

Compassionate End-of-Life Care in the Intensive Care Unit Involves Early Establishment of Treatment Goals

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Compassionate end-of-life care is crucial in the intensive care unit (ICU) setting. Critical care involves the most highly invasive environment in the hospital. Many routine aspects of critical care can be traumatic, including mind-altering medication, noise pollution, disrupted sleep-wake cycles, and loss of autonomy. Patients furthermore experience treatment such as line insertion, ventilation, vasopressors/inotropes, and hemofiltration. However, intensive treatment must be balanced with an understanding of its limitations—namely, potential futility and prolongation of distress. Indeed, a significant proportion of ICU patients have a background of frailty, and therefore have poor bodily reserve to deal with persistent insults to organ function. Forward-thinking discussions are crucial between patients, next-of-kin, and staff to ensure ongoing care prioritizes patients' best interests; we highlight the importance of early involvement in these discussions.

Decisions to shift medical management to focus on end-of-life care can involve withholding or withdrawing life-prolonging therapies, to focus on alleviating symptoms (Table 1), either in ICU or on hospice transfer. Here, palliative care specialists are involved in titrating comfort medications as needed. Indeed, a US trial of patients randomized to early palliative care team involvement demonstrated a reduced incidence of intubation, tracheostomies, and readmissions (1).

Defining best interests is difficult and cannot be done in isolation. This “shared decision-making” process is that of two-way communication, with a goal of not only informed decision-making, but crucially also the establishment of patient and next-of-kin values, to gather insight from those who understand a patient’s life, wishes, and medical condition. Questions that may be discussed include: what is the nature of their condition; what is their physical/neurological prognosis; what is their baseline in independently managing daily life; and crucially, asking the patient themselves and their next-of-kin how they want the balance of ongoing medicalization and comfort care to be weighed up.

Communication can be a difficult process, involving multiple conversations to establish understanding and wishes on ongoing management. Receiving information on poor prognosis may be traumatic for next-of-kin to process. Over these conversations, next-of-kin commonly asks about the likelihood of recovery and the consequences of further procedures. Challenges arise where views of next-of-kin are at odds with the ICU team, for example requesting continuing invasive therapeutic strategies, or where turning off life support is in conflict with religious beliefs. A large-scale multicenter observational study in the United States showed high discordance, one-third of cases, in views on the appropriateness of treatment between patients/next-of-kin and staff (2). Disagreements on the futility of life-sustaining treatment in particular is often the main issue, underlying 63% of conflict in one US study (3). There is an understanding that a desired outcome of medical management in ICU may involve some level of discomfort or pain, but therein lies the issue of identifying where the acceptable threshold of suffering is intolerable based on the likelihood of clinical recovery. Chaplains may be brought in to provide religious support, consolidating potentially conflicting values. Research shows high appreciation by patients and relatives for supporting religious and spiritual needs (4).

Transitioning the model of care for a patient may be highly traumatic for next-of-kin to process and can often

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Table I. Medication Used in the ICU During Comfort Care.

Symptom	Class of medication	Example	Effects	Formulation	Additional information
Pain	A stepwise "ladder" approach is used when managing pain: Nonopioid analgesics Paracetamol and NSAIDs (eg, Ibuprofen)	Pain relief		Oral (PO)/Intravenous (IV) PO	Prescribed "as needed" or regular
Opioids	Codeine Tramadol Morphine	Moderate pain relief Moderate pain relief Strong pain relief		PO PO PO	Prescribed "as needed," or regular with "as needed" doses for breakthrough pain
				- Immediate release tablets/ capsules - Immediate release oral solution - Modified release tablets/ capsules IV Subcutaneous (SC)	Side effects: - Constipation - Nausea/vomiting - Drowsiness - Delirium - Respiratory depression - Dry mouth - Itch
	Oxycodone Fentanyl, Buprenorphine	Strong pain relief; alternative to morphine		PO or SC or Transdermal	Used with intolerance to morphine or significant kidney impairment
Agitation and delirium	- Initially, nonpharmacological treatment including environmental orientation (eg, availability of calanders/clocks, daylight, and presence of next-of-kin), avoiding sensory deprivation (eg, glasses, hearing aids) - Treat other causes (eg, pain, infection, drug withdrawal, nutrition/hydration, constipation)			SC as needed PO or IV or SC PO, IV, SC, or Intramuscular (IM)	Rapid onset, short-acting Avoid if Parkinsonism; specialist advice needed if requiring regular doses
Benzodiazepines Antipsychotics	Midazolam Levoramepromazine Haloperidol			Minimize agitation and hallucinations	
Primarily, address underlying cause of breathlessness as appropriate (eg, pneumonia, bronchospasm, heart failure, PE, anxiety)	Oxygen Fan therapy Low-dose morphine			Alleviate shortness of breath and NA Moderate evidence for reduction in shortness of breath ⁹	
Opioids				2.5-5 mg 4 hourly IV or subcutaneously; or if on opioids already, consider increasing regular or "as needed" dose	Titrate to response
Corticosteroids if stridor/ superior vena cava obstruction/ Post-radiotherapy bronchospasm	Dexamethasone		Reduce inflammation related breathlessness	PO/IV	Dose depending on cause
Nausea and vomiting	Dopamine antagonists			Metoclopramide, haloperidol	Work centrally in the brain (and enhance GI transit for metoclopramide) to reduce symptoms of nausea and vomiting
					Haloperidol recommended for biochemical disturbance cause of vomiting. Metoclopramide recommended for GI origin of vomiting (eg, gastric stasis)

(continued)

Symptom	Class of medication	Example	Effects	Formulation	Additional information
Antihistamine/antimuscarinic	Cyclizine	Acts centrally on balance and vomiting center of brain	PO/SC	Recommended with cerebral irritation/vertigo/oropharyngeal irritation causes of vomiting	
5-HT3 antagonist	Ondansetron	Acts centrally to reduce vomiting/ nausea	PO/SC	Used post-chemotherapy or alongside other anti-sickness	-
Secretions	Anticholinergics	Hyoscine, Glicopyrrrolate	Reduce production of secretions	PO/SC	-

Abbreviation: ICU = intensive care unit.

involve back-and-forth discussions. In these situations, discussions staggered over time may be useful to pace gathering information. Reapproaching discussions on values can give next-of-kin space to reflect, after any initial shock or grief. Next-of-kin may be allowed longer bedspace time, to provide emotional space and clarity on a patient's condition.

Within these discussions, teams may specifically ask about plans for whether specific ICU therapies should be withheld or withdrawn. Particularly, potential tracheostomy insertion is a salient time for reapproaching discussions, given this is often a checkpoint that raises the question of medical futility and appropriateness of prolonging suffering; additional issues are limits on the use of vasopressor/inotropes, ventilatory support, and cardiopulmonary resuscitation.

These are similar questions ICU teams also ask from other medical specialties when a patient is being referred. Thus, from the moment of accepting admissions, ICU teams should start to establish wishes on limits, "ceilings," of care. Notably, this is hindered where next-of-kin details are not universally routinely recorded. US physician interviews show that the timing of these discussions is largely physician-determined, based on "prognostication" rather than patient-focused factors (5). When these discussions are started early, there comes an opportunity to process a patient's condition. Multicentre Canadian qualitative patient and next-of-kin interviews show early inclusion of end-of-life discussions were considered highly important and that inclusion of a greater number of recommended elements in conversations was highly correlated with patient satisfaction (6).

Formalizing referral proformas for ICU admissions can ensure this is not omitted when patients are initially being assessed. Documented plans of agreed appropriate ceilings of care, also known as "Advanced Serious Illness Planning" can be highlighted through proformas at the front of patient records, ensuring continuity of care even when patients are transferred between wards and ICU.

Healthcare staff interviews have shown that the timeliness of end-of-life care decisions is clinician-dependent, affected by variable experience in communication training and in evaluating critical care prognosis (7). Thus, ICUs must support trainees by incorporating sessions into training programs—in particular, using role-play to demonstrate communication models in sensitively approaching shared decision-making. Scripts that can be used in guidelines can follow the format of eleven literature-determined guideline-recommended goals of end-of-life discussions (6). It is necessary that these discussions have a clear structure—establishing what is known, signposting and laying out medical details, with space for questions. Additionally, early mentorship is key for both ICU and non-ICU juniors through involvement in first-hand discussions, usually carried out by seniors. The burden of these emotional conversations can take a toll—and ICU teams should establish clear networks where staff can support each other, and seek counseling tailored to healthcare professionals.

Over the COVID-19 pandemic, ICUs have seen huge admissions pressures, alongside managing infection control, high staff turnover, and burnout. During the first wave, 12% of COVID-19 patients in Italy required ICU care, with frequent coexistent comorbidities and frailty (8). Additionally, ventilator demand has been limited by capacity, on average 2.3 beds per 100,000 in lower-income countries (8). In some cases, resultant visiting restrictions have impeded staff-to-kin communication and prevented patients seeing loved ones physically, resulting in significant distress and fears of dying alone. Here, virtual telecommunication via ICU phones and tablets has been a means of minimizing isolation, for example through the UK Life Lines project. Elsewhere, for example, through the Australian Critical Care guidelines, to preserve moments with loved ones, next-of-kin have been allowed to spend time with end-of-life patients; this has sometimes been via individual patient rooms, limited by PPE measures and numbers permitted (9). Even in trying circumstances, this highlights the importance of placing and maintaining the emphasis of humanity within patient-centered ICU care, by preserving contact with next-of-kin by any means possible.

Research has shown satisfaction of next-of-kin with end-of-life care in the ICU setting is indeed higher than on medical wards, demonstrating that decisions on the medicalization of care in the intensive care setting are largely well-considered in the context of patients' overall well-being (10). ICU teams must continuously strive to ensure these shared decision-making discussions occur early, allowing compassionate care to be placed at the heart of ICU management.

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References

1. Ma J, Chi S, Buettner B, Pollard K, Muir M, Kolekar C, et al. Early palliative care consultation in the medical ICU: a cluster randomized crossover trial. *Crit Care Med.* 2019;47:1707-15.
2. Wilson ME, Dobler CC, Zubek L, Gajic O, Talmor D, Curtis JR, et al. Prevalence of disagreement about appropriateness of treatment between ICU patients/surrogates and clinicians. *Chest.* 2019;155:1140-7.
3. Breen CM, Abernethy AP, Abbott KH, Tulsky JA. Conflict associated with decisions to limit life-sustaining treatment in intensive care units. *J Gen Intern Med.* 2001;16:283-9.
4. Johnson JR, Engelberg RA, Nielsen EL, Kross EK, Smith NL, Hanada JC, et al. The association of spiritual care providers' activities with family members' satisfaction with care after a death in the ICU*. *Crit Care Med.* 2014;42:1991-2000.
5. Gutierrez K. Prognostic categories and timing of negative prognostic communication from critical care physicians to family members at end-of-life in an intensive care unit. *Nurs Inq.* 2013;20:232-44.
6. You JJ, Dodek P, Lamontagne F, Downar J, Sinuff T, Jiang X, et al. What really matters in end-of-life discussions? Perspectives of patients in hospital with serious illness and their families. *CMAJ.* 2014;186:E679-87.
7. Visser M, Deliens L, Houttekier D. Physician-related barriers to communication and patient- and family-centred decision-making towards the end of life in intensive care: a systematic review. *Crit Care.* 2014;18:604.
8. Phua J, Weng L, Ling L, Egi M, Lim C-M, Divatia JV, et al. Intensive care management of coronavirus disease 2019 (COVID-19): challenges and recommendations. *Lancet Respir Med.* 2020;8:506-17.
9. Ning J, Slatyer S. When 'open visitation in intensive care units' meets the COVID-19 pandemic. *Intensive Crit Care Nurs.* 2021;62(0964-3397):102969.
10. Rolnick JA, Ersek M, Wachterman MW, Halpern SD. The quality of end-of-life care among ICU versus ward decedents. *Am J Respir Crit Care Med.* 2020;201:832-9.