Transition to end of life care for critically ill patients and their families

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Direction of travel

• Why we need to pay attention to end of life care in ICU
• ICU as a place to die
• How to we get to ‘good’ death?
"Success from a resuscitation attempt relates as much to the process of the resuscitation (family consultation, respecting patient’s wishes) as to the outcome."

Survival is the expectation such that: “every sudden death has become an unwanted death.”

Resuscitation (or not) for individual patients is much more publicly debated.

The first contact many people will have with critical illness is when the pt is in ICU...
Poor death: failure to rescue

‘Many patients had multiple reviews in the 48 hours prior to cardiac arrest, 160/391 had more than 5 reviews.

No evidence of escalation to more senior staff in patients who had multiple reviews.’

64% of arrests were considered to be predictable

38% were thought to be predictable and avoidable

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ICU as a place to die

Patients with cancer who died in an intensive care unit (ICU) or hospital experienced

- more physical and emotional distress and
- worse QoL at the EOL (all $P \leq .03$),

compared with patients who died at home with hospice. Wright et al J Clin Onc 2010; 28 (29): 4457

- As number of interventions increases, the quality of life decreases.
- Impact on bereavement adjustment. Caregivers of patients receiving aggressive care were also at higher risk for:
  - major depressive disorder,
  - experiencing regret
  - feeling unprepared for pts death,

Worse QoL and worse self-reported health Wright AA et al JAMA 2008; 300: 1665
Impact on clinicians

CONFLICUS study - prevalence, characteristics, and risk factors for conflicts in ICUs

More staff conflicts when nurses/physicians had been caring for dying pts or providing pre/post mortem care within the last week OR 1.53 (1.33–1.76) p<0.001

(Azoulay et al 2009)

- How
  - Palliative care
  - Timely decision making
- Where
  - Palliative/End of Life care in ICU
  - Hospice referrals
  - ICU patients transferred home to die

Good death

Good
High quality ICU palliative care: pt/family views

Communication by clinicians
- timely, ongoing, clear, complete, sensitive,
- addressing condition, prognosis, treatment

Patient-focused decision-making
- aligned with values, goals, preferences

Clinical care of the patient
- comfort, dignity, personhood, privacy, continuity

Care of the family
- proximity/access, support including bereavement care

Nelson et al. “In their own words”: recovered patients and families of survivors and non-survivors define high-quality ICU palliative care Crit Care Med 2010; 38: 808

FREE - Family Reported Experiences Evaluation

- 20 critical care units in NHS hospitals throughout the UK.
- Family members of patients who stayed in the critical care unit for 24 hours or more were invited to participate
- Family Satisfaction in the Intensive Care Unit (FS-ICU) posted to family members three weeks after the patient was discharged from the critical care unit.
- Headline finding: family members of patients who died had significantly higher satisfaction than those who survived.....
Timely decision making: nurses’ support for families during active treatment withdrawal (Coombs et al. 2017)

Integrative review to explore how nurses prepare families for, and support families during, withdrawal of life-sustaining treatments in intensive care.

- Search identified N = 479 papers,
- n = 24 papers included
- Range of research approaches:
  - qualitative (n=15);
  - quantitative (n=4);
  - mixed methods (n=2); case study (n=2); and discourse analysis (n=1)
- No distinction between treatment withdrawal and EoLC

Theoretical model (Coombs et al. 2017)
Review conclusions

• Greater understanding needed of the language that can be used with families to describe death and dying in intensive care.
• Clearer conceptualisation of the relationship between the medically focussed withdrawal of life-sustaining treatments and patient/family centred end-of-life care
• Make the nursing contribution at this time more visible.

Information provided to families before and during life-sustaining treatment withdrawal (Ranse et al 2016)

• Online cross-sectional study
• N=159 critical care nurses in Australasia
• Preparing Families for Treatment Withdrawal questionnaire (Kirchhoff et al 2003)
  • 4 domains based on Self Regulation Theory:
    1. Physical sensations and symptoms,
    2. Temporal characteristics,
    3. Environmental features
    4. Causes of sensations, symptoms and experiences
• 40 descriptors: 1-5 rating scale (Never, Rarely, Sometimes, Often, Always)

RESULTS: Mean scores ranged from 2.60 (SD 1.10) to 4.87 (SD 0.41)
Only 7 items scored < 3.0 - most of the information items were provided by nurses at least ‘sometimes’
### Ten least frequently provided items (Ranse et al 2016)

<table>
<thead>
<tr>
<th>Item</th>
<th>M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incontinent of urine</td>
<td>2.60 (1.10)</td>
</tr>
<tr>
<td>Change in pupil response</td>
<td>2.64 (1.23)</td>
</tr>
<tr>
<td>Skin dry</td>
<td>2.77 (1.19)</td>
</tr>
<tr>
<td>Flaccid</td>
<td>2.85 (1.16)</td>
</tr>
<tr>
<td>Rigid/stiffness</td>
<td>2.89 (1.11)</td>
</tr>
<tr>
<td>Loss of bowel control/incontinent</td>
<td>2.92 (1.11)</td>
</tr>
<tr>
<td>Decreasing urine output</td>
<td>2.95 (1.16)</td>
</tr>
<tr>
<td>Skin moist/clammy</td>
<td>3.07 (1.21)</td>
</tr>
<tr>
<td>Spastic movements/seizure activity</td>
<td>3.23 (1.10)</td>
</tr>
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<tr>
<td>Reassurance to family of patient comfort</td>
<td>4.87 (0.41)</td>
</tr>
<tr>
<td>Be available for support as family needs</td>
<td>4.85 (0.45)</td>
</tr>
<tr>
<td>Emotional support</td>
<td>4.84 (0.46)</td>
</tr>
<tr>
<td>Pain medications/sedation provided</td>
<td>4.81 (0.51)</td>
</tr>
<tr>
<td>Emotional support – re: decision to withdraw</td>
<td>4.69 (0.58)</td>
</tr>
<tr>
<td>Variable time frame for death</td>
<td>4.67 (0.23)</td>
</tr>
<tr>
<td>Offer religious support</td>
<td>4.67 (0.65)</td>
</tr>
<tr>
<td>May be able to hear/encourage talking to patient</td>
<td>4.62 (0.75)</td>
</tr>
<tr>
<td>May be able to feel/encourage touch</td>
<td>4.60 (0.79)</td>
</tr>
<tr>
<td>Offer spiritual care</td>
<td>4.59 (0.75)</td>
</tr>
</tbody>
</table>

**Overall**
- Highlights important nursing role in this aspect of EoLC
- Useful indicators for staff education
- Important for workload estimates
- Crucial to support staff ....
Perceptions of a good death: a qualitative study in intensive care units in England and Israel

• 55 RNs in ICUs in Israel (n=4) and England (n=3)
• Purposively sampled: age, ICU experience, country
• Focus Groups and Individual Interviews
• FINDINGS: more similarities than differences
• 4 themes representing ‘good death’:
  i) timing of communication,
  ii) accommodating individual behaviours (patients/family/staff),
  iii) appropriate care environment and
  iv) achieving closure

Summary

We need to consider:
• How to optimise the patient’s chances of ‘good’ death
• Timely decision-making – DNACPR? TEP?
• Be honest with ourselves about what can be achieved
• Be honest with the patient and family
• Engender trust from the public (and the media...)
• Support each other with time and resources
Thank you

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