Withdrawing & Withholding Support for AKI: Ethical Issues in the ICU

Lynette Cederquist MD
University of California, San Diego, School of Medicine

Noel Gibney MD
Division of Critical Care Medicine
Faculty of Medicine and Dentistry
University of Alberta
Disclosure

I have no relationship that could be perceived as placing me in a real or apparent conflict of interest in the context of this presentation.
“One can survive anything nowadays, except death.”

- Oscar Wilde
A National Survey of End-of-life Care for Critically Ill Patients

THOMAS J. PRENDERGAST, MICHAEL T. CLAESSENS, and JOHN M. LUCE

Department of Medicine, Veterans Administration Medical Center, White River Junction, Vermont; Department of Medicine, Dartmouth Medical School, Lebanon, New Hampshire; Institute of Palliative Care, University of Ottawa, Ottawa, Ontario, Canada; Department of Medicine and Institute for Health Policy Studies, University of California, San Francisco; and San Francisco General Hospital, San Francisco, California
- 6,303 deaths in 131 ICUs at 110 institutions in 38 states.
- 393 patients were brain dead.
- Remaining 5,910 patients who died,
  - 1,544 (23%) received full ICU care including failed cardiopulmonary resuscitation (CPR);
  - 1,430 (22%) received full ICU care without CPR;
  - 797 (10%) had life support withheld
  - 2,139 (38%) had life support withdrawn.
- Wide variation in practice among ICUs,
- limitation of life support prior to death is the predominant practice in American ICUs associated with critical care training programs.

131 ICUs at 110 institutions in 38 states.

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<table>
<thead>
<tr>
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<tbody>
<tr>
<td>Total ICU admissions</td>
<td>74,502</td>
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<tr>
<td>Total ICU deaths</td>
<td>6,303</td>
</tr>
<tr>
<td>(8.5% mortality)</td>
<td></td>
</tr>
<tr>
<td>Brain deaths</td>
<td>393</td>
</tr>
<tr>
<td>(6.2% of deaths)</td>
<td></td>
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<tr>
<td>Patients facing end-of-life decisions</td>
<td>5,910</td>
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<tr>
<td>Full resuscitation</td>
<td>1,544</td>
</tr>
<tr>
<td>(26%)</td>
<td></td>
</tr>
<tr>
<td>Withholding of resuscitation</td>
<td>1,430</td>
</tr>
<tr>
<td>(24%)</td>
<td></td>
</tr>
<tr>
<td>Withholding of life support</td>
<td>797</td>
</tr>
<tr>
<td>(14%)</td>
<td></td>
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<tr>
<td>Withdrawal of life support</td>
<td>2,139</td>
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<tr>
<td>(36%)</td>
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Wide variation in practice among ICUs, limitation of life support prior to death is the pre-dominant practice in American ICUs associated with critical care training programs.
Variability of practice

• Took > 48 h for medical staff to reach consensus on the recommendations for 16% of the patients.

• In 5% of cases patients and families refused recommendations to limit life support; when families and physicians differed, physicians invariably deferred to the perceived wishes of patients as expressed through their families.
End-of-Life Practices in European Intensive Care Units
The Ethicus Study

JAMA. 2003;290:790-797
<table>
<thead>
<tr>
<th>Region</th>
<th>Unsuccessful CPR</th>
<th>Brain Death</th>
<th>Withholding Life-Sustaining Treatment</th>
<th>Withdrawing Life-Sustaining Treatment</th>
<th>Active Shortening of the Dying Process</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern</td>
<td>154 (10.2)</td>
<td>48 (3.2)</td>
<td>575 (38.2)</td>
<td>714 (47.4)</td>
<td>14 (0.9)</td>
</tr>
<tr>
<td>Central</td>
<td>217 (17.9)</td>
<td>92 (7.6)</td>
<td>412 (34.1)</td>
<td>409 (33.8)</td>
<td>79 (6.5)</td>
</tr>
<tr>
<td>Southern</td>
<td>461 (30.1)</td>
<td>190 (12.4)</td>
<td>607 (39.6)</td>
<td>275 (17.9)</td>
<td>1 (0.1)</td>
</tr>
<tr>
<td>Total</td>
<td>832 (19.6)</td>
<td>330 (7.8)</td>
<td>1594 (37.5)</td>
<td>1398 (32.9)</td>
<td>94 (2.2)</td>
</tr>
</tbody>
</table>

Range between countries, %: 5-48, 0-15, 16-70, 5-69, 0-19

Hospital mortality, %: 100, 100, 89, 99, 100

Abbreviation: CPR, cardiopulmonary resuscitation.

*P < .001, χ² test for the association between region and end-of-life practice. Brain death was excluded from the analysis.
Table 3. Distribution of End-of-Life Practices by Physician’s Religion*  

<table>
<thead>
<tr>
<th>Physician’s Religion</th>
<th>Total No. of Patients</th>
<th>Unsuccessful CPR</th>
<th>Withholding Life-Sustaining Treatment</th>
<th>Withdrawing Life-Sustaining Treatment</th>
<th>Active of the Shortening Process</th>
</tr>
</thead>
<tbody>
<tr>
<td>Catholic</td>
<td>1415</td>
<td>317 (22.4)</td>
<td>450 (31.8)</td>
<td>583 (41.2)</td>
<td>65 (4.6)</td>
</tr>
<tr>
<td>Protestant</td>
<td>854</td>
<td>84 (9.8)</td>
<td>380 (44.5)</td>
<td>379 (44.4)</td>
<td>11 (1.3)</td>
</tr>
<tr>
<td>Greek Orthodox</td>
<td>277</td>
<td>109 (39.4)</td>
<td>131 (47.3)</td>
<td>37 (13.4)</td>
<td>0</td>
</tr>
<tr>
<td>Jewish</td>
<td>369</td>
<td>60 (16.3)</td>
<td>251 (68.0)</td>
<td>58 (15.7)</td>
<td>0</td>
</tr>
<tr>
<td>Islam</td>
<td>38</td>
<td>14 (36.8)</td>
<td>15 (39.5)</td>
<td>9 (23.7)</td>
<td>0</td>
</tr>
<tr>
<td>None</td>
<td>878</td>
<td>209 (23.8)</td>
<td>338 (38.5)</td>
<td>313 (35.6)</td>
<td>18 (2.1)</td>
</tr>
<tr>
<td>Unknown/other</td>
<td>87</td>
<td>39 (44.8)</td>
<td>29 (33.3)</td>
<td>19 (21.8)</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>3918</td>
<td>832 (21.2)</td>
<td>1594 (40.6)</td>
<td>1398 (35.7)</td>
<td>94 (2.4)</td>
</tr>
</tbody>
</table>

Abbreviation: CPR, cardiopulmonary resuscitation.  
*P<.001, χ² test for the association between physician’s religion and end-of-life practice. Brain death and religion unknown/other categories were excluded from the analysis.
Withdrawal of ventilatory support

- Netherlands – no issues
- Israel – must use timer
- Italy – technically legal but risk of prosecution
Edmonton area ICUs 2010

- 3421 admissions to multisystem ICUs in 5 hospitals
- 20,653 patient days
- Average APACHE II score 20-22
  - Total deaths 448 (13%)
- Deaths with CPR 72 (16%)
- 84% of ICU patients died with therapy withheld or withdrawn
Withdrawning & Withholding Support for AKI: Ethical Issues in the ICU

Lynette Cederquist MD
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Objectives:

- Review RPA/ASN guidelines for limitation of dialysis in patients with AKI:
  - Informed consent and refusal
  - Estimation of prognosis
  - Conflict resolution
  - Advance directives
  - Withholding and withdrawing dialysis
  - Time-limited trials of dialysis
  - Palliative care
Clinical Practice Guideline on Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis

JOHN H. GALLA
Renal Physicians Association/American Society of Nephrology Working Group, Washington, DC

Withholding and Withdrawing Dialysis in the Intensive Care Unit: Benefits Derived from Consulting the Renal Physicians Association/American Society of Nephrology Clinical Practice Guideline, Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis

Samir S. Patel* and Jean L. Holley†
*Department of Medicine, George Washington University, Washington, DC and †Department of Internal Medicine, University of Illinois, Urbana-Champaign, Illinois
Decision making in acute illness:

- Acute illness perceived as reversible in isolation from significant chronic illness
- Patients who would not be good candidates for chronic dialysis may be considered more favorably for temporary dialysis
- Critically ill patients frequently unable to make decisions and lack an advance directive

Feb. 2000, Renal Physicians Association and the American Society of Nephrology published clinical practice guideline: *Shared Decision-Making in the Appropriate Initiation and Withdrawal from Dialysis*

- As of 2007, only 21% of nephrologists aware
- 84% of those aware found them useful in clinical decision making

Informed Consent:

“The willing acceptance of a medical intervention by a patient after adequate disclosure by the physician of the nature of the intervention, its risks, and benefits, as well as of alternatives with their risks and benefits”

This includes the anticipated outcome of not treating

...Informed consent

- This includes the anticipated outcome of not treating
- Disclosure is judged “adequate” by two standards:
  - Information that is commonly provided by competent practitioners in the community or specialty
  - Information that would allow reasonable persons to make prudent choices in their own behalf
In hospital mortality rates of ARF in ICU patients remain high, 28–90%.

SUPPORT trial: Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment:
- 490 patients who developed ARF, initiated dialysis during study period.
- 69% of these had acute respiratory failure or multi-organ system failure, and/or malignancy
  - Median survival was 32 days
  - 27% alive 6 months later

“A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). JAMA 274: 1591–1598, 1995
Multiple scoring systems offered to predict survival in patients with ARF or AKI

- Beginning and Ending Supportive Therapy for the Kidney (BEST Kidney) investigators examined 29,269 critically ill patients in 23 countries:
  - 1738 developed ARF
  - 1260 underwent RRT
  - Over-all in-hospital mortality 60%
  - Independent risk factors for mortality:
    - vasopressors,
    - Mechanical ventilation
    - Septic shock
    - Cardiogenic shock
    - Hepatorenal syndrome

Estimation of prognosis:

- **RIFLE Criteria:** Risk of renal failure, Injury to the kidney, Failure of kidney, Loss of kidney function, and End-stage renal failure
- Prognostic models to predict mortality in ICU patients only 80–85% accurate.

...Estimation of prognosis:

- In addition to estimation of survival, predicting likelihood of recovery of kidney function is vital to informed decision making.
  - Will quality of life on chronic dialysis be acceptable to the patient?
    - SUPPORT trial: 62% of survivors rated their QOL as good or better
    - Multiple studies report diminished QOL and physical function among survivors of ARF, but preserved satisfaction with life.
Appropriate situations for withholding or withdrawing dialysis

- A fully informed patient with decision-making capacity who refuses dialysis or asks that dialysis be discontinued.
- A patient who does not currently possess decision-making capacity but previously indicated refusal of dialysis in an oral or written advance directive.
- A patient who does not currently possess decision-making capacity and whose properly appointed legal agent refuses dialysis or asks that dialysis be discontinued.
- A patient who has irreversible, profound neurological impairment such that he or she lacks signs of thought, sensation, purposeful behavior, and awareness of self and environment.

Appropriate situations for withholding or withdrawing dialysis:

- Patients with a terminal illness from a nonrenal cause, or whose medical condition precludes the technical process of dialysis
  - End stage liver disease, not a transplant candidate
  - Advanced malignancy
  - Advanced CHF
  - Advanced lung disease
When the physician and treating team believe continuation of treatment is no longer beneficial, or **futile**, conflicts arise.

**How do we define medical futility?**
- No universally accepted definition
- 2 categories:
  - Quantitative definitions: Treatments with a less than 5% chance of benefitting the patient
  - Qualitative definitions: Treatments with no **reasonable** chance of benefit
- Most hospitals include a definition in their policies: important to know your hospital’s definition!
Regardless of definition, most policies surrounding medical futility focus on a process of conflict resolution:

- Ensure that members of the treating team are in agreement before informing the patient/family
- Start with a family meeting
Family meeting: Who should be there?

- The family defines its own members
- Sometimes this may be a large number
- Doctor is “bearer of (bad) news”
- Nurse is “family support” person
- Perhaps other staff (not many)
Before all family meetings

- Be fully briefed and up to date
- Find out what they have been told
- Know the name the family use when referring to the patient
- Be aware of family relationships
- Have a pre-determined meeting plan
  - Who will run the meeting?
  - What is the purpose?
- Discuss plan between all involved members of the treating team
Setting up for the meeting

- Large enough room for family size
  - Waiting rooms are not ideal
  - Sometimes there will be >30 people
  - Make sure “key-players” will be present
- Away from the bedside and “traffic”
- Privacy and quiet
- No cell-phone, pager or intercom
- Someone else taking these calls
Conduct of family meetings

- Allow introductions of all present
- Ask them what they have heard
- Convey with evident compassion and in plain non-medical language
  - Accurate sequence of events
  - Realistic assessment of prognosis
  - The patient and family must be informed if the physician(s) have determined that they believe continuation of life sustaining treatment is non-beneficial or futile.
- Emphasize shared goals – “we all want to do what is best for your loved one”
Conduct of family meetings

- CT/other visual information may help
- Allow time to answer any questions
- Ensure that the family understand
- Ensure that they agree with the proposed care plan
- Ensure that trust has been established
- Set a timeframe for the next meeting
Try to determine underlying reason(s) family insist on treatment(s) not recommended:

- Mistrust – more common in minority, lower socioeconomic status patients
- Religious beliefs – hoping for a miracle
  - “It’s not up to the doctors to decide, it’s up to God”
- Guilt – “The daughter from N.Y.” syndrome
- Secondary gain – collecting mom’s pension
....conflict resolution:

- Request second opinion regarding futility of treatment
- Request ethics consultation
- If all in agreement, and conflict not resolved, determine what your institution supports regarding unilateral limitation of non-beneficial treatments.
Advance Directives

- Protect patient and family control over end of life care
- Extend patient’s autonomy beyond point when patient has lost decision making capacity
- Patients and families overwhelmingly expect health care providers to initiate discussions regarding advance care planning.

Two primary purposes:

- Designates who the patient selects to act as their D.P.O.A. for healthcare
- Allows instructional statements regarding the patient’s wishes for end of life care:
  - I do not want my life to be prolonged if the likely risks and burdens of treatment would outweigh the expected benefits, or if I become unconscious and, to a realistic degree of medical certainty, I will not regain consciousness, or if I have an incurable and irreversible condition that will result in my death in a relatively short time.
  - I want my life to be prolonged as long as possible within the limits of generally accepted medical treatment standards.
Most patients have never completed one (80%)
Often lost, unobtainable
Even when patient has one, does not ensure the patient’s wishes will be honored.

**Advance Directive:**
- Designates patient’s choice of DPOA for Health Care
- Must be completed by an individual with decision making capacity
- Includes vague statements regarding treatment preferences
- Should be completed by all people of all ages.

**POLST:**
- Does not designate or determine DPOA or surrogate
- Can be completed for a patient who lacks decision making capacity.
- Specific treatment orders signed by a physician
- Appropriate for people with limited life expectancy.
- Complements A.D., does not replace
Agreeing on common attainable goals

“No wind is the right wind if you don’t know what port you are sailing for.”

-Seneca

Requires accurate diagnosis, prognosis, communication and trust
Walter was a 67 year old man who was the primary care-giver for his wife.

He developed cough with production of large amounts of watery sputum and increasing shortness of breath over 4 months.

Had multiple courses of antibiotics.

Admitted to hospital in mid-August with apparent severe left sided pneumonia.

His condition deteriorated and he was resuscitated and admitted to ICU where he needed intubation and mechanical ventilation.

Investigations eventually showed that he had a rare but extensive form of lung cancer spread primarily throughout his left lung. This cancer produced large quantities of mucus and was drowning his other lung.

Walter explained, by writing, that he was the primary care-giver for his wife and, if possible, would value any extra time to get his affairs in order.

Discussions with thoracic surgeon.
Walter

- Had right pneumonectomy Sept 5.
- Condition improved since no more mucus from right lung.
- Left lung function improved.
- Weaned from ventilator and recovered from surgery.
- Readmitted to hospital Nov 7
- Died Nov 29.
Decision Making

- **How?**
  - Usually incremental
  - Often, no CPR order precedes withdrawal

- **Who has input?**
  - Patient (rarely competent)
  - Advance directive (rarely)
  - Family
  - Multidisciplinary team
  - Family physician
  - Intensivist
  - Ethics committee

- **Who makes decision?**
  - Patient
  - MD
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; Patsy D. Treece, RN, MN; Sarah E. Shannon, PhD, RN; Gordon D. Rubenfeld, MD, MSc; Donald L. Patrick, PhD, MSPH; J. Randall Curtis, MD, MPH

Crit Care Med 2004; 32:1484–1488
The most important elements were:
- To have trust in the treating physician,
- To avoid unwanted life support,
- To have effective communication,
- To have continuity of care and life completion.

Variation in the perception of what matters the most indicates the need for customized or individualized approaches to providing end-of-life care.
Margaret and Harry

- Married in U.K. Immigrated to Canada, No children
- Harry worked for Edmonton Transit System
- Margaret worked as executive secretary
- Margaret developed severe Rheumatoid Arthritis age 48 yrs
- Progressive joint deformities and immobility
- Seriously disabled by age 60 yrs
- Treated with many medications
- Developed severe lung fibrosis, required oxygen
- Not particularly short of breath-minimal activity however
- Harry retired early to devote himself to Margaret’s care
- Margaret (age 76) developed a severe chest infection which progressed to pneumonia
- No advance directive. Discussions with Harry who insisted on full aggressive therapy and life support.
Margaret and Harry

- Admitted to ICU and required intubation and mechanical ventilation
- CXR showed lungs severely damaged by fibrosis and, now, new pneumonia
- Despite full intensive therapy for 4 weeks remained completely dependent on ventilator. Tracheotomy performed.
- Margaret was delirious but seemed to be asking to be taken of the ventilator.
- Multiple discussions with Harry – adamant that he wanted ongoing aggressive care. Ethics consult. Threatened to bring criminal charges and civil suit if Margaret removed from life support.
- Family physician, Dr. Zetter contacted. He had cared for Margaret and Harry for 26 years.
- Further discussions with Harry, Dr. Zetter and intensivists. Dr. Zetter reiterated what had been previously stated. Harry agreed to allow withdrawal of life support.
- Margaret was palliated and life support was withdrawn. She died peacefully with Harry at the bedside.
- Harry visited the ICU every Sunday morning for the next year to chat with staff.
Trust

- It takes years to build up trust, and only seconds to destroy it.

-Anonymous
Care of the dying patient

- Communication as possible
- Respect wishes, make a will etc.
- Avoidance of suffering in all its forms
- Maintenance of dignity and respect
- Nursing comfort care
- Continue to review patient on rounds
Withdrawal of intensive therapies

- First establish medical consensus
  - Assemble all the information needed
  - Several days may sometimes be required
  - Establish definitive prognosis
  - Consensus of intensivists and others
  - Medical recommendation for withdrawal
  - Document all of these issues explicitly
Withdrawal of therapies

- Another family meeting
  - Explain prognosis in detail
  - Explain medical recommendation “withdrawal of intensive therapies”
  - Answer any and all questions
  - Seek consensus – do not ask permission
  - Explain exactly what will happen

- After the meeting
  - Care is not withdrawn, only therapies
Role of Pastoral Care/Social Work

• Vital for:
  • Family support, troubleshooting
  • Spiritual support
  • Completion of information loop
    • Resolution of poorly understood issues
    • Resolution of poorly communicated issues

• Consider:
  • Religious and cultural beliefs, rites
Withdrawal of Life Support

- Discontinuation of hemodialysis
- Vasopressor withdrawal
  - In severe septic shock
  - Usually no further changes required
- Oxygen concentration reduction
  - Room air
- Discontinuation of ventilatory support
  - PEEP discontinuation
  - Low level pressure support
  - T-piece
- Extubation
Terminal Sedation/Analgesia in ICU

- **Analgesia** – usually by infusion
  - Morphine
  - Fentanyl
  - Dilaudid

- **Sedation**
  - Benzodiazepines
    - Diazepam, Midazolam, Lorazepam
  - Propofol
Analgesia/Sedation Regimes

- Morphine 10-20 mgs/hr - titrate to:
  - Patient comfort
  - Resp rate 6-30/min
  - Abolish nasal flaring
  - Lorazepam 2-4 IV mgs q1H and prn.
- Morphine 10-15 mgs/hr with midazolam 5-10 mgs/hr by infusion
- Morphine 10-15 mgs/hr with propofol infusion 1 mg/kg/hr with titration.
- Fentanyl 100-300 mcg/hr used instead of morphine.
“Death is a punishment to some, to some a gift and to many a favour.”

-Seneca
Euthanasia or Palliative Care?

- Determined by clinical situation and intent (principle of “double-effect”)
  - If only issue is timing of inevitable death issue is clear providing intent is to relieve suffering.
  - If uncertain, continue aggressive therapy but often with clear (but changeable) limits.
    - no CPR
    - no dialysis
    - blood product limit
    - vasopressor/inotrope ceiling.
Relieving suffering or intentionally hastening death: Where do you draw the line?*

Charles L. Sprung, MD; Didier Ledoux, MD; Hans-Henrik Bulow, MD; Anne Lippert, MD; Elisabet Wennberg, MD, PhD; Mario Baras, PhD; Bara Ricou, MD; Peter Sjokvist,† MD; Charles Wallis, MD; Paulo Maia, MD; Lambertius G. Thijs, MD; Jose Solsona Duran, MD; and the ETHICUS Study Group

Crit Care Med 2008;36:8–13
Spectrum of actions between palliative care and euthanasia.

- **Relieve pain**
- **Partially relieve pain**
- **Partially hasten death**
- **Explicitly hasten death**
- **Inadequate dose to shorten life**
- **Adequate dose of drug to sometimes hasten death**
- **Adequate dose of drug to usually hasten death**
Time to death
Medical Observations

Why Opioids and Sedatives May Prolong Life Rather Than Hasten Death After Ventilator Withdrawal in Critically Ill Patients

Jan Bakker, MD, PhD, Tim C. Jansen, MD, Alex Lima, MD, and Erwin J. O. Kompanje, MD, PhD
Management of Secretions

- Consider keeping artificial airway
- Suction prn.
- Reduce volume of oral secretions-glycopyrrolate
Special requests................
Madeline and Hans

- Madeline and Hans had lived together in a common-law relationship for over 20 years.
- She was a heavy smoker and developed severe emphysema requiring continuous oxygen therapy.
- Madeline developed a severe chest infection and was rushed to the emergency dept where she was found to be in respiratory failure and required emergency intubation and mechanical ventilation.
- Had tracheotomy performed after a week.
- No progress weaning from ventilator after 3 weeks.
- Discussions were initiated around end-of-life choices.
- Madeline indicated that she did not want to prolong life support indefinitely.
ICU Wedding
Thomas and family

- 85 year-old man living at home with home care assistance. Widower.
- Ex-heavy smoker, emphysema, home oxygen
- SOB with minimal exertion
- Multiple other medical problems
  - Previous stroke, myocardial infarction, high blood pressure, chronic kidney disease, hyperlipidemia.
- Good quality of life, friends visited.
- 3 very attentive children, no personal directive.
- Mar 19 admitted to hospital with confusion, weakness and shortness of breath
- Found to be in respiratory failure due to pneumonia. Admitted to ICU and placed on ventilator.
- Course complicated by septic shock, acute myocardial infarction, acute liver injury and acute kidney injury
• Despite very unstable initial course, stabilized somewhat but remained dependent on ventilator. Tracheostomy.
• Kidney function slowly continued to deteriorate.
• Children indicated Thomas’ father lived to 95 years of age and he wished to outlive his father!
• Weeks passed with a different intensivist most weeks
• Each intensivist indicated that Thomas was very sick and probably would not survive. Children consistently insisted that continued support be provided. Agreement on no CPR, no dialysis.
• Progressive mental decline despite receiving minimal sedation. CT and MRI scan showed severe cerebral atrophy with old strokes.
• 8 weeks into course. Developed new pneumonia. Treated with antibiotics. Developed pleural effusions bilaterally. Treated with pleural drains.
• Comatose. Family at bedside insisting Thomas would rally. Taking notes. Arguing with staff.
Thomas and family

- Intensivist met with family, expressed sympathy for their situation and admiration for their dedication but indicated clearly that Thomas was dying and that further ongoing therapy would only delay the inevitable. Indicated that life support therapies would be withdrawn the day after next and patient would be allowed to die in peace and dignity.
- Children asked for basis of that opinion which was given. They then asked about how withdrawal and palliation would happen. It was agreed that this should occur the next day. They subsequently indicated they had already made contact with a funeral home.
- They asked if Thomas could be brought home to die.
- They needed to push the critical care team to the bitter end and needed to hear that there was no hope and that death was inevitable in order to fulfill their perceived responsibilities.
Going home to die - the final frontier
THE NEW ZEALAND MEDICAL JOURNAL
Vol 117 No 1196  ISSN 1175 8716

Caring for patients and families at the end of life: withdrawal of intensive care in the patient's home
Sue Mann, David Galler, Pamela Williams, Paul Frost

Going home to die from surgical intensive care units
Yu-Chen Huang
Sheng-Jean Huang
Wen-Je Ko

Should we discharge comatose patients from intensive care to die in their own bed at home after withdrawal of mechanical ventilation?
Erwin J. O. Kompanje

A good death
Brigitte C. Beuks
Aafke C. Nijhof
John H. J. M. Meertens
Jack J. M. Ligtenberg
Jaap E. Tulleken
Jan G. Zijlstra
Criteria for ICU-home death

The following conditions need to be met (and fully explained to the patient’s family):

- Further treatment is futile or inappropriate, and death is inevitable.
- The patient can be extubated and their inotropes stopped on arrival at the family home.
- A palliation plan has been established and in place prior to the patient leaving hospital. (This may involve the general practitioner, district nurse, palliative care practitioner, or hospice service.)
- The in-house bereavement team is involved in the planning and always meets the family prior to transfer home.
- The patient’s home is within a reasonable distance of the hospital (10 miles) and transporting the patient is logistically possible.
- Cultural and spiritual support is always offered and made available if required.
- When the patient finally passes away, a death certificate can be issued without referral to the coroner (medical examiner). If there is any doubt, the coroner should first be approached about referral (before the subject is mentioned to the patient’s family).

Mann S et al NZ Med J 2004
Procedure for home death

- Nurses must be experienced, confident, and have already established a close relationship with the grieving family. In addition, the nurses’ security must be assured.
- Two nurses are accompanied by paramedics and stay in frequent communication with the ICU by cell phone. This provides continuity of care and ensures that the process is performed in a smooth manner.
- Patients usually require the same or more supportive treatment en route that they have required in the ICU.
- Patients are sedated with infusions of morphine and midazolam. Neuromuscular paralysis is never used.
- Patients are extubated and vasoactive medications are withdrawn.
- Narcotics and sedative infusions continued and titrated.
- “Patients and their families need reassurance that dying at home will not entail medical deprivation” – Wanzer NEJM 1989.
Going home to die from surgical intensive care units

<table>
<thead>
<tr>
<th>Year</th>
<th>2003</th>
<th>2004</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
</tr>
</thead>
<tbody>
<tr>
<td>ICU admissions</td>
<td>2,620</td>
<td>3,755</td>
<td>4,192</td>
<td>4,131</td>
<td>4,132</td>
</tr>
<tr>
<td>ICU mortality</td>
<td>145 (5.5%)</td>
<td>200 (5.3%)</td>
<td>296 (7.1%)</td>
<td>232 (5.6%)</td>
<td>276 (6.7%)</td>
</tr>
<tr>
<td>Home to die</td>
<td>64 (44.1%)</td>
<td>77 (38.5%)</td>
<td>81 (27.4%)</td>
<td>56 (24.1%)</td>
<td>68 (24.6%)</td>
</tr>
</tbody>
</table>
Dying at home

- Need experienced ICU transport team and strong linkage with community home care and community palliative care.
- Allows for patients/families in minority/ethnic groups to have their values respected at end-of-life.
Summary

- Team consensus that patient is dying.
- Trust.
- Agreement on common attainable goals.
- Clear communication that patient is dying.
- Development on plan for palliation of symptoms and withdrawal of life support.
What the caterpillar calls the end of the world, the master calls a butterfly.

-Richard Bach
Thank you for your attention