sobbing, social withdrawal, psychological-somatic, loss of sleep disturbances, exhaustion
- Somatic complaints, physical complaints similar to those in the deceased

Immunological and endocrine changes
- Susceptibility to illness, disease, mortality

Guilt
I am convinced that the variability in the decision-making process is somewhere else.
Lost in “sympt-dromes”

- Moral distress
- Dissatisfaction
- PTSD
- Burnout
- Anxiety
- Depression
- Perception of inappropriate care

- Nurse turnover
- Back pains
- Divorce
- ICU conflicts
- Nurse hastening patient’s death
- Suicidal ideations
- …
Conflicts
Communication gaps
Sub-optimal behaviors
Making difficult decisions
Family grief
Physical strain
Working hours

Burnout Syndrome
Depression
Generalized anxiety
PTSD
Welcome on board ...
TABLE 3. LIST OF TRAUMATIC EVENTS RELATED TO WORK AS AN INTENSIVE CARE UNIT NURSE

- Post mortem care
- Seeing patients die
- Combative patients
- Involvement with end-of-life care
- Verbal abuse from family members
- Verbal abuse from physicians
- Verbal abuse from other nurses
- Open surgical wounds
- Massive bleeding
- Trauma-related injuries
- Performing “futile” care to patients
- Performing cardiopulmonary resuscitation
- Stress related to feeling overextended due to inadequate nurse-to-patient ratios
- Stress related to not being able to save a specific patient
Prevalence and Factors of Intensive Care Unit Conflicts
The Conflicitus Study

Élie Azoulay¹, Jean-François Timsit², Charles L. Sprung³, Marcio Soares⁴, Kateřina Rusinová⁵, Ariane Lafabrie¹, Ricardo Abizanda⁶, Mia Svantesson⁷, Francesca Rubulotta⁸, Bara Ricou⁹, Dominique Benoit¹⁰, Daren Heyland¹¹, Gavin Joynt¹², Adrien Français², Paulo Azevedo-Maia¹³, Radoslaw Owczuk¹⁴, Julie Benbenishty³, Michael de Vita¹⁵,

Invitations to participate in the Conflicitus Study were sent by e-mail to the 240 members of the ESICM Ethics section mailing list.

- 40 e-mails were no longer active
- 8 invitees had left the ICU
- 2 invitees refused to participate
- 100 invitees failed to answer the email

90 (46.8%) respondents agreed to participate including
26 National Coordinators (29 countries, 397 ICUs)

9274 questionnaires were sent to 397 ICUs

- 6 ICUs failed to receive IRB approval on time
- 13 ICUs refused secondarily
- 55 ICUs did not mail back the questionnaires

7498 (80.9%) questionnaires were received
7358 evaluable questionnaires from
323 (81.4%) ICUs (24 countries)

2090 (28.4%) respondents did not report any conflict
5268 (71.6%) respondents with at least one conflict

4859 (66%) respondents reported one conflict
409 (5.5%) respondents reported more than one conflict
Burnout Syndrome in Critical Care Nursing Staff

Marie Cécile Poncet¹, Philippe Toullie¹, Laurent Papazian², Nancy Kentish-Barnes¹, Jean-François Timsit³, Frédéric Pochard⁴, Sylvie Chevret⁵, Benoît Schlemmer¹, and Élie Azoulay¹
And now … (so what …?)

- What did we learn from this multidisciplinary research and what could we recommend for the future?

- Will we be able to use these new markers to intervene and improve practices?

- Are we only able to understand why our colleagues are sometimes so … tough
Is BOS a problem?

![Bar chart showing various conditions and their levels.](chart.png)
Each additional patient per nurse was associated with:
- a 7% increase in the likelihood of dying
- a 23% increase in the odds of burnout
- a 15% increase in the odds of job dissatisfaction
Perceptions of Appropriateness of Care Among European and Israeli Intensive Care Unit Nurses and Physicians

Ruth D. Piers, MD
Elie Azoulay, MD, PhD
Bara Ricou, MD
Freda DeKeyser Canz, RN, PhD
Johan Decruyenaere, MD, PhD
Adeline Max, MD
Andréj Michalsen, MD
Paulo Azevedo Maiato, MD
Radoslaw Owczuk, MD
Francesca Rubulotta, MD
Pieter Depuydt, MD
Anne-Pascale Meer, MD
Anna K. Reyners, MD, PhD
Andrew Aquilina, MD
Maarten Bekaert, MSc
Nele J. Van Den Noortgate, MD, PhD
Wim J. Schrauwen, MSc
Dominique D. Benoit, MD, PhD
for the APPROPRIICUS Study Group of the Ethics Section of the ESICM

- 1953 clinicians in 82 ICUs in 9 European countries and Israel.
- PIC: situation in which the clinician acts in a manner contrary to his/her personal and professional beliefs.
- PIC: 27%. Disproportionate care +++
- PIC independently associated with:
  - Symptom control decisions;
  - Involvement of nurses in EOL decision making;
  - Good collaboration (nurses & doctors);
  - Freedom to perform one’s work-related tasks
- PIC was independently associated with higher intentional job leave.
Nurse behaviors in dying patients

The following elements were not at odds with medical orders

- Care: 25
- Nursing: 25
- Monitoring: 39
- Sedation: 30.1
- Antibiotics: 4
- Vasopressors: 1.5

Azoulay et al. ESICM 2011
Helping RCTs to get out of the closet: (at least) 3 conditions …

1. Design a feasible intervention

2. Design an intervention and test it in another set of ICUs

3. Find the appropriate outcome variable of interest
### Effect of a Quality-Improvement Intervention on End-of-Life Care in the Intensive Care Unit

A Randomized Trial

J. Randall Curtis¹,², Elizabeth L. Nielsen¹, Patsy D. Treece¹, Lois Downey¹, Danae Dotolo¹, Sarah E. Shannon², Anthony L. Back³, Gordon D. Rubenfeld⁴, and Ruth A. Engelberg¹

<table>
<thead>
<tr>
<th>Measure</th>
<th>Control</th>
<th>Intervention</th>
<th>P Value</th>
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<tr>
<td>FAMILY QOL Satisfaction with care</td>
<td>61.8 (23.9)</td>
<td>75%</td>
<td>0.33</td>
</tr>
<tr>
<td>FAMILY QOL Satisfaction with DM</td>
<td>59.9 (21.9)</td>
<td>76.3%</td>
<td>0.63</td>
</tr>
<tr>
<td>ICU days to ventilator withdrawal</td>
<td>5</td>
<td>7.5</td>
<td>0.81</td>
</tr>
<tr>
<td>Avoided CPR in last hour of life</td>
<td>87.1%</td>
<td>89.4%</td>
<td>0.81</td>
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<tr>
<td>DNR orders at death</td>
<td>82.7%</td>
<td>82.1%</td>
<td>0.68</td>
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<tr>
<td>Pain assessment</td>
<td>79.2%</td>
<td>77.2%</td>
<td>0.81</td>
</tr>
<tr>
<td>Life support withheld or withdrawn</td>
<td>72.3%</td>
<td>68.7%</td>
<td>0.10</td>
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- Cluster-randomized trial randomizing quality-improvement intervention based on self-efficacy theory to improve ICU end-of-life care.

- (1) clinician education about palliative care, (2) identification and training of ICU clinician local champions for palliative care, (3) academic detailing of nurse and physician ICU directors, (4) feedback of individual ICU specific quality data including family satisfaction, and (5) implementation of system supports such as palliative care order forms.

• Cluster-randomized trial randomizing quality-improvement intervention based on self-efficacy theory to improve ICU end-of-life care.
A Communication Strategy and Brochure for Relatives of Patients Dying in the ICU

130 patients included

PTSD (IES), Anxiety and Depression (HADS)

63 Intervention
56 (88.9%) family interviewed

63 Standard care
52 (82.5%) family interviewed
OPEN
Your ICU Doors
To the Relatives

You have nothing to hide

You can be proud of how you care
Happy hours for ICU relatives
(Famirea)

We’ve changed happy hours to an « Interlude for reflection »
View through a Window May Influence Recovery from Surgery

Roger S. Ulrich

• Definition of high-quality ICU palliative care
  – Communication by clinicians
  – Patient-focused medical decision-making:
  – Clinical care: dignity, treating the patient as a person
  – Protecting privacy
  – Care of the family: Providing access, proximity, and support
Important questions asked by family members of intensive care unit patients

Vincent Peigne, MD; Marine Chaize, MS; Bruno Falissard, MD, PhD; Nancy Kentish-Barnes, PhD; Katerina Rusinova, MD; Bruno Megarbane, MD, PhD; Nicolas Bele, MD; Alain Cariou, MD, PhD; Fabienne Fieux, MD; Maite Garroute-Orgeas, MD; Hugues Georges, MD; Merce Jourdain, MD, PhD; Achille Kouatchet, MD; Alexandre Lautrette, MD; Stephane Legriel, MD; Bernard Regnier, MD; Anne Renault, MD; Marina Thirion, MD; Jean-Francois Timsit, MD, PhD; Dany Toledano, MD; Sylvie Chevret, MD, PhD; Frédéric Pochard, MD, PhD; Benoît Schlemmer, MD; Elie Azoulay, MD, PhD
Answering to “What do you think the patient would choose?” is emotionally, cognitively, and morally complex.

We should stop distributing patient’s values expertise to surrogates and technical/medical expertise to physicians.

Many surrogates need assistance in identifying and working through the sometimes conflicting values relevant to medical decisions near the end of life.
End-of-life care in the intensive care unit: A research agenda

Gordon D. Rubenfeld, MD, MSc; J. Randall Curtis, MD, MPH; for the End-of-Life Care in the ICU Working Group

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My 2013-2023 research agenda

1. Understanding variability
2. Addressing relative’s unwillingness to share decisions …
3. Using interventions to improve the standard of care and breaking ICU walls
4. Understand long term outcomes and bereavement
5. Using qualitative research to understand what statistics say on our data
I hope that we will be equally successful in the next decade.
Thank you for the invitation
My conflict of interest:

I am impressed by all that has been made!
## The ETHICUS study: EOL practices in 37 ICUs in 17 European countries

<table>
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<tr>
<th>Europe</th>
<th>Unsuccessful CPR</th>
<th>WH</th>
<th>WD</th>
<th>Active shortening of the dying process</th>
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<td><strong>Northern Europe</strong></td>
<td>154 (10.2%)</td>
<td>575 (38.2%)</td>
<td>714 (47.4%)</td>
<td>14 (0.9%)</td>
</tr>
<tr>
<td><strong>Central Europe</strong></td>
<td>217 (17.9%)</td>
<td>412 (34.1%)</td>
<td>409 (33.8%)</td>
<td>79 (6.5%)</td>
</tr>
<tr>
<td><strong>Southern Europe</strong></td>
<td>461 (30.1%)</td>
<td>607 (39.6%)</td>
<td>275 (17.9%)</td>
<td>1 (0.1%)</td>
</tr>
<tr>
<td><strong>Whole Europe</strong></td>
<td>832 (19.6%)</td>
<td>1594 (37.5%)</td>
<td>1398 (32.9%)</td>
<td>94 (2.2%)</td>
</tr>
<tr>
<td><strong>Hospital mortality</strong></td>
<td>100%</td>
<td>89%</td>
<td>89%</td>
<td>100%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>832 (19.6%)</td>
<td>1594 (37.5%)</td>
<td>1398 (32.9%)</td>
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Sprung et al. JAMA 2003;290:790-7
Nurses reported engaging in euthanasia or assisted suicide without request of patients and surrogates (7%) or without request of the attending physician (8%).

7% of the nurses reported having engaged in clandestine practice in order to hasten death (saline instead of vasopressors).

19% of the nurses reported engaging in acts to hasten patient death.
Mortality after the Hospitalization of a Spouse

Nicholas A. Christakis, M.D., Ph.D., M.P.H., and Paul D. Allison, Ph.D.

- Hospitalization of a woman was associated with an increase in her husband’s risk of death of 4.5%.
- Hospitalization of a man was associated with an increase in his wife’s risk of death of 2.7%.
- The death of a wife was associated with an increase in a husband’s risk of death of 21 percent.
- The death of a husband was associated with an increase in a wife’s risk of death of 17%.
An Empirical Examination of the Stage Theory of Grief

Paul K. Maciejewski, PhD
Baohui Zhang, MS
Susan D. Block, MD
Holly C. Prigerson, PhD

JAMA. 2007;297:716-723

Figure 1. Hypothesized Stage Theory of Grief

Disbelief, Yeaming, Anger, Depression, Acceptance

Time From Loss

Indicator Rating