

Key points

- The patient and family perspective on inappropriateness of intensive care at the end of life often differs from the clinician's opinion due to the nonmedical frame of mind.
- To improve satisfaction with communication on treatment goals, consultation on patient values and inclusion of social constructs in addition to clinical prediction is a good start to reconcile differences between physician and health service users' viewpoints.
- During pandemics, where health systems may collapse, different admission criteria driven by the need to ration services may be warranted.

Educational aims

- To explore the extent to which older patients and their families are involved in decisions about appropriateness of intensive care admission or treatments
- To understand how patients or their families define inappropriate intensive care admission or treatments
- To reflect on the implications of decision to admit or not to admit to the intensive care unit in the face of acute resource shortages during a pandemic

Review

Appropriateness of intensive care treatments near the end of life during the COVID-19 pandemic

The patient and family perspective on the appropriateness of intensive care unit (ICU) treatments involves preferences, values and social constructs beyond medical criteria. The clinician's perception of inappropriateness is more reliant on clinical judgment. Earlier consultation with families before ICU admission and patient education on the outcomes of life-sustaining therapies may help reconcile these provider-patient disagreements. However, global emergencies like COVID-19 change the usual paradigm of end-of-life care, as it is a new disease with only scarce predictive information about it. Pandemics can also bring about the burdensome predicament of doctors having to make unwanted choices of rationing access to the ICU when demand for otherwise life-saving resources exceeds supply. Evidence-based prognostic checklists may guide treatment triage but the principles of shared decision-making are unchanged. Yet, they need to be altered with respect to COVID-19, defining likely outcomes and likelihood of benefit for the patient, and clarifying their willingness to take on the risks inherent to being in an ICU for 2 weeks for those eligible. For patients who are admitted during the prodrome of COVID-19 disease, or those who deteriorate in the second week, clinicians have some lead time in hospital to have appropriate discussions about ceilings of treatments offered based on severity.

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Quality end of life and medicalisation of natural dying in the intensive care unit

Older patients at the end of life are often repeatedly admitted to hospital and require admissions to the intensive care unit (ICU), yet their outcomes remain poor, many do not survive admission and others die within months of ICU discharge [1, 2]. Of those that survive an ICU stay, their long-term quality of life and physical health are often severely compromised after

hospital discharge [3]. High quality end-of-life care in the ICU has been defined by families as encompassing timely and compassionate communication, shared decision-making incorporating patient treatment goals and values, avoidance of prolongation of dying, and preservation of comfort and dignity [4]. Despite this, with increasingly available technology to prolong life – the medicalisation of death [5] – has resulted in many of these ICU admissions deemed inappropriate from a medical perspective [6] and in some cases, unwanted by the patients themselves, who would largely prefer less aggressive treatments at the end of life [7].

 @ERSpublications

The #COVID19 crisis has raised the importance of and impetus for carrying out early goals-of-care discussions with patients admitted to hospital, especially those whom have been shown to have high risk of death even with ICU admission <https://bit.ly/2UNV6cu>



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Factor affecting clinicians' perception of inappropriateness

Clinicians may generally have some understanding of what constitutes inappropriate care at the end of life [8] but there is no consensus.

Treatments are considered medically inappropriate due to many factors: the intensity of resource use is deemed to be more substantial than warranted [9]; patients being too ill to benefit from ICU management [10]; unnecessary treatments when there is little hope of surviving the ICU stay [11]; the intervention is expected to have a negligible impact on recovery of independence [8]; or the treatment having a possible adverse bearing on the health outcome or quality of life of the person [12]. Yet doctors still administer aggressive treatments to patients at the end of life [13], even though recognition of dying has occurred [14]. This may create confusion among patients' and families' understanding of the expected disease trajectory. It is then not surprising that no consensus on the patient or family perception of what constitutes appropriate admission to the ICU or appropriate treatment in an ICU are available either [8, 15, 16]. In some countries (including Australia and New Zealand), doctors have the right not to deliver treatment that they consider futile and are not obliged to seek consent from surrogate decision-makers or patients to cease inappropriate treatments [17, 18]. Instead they have long been considered to be first in line to determine appropriateness or futility of treatment [19] as they are, by default, acting in the best interest of patients. As such, families do not have the legal right to insist on specific interventions [20], although there are examples of legal cases where families have prevented what they consider to be inappropriate care, whether it is the right to continue or discontinue active treatment. The culture of setting treatment goals on behalf of patients without discussing alternative care pathways before aggressive treatments are administered has started to change in recent times with support for shared decision-making between clinicians and patients or their surrogates.

Patient and family perceptions of inappropriateness

The terms "inappropriate" and "futile" are generally not used by patients or their surrogates but a survey of ICU patients and their surrogates in the USA and Hungary reported that "too much treatment" was perceived as inappropriate mainly due to misalignment with either patient or family wishes, or because it caused unacceptable suffering or was too costly [21, 22]. In a small US veterans' clinic

study, elderly outpatients defined "futility" as those treatments administered when the patient "has nothing to look forward to" or "is a vegetable", or the treatments are "a waste of time and money" [12]. Factors predisposing participants to categorise end-of-life interventions as futile were a low likelihood of treatment success, a limited expected effect on the patient's longevity and quality of life, and an anticipated emotional and financial cost to the family in countries where universal healthcare was not available [12]. Medicare beneficiaries in the USA (mostly older people aged ≥ 65 years and younger people with disabilities) were less likely to consider admission to an ICU within 30 days of death for patients with advanced-stage cancer as excellent quality of care [23]. This view was associated with the place of death not being consistent with the patient's wishes. Perceived inappropriateness and lack of satisfaction with care in the ICU are reported to be significantly associated [21, 24]. Yet satisfaction may not always be a good surrogate for appropriateness as cognitive dissonance remained in other cases where survival was preferred to palliation and thus, aggressive care in the ICU was paradoxically associated with higher levels of surrogate satisfaction [25].

Readiness to communicate and accept decision making

Traditionally, the teaching has been that decisions about withdrawing or withholding intensive therapies need to be made when there is no longer a true prospect of benefit for the patients but a possibility of treatment causing more harm than good. Patients or families are often asked to participate in these decisions after a patient has been admitted to ICU [26, 27] but conflict over the end-of-life care in the ICU still occurs and strategies to resolve this conflict are not always successful [28]. Family involvement in critical decisions in the ICU is known to lead to psychological distress, anxiety and depression regardless of whether patients die or survive the ICU admission [29]. Increasingly, there is an awareness that patients are willing to accept some degree of suffering for a positive outcome, but the majority are unlikely to accept ending up in a dependent state [30]. Discussions with surrogate decision makers in the ICU should focus on these patient values, rather than the traditional mortality discussions [31].

A first step in the decision-making process is understanding the likely prognosis for that patient given their past medical history and the condition for which they are being treated. Ideally, wherever possible, current estimates of outcomes for similar patients are useful to create a starting point for the discussion of the likelihood of recovery. This discussion should not provide only the delivery of negative prognostic information to families [32], a

practice that unfortunately, more often than not, involves spending more time speaking to families and less time listening to their concerns [33, 34]. The central theme of these conversations is clarifying the treatment goals. That is, deciding whether the aim of treatment is curative, palliative or terminal depending on the expected response and clinical outcomes, and giving the patient or family the opportunity to decline treatments if they so wish [35]. Lack of consultation with patients or lack of control over decisions on treatment, discontinuation by families, or inadequate communication are some of the main reported causes of dissatisfaction with ICU management (table 1).

What is different about ICU admission appropriateness in a pandemic?

Empowering people to make choices about their own health should become routine in the future. This would include, where available, giving prognostic information to people prior to hospital admission and ICU transfer [45, 46] and before the severity of illness takes away the patient’s ability to make these decisions. If this has not occurred, then the earlier people receive information, the better, as aggressive treatments may not be compatible with a “good death” [47].

The unprecedented escalation of patient load in emergency departments and ICUs associated with the 2019 coronavirus disease (COVID-19) has forced clinicians to accelerate the numbers of end-of-life discussions in some countries [48]. Furthermore, the time pressures of this worldwide crisis and the rapidity of the clinical progress of the disease means that people may be faced with these considerations as a matter of urgency [39]. While there remains medical uncertainty about all the potential outcomes of COVID-19, the rapid sharing of international experiences has already provided us with useful information about the likely outcomes for patients who end up requiring mechanical ventilation [49]. Reports have emerged of the association between older age (≥60 years) and higher severity of respiratory illness, more common development of acute respiratory distress and longer course of illness [50]. The outcomes for COVID-19 patients who require mechanical ventilation are much poorer than those not on ventilators (66.3% versus 19.4% in-hospital death) and there is higher mortality than from other types of viral pneumonia [51]. In older age groups and those requiring invasive ventilation, mortality approaches 70% [52, 53]. This calls for clinicians to help families understand the aim of limitations of treatments, and discuss potential futility of aggressive treatments and the need to ethically cease intervention [45]. For patients who are admitted during the prodrome of COVID-19

Table 1 Domains covered by the definitions of perceived inappropriateness of or dissatisfaction with ICU management

First author [ref.]	Inconsistent with patient/family values	Not accepting prognosis/conflict with prediction	Lack of consultation with patient/lack of control by family	Inadequate communication#	Too aggressive/causing suffering	Cost	Lack of understanding of limitations of life-sustaining therapies	Lengthy ICU stay
Quantitative studies								
LE GUEN [36]			•					•
WRIGHT [23]	•				•			
WILSON [21]	•				•			
You [37]				•				
LEWIS-NEWBY [38]			•	•				
GRIES [39]	•	•	•					
TENO [40]	•		•					
BREEN [41]		•			•			
RIVERA [42]	•	•						
Qualitative studies								
ZIER [43]	•	•						
WILLMOTT [44]	•							
WORKMAN [25]			•	•	•			•
RODRIGUEZ [12]	•							

#: includes treatment options, consequences, preferences, treatment goals or values.

disease or deteriorate in the second week, clinicians have some lead time in hospital to have appropriate discussions about ceilings of treatments offered (*i.e.* offer ward-based therapies, noninvasive or mechanical ventilation according to the patient's needs, values, preferences and potential benefit).

The need to prevent transmission of infection between patients, relatives and healthcare workers has led to hospitals reducing visitor numbers [54]. It is possible that patients will die without any or all of their family and loved ones around them. In the meantime, some units have resorted to innovative solutions involving video and telephone links, but these remain inferior to face-to-face family meetings.

An even more burdensome predicament of doctors is the possible need to make unwanted choices of rationing access to the ICU when demand for life-saving resources exceeds supply. Criteria for ICU admission, discharge and triage have been in place for over two decades [16, 55, 56] and rely heavily on clinicians' judgment. These have relied on many factors, such as the seriousness of the presenting illness, age, levels of frailty, the trajectory of a person's deterioration, the person's likelihood of benefit during and after ICU stay, and the attitudes and beliefs of the person being considered for life support in an ICU. Implicitly, local resource availability is also considered. Other ethical issues need to be considered, such as governments triaging the need for supportive infrastructure like ventilators and beds, as well as the provision of those resources in a fair and equitable fashion. Although ICU triage may be considered "business as usual", given that the fluctuating demand may approach capacity routinely during winter seasons, this process is based on a belief that the ICU has little to offer those of advanced age with irreversible progressive disease. The pandemic triage is fundamentally different. Resources may not be available to manage every patient as usual and survival may be diminished once resources are exhausted, as it has been the case in previous influenza epidemics in some health systems [57]. Current European guidelines for hospital preparedness and management of COVID-19 do not include refinements to ICU admission criteria [58] in the face of extraordinary pandemic demands. Various objective checklists, such as the Simplified Acute Physiology Score (SAPS) II and the Acute Physiologic Assessment and Chronic Health Evaluation (APACHE) II [59], can be used as references to determine mortality risks according to prognostic parameters, but tools to select and reject patients on the basis of ICU bed shortage are not tested in first-world medicine, poorly socialised and little understood, and will impact clinicians and society in ways not previously experienced in the developed world outside wartime. One suggestion is to use a multiprinciple allocation framework, whereby the decision makers use a combination of the likelihood to benefit from intensive care based on their illness severity, their

comorbidities and a consideration of their life cycle considerations (assigning higher relative priority to younger patients with dependents, or healthcare workers) [60]. Fidelity in the administration of the framework is required to prevent stigma or disadvantage among already vulnerable groups (*e.g.* indigenous populations, the homeless and disabled persons) [61]. Although mechanisms for dealing with regional disasters exist (earthquakes, mass shootings, *etc.*) where patients can be diverted or retrieved to areas of increased resources to reduce mismatch, pandemics are unique in their ability to overwhelm every resource, often simultaneously. This process is worsened as, unlike many disease processes, clinical staff are at equal or higher risk of being affected. Even if some areas are less directly affected, diversion of resources such as personal protective equipment or ventilators to those overwhelmed may impact their capability to provide healthcare.

In an overwhelmed health system, the definition of appropriateness may be transformed by the scale of the emergency. That is, the good intentions of implementing shared decision making may not be realistic if a prior end-of-life discussion has not been held [36] or the resources are not there to align with patient expectations.

The dilemma is that not arriving at a joint clinician-patient decision contravenes the principle of patient autonomy [12] and there is corresponding loss of dignity [62]. The question emerging is whether in the midst of a pandemic that carries devastating economic consequences on the health system, there is the opportunity to reach satisfactory negotiation between clinicians and patients or families on the extent of ICU care to be administered, including the decision not to admit to the ICU to avoid prolonging suffering before death. The ideal situation recommended by peak professional bodies would be where the decision is neither doctor-driven nor patient/surrogate-driven [17] but a reconciliation of the two perspectives.

A way forward

Strategies that have been shown to reassure families of the appropriateness or inappropriateness of the ICU treatments and generate more satisfaction include obtaining consent [63], better step-by-step communication updates as status and indications for treatment change, sufficient time for information exchange, consistent information, and knowing the role of each service provider [64]. While surviving the ICU to discharge is heralded as a "success", even if from the patient's perspective, communicating the expected long-term quality of life after ICU discharge may also assist families in making informed decisions about treatment goals [65]. However, it is acknowledged that these are early days in the history of COVID-19 to confidently or accurately predict long-term outcomes.

Consultation before ICU admission, if feasible, could contribute to less dissatisfaction, as it is known that the timing of negative prognostic communication is associated with the preparedness of families and the complexity of decision making [32]. While many families accept recommendations for withdrawing or withholding treatment [66], unreasonable expectation of recovery still contributes to patient or family requests for medically inappropriate treatments [43], which may not be satisfied under current circumstances. Early and proactive palliative care consultations can alleviate the pressure on other health professionals.

Much education on the difference between withdrawing treatment, withholding treatment and allowing to die [67] is still needed to improve public understanding of the role and implications of palliative and comfort care, and the potential inappropriateness of ICU admission. When some certainty of the irreversibility of a patient's condition is present, the end-of-life transition in the ICU can be a coordinated effort and orders for limitations of life-sustaining treatment must not imply abandonment of patient care [68].

When there are discordant opinions between families and health professionals, if feasible, decisions to admit the dying elderly for short periods to trial care in the ICU may be appropriate in an attempt to address the discordance and give time to families to adjust to the bad news [69]. Clinicians may advocate for these time-limited ICU intensive treatments until the prognosis is more certain or until differences of opinion within families are reconciled as families realise the treatment goals need to change from curative to palliative [69]. One difficulty with COVID-19 is for those who end up requiring intensive care, the median duration of treatment needs to be 10–12 days (reported interquartile ranges 7–12 and 10–18 days) [70, 71], which reduces the ability to offer “short trials” of advanced treatments. Generally, the median length of ICU stay including all critical conditions is about 2–4 days, and for pneumonia under nonpandemic situations, is generally around 7 days for patients of all ages [72].

A clear ICU admission guideline for catastrophic emergencies

For over two decades, guidelines have stated that restricting ICU admission for the elderly is unethical if the decision is made only on the grounds of age [2, 60]. The impact of frailty and pre-existing comorbidities on short-term mortality [73] should also be considered in the algorithm. However, as mentioned above, data indicate that in the COVID-19 pandemic, advanced age and prognosis are directly related. Information and the uncertainty around prognosis have to be shared with patients, their carers and society in an open

Self-evaluation questions

- 1 Which of the following aspects of ICU inappropriate treatments is true for patients and families?
 - a. Could mean insufficient treatment
 - b. Can mean “too much” treatment
 - c. Could be interchangeable with dissatisfaction with ICU care
 - d. Care inconsistent with patient values
 - e. All the above
- 2 Inappropriate ICU treatments for doctors mean
 - a. too late to benefit
 - b. too costly
 - c. unlikely to survive
 - d. All the above
 - e. a and c only
- 3 Which of the following are anticipated risks during pandemics?
 - a. Having to ration access to the ICU without clear guidelines
 - b. Not having time for informed shared decision making
 - c. Be accused of ageism
 - d. Family conflict with clinicians
 - e. All the above
- 4 There is evidence that consultation with the primary caregiver or family decision maker can facilitate the decision not to admit a patient to ICU in global emergency situations.
 - a. True
 - b. False
- 5 Which strategy has shown to reassure families of the appropriateness of ICU admission and increase satisfaction?
 - a. Inconsistent clinical information
 - b. Withholding prognostic information from families
 - c. Uncoordinated step-by-step communication
 - d. Communicating expected long-term quality of life after ICU discharge
- 6 The decision-making process near end of life can include
 - a. providing the patient/family the opportunity to refuse treatment
 - b. prognostic information
 - c. clarifying treatment goals and personal values
 - d. all the above

and transparent way. Urgently needed during this pandemic if resources were to become scarce, is a guiding pathway for decision making that includes prognostic thresholds on the likelihood of benefit and an end-of-life discussion about palliative care with families on reasonable care aligned with patient's values. A good generic start could include the components illustrated in figure 1.

The family conference or other approaches to joint decision making are opportunities for reconciling differences of opinion and for enhancing families understanding of the consequences of inappropriate ICU care at the end of life. It is important to understand factors beyond religious objections that make surrogate decision-makers disagree with medical recommendations and insist on interventions when the chances of survival are

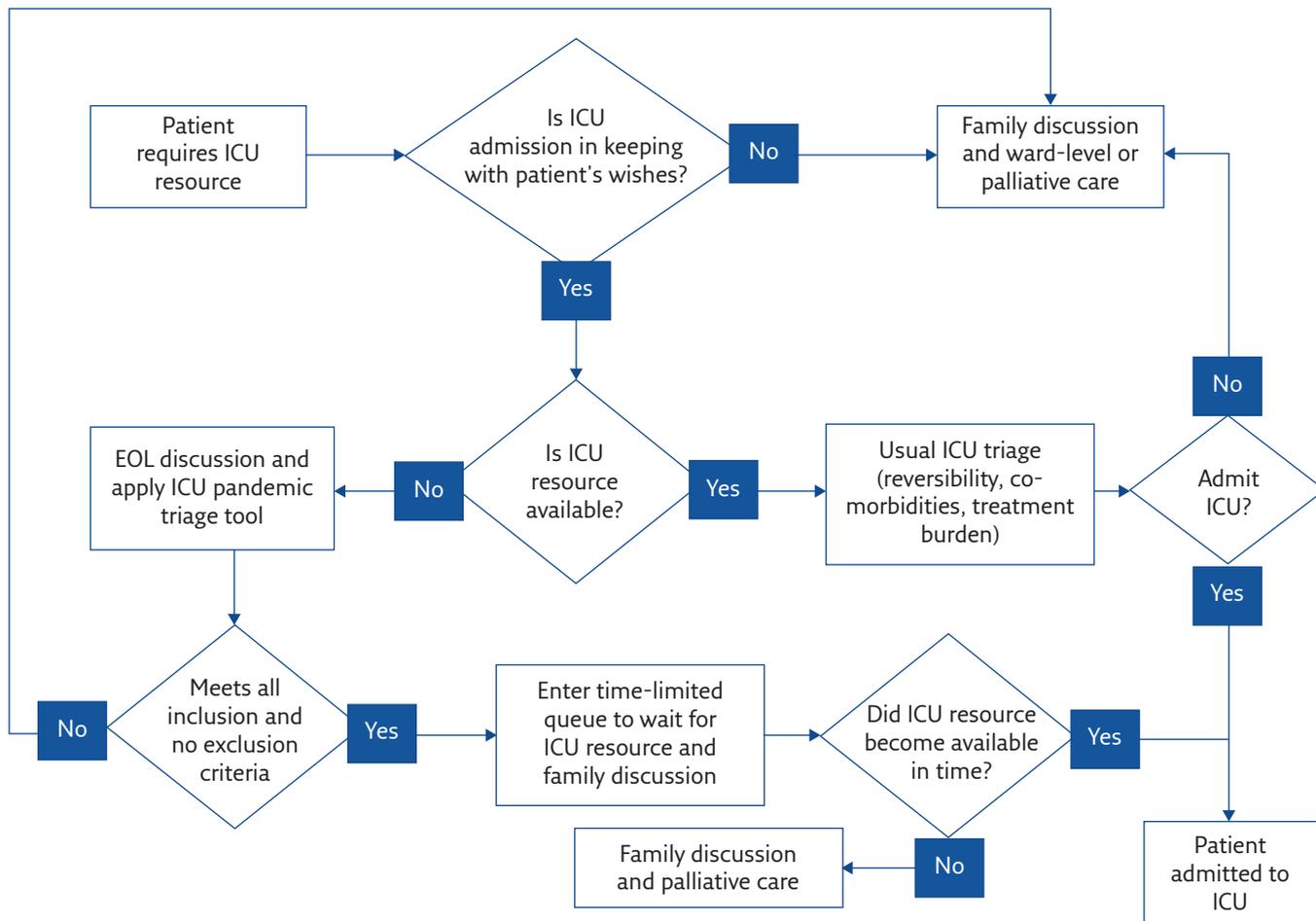


Figure 1 Generic triage protocol guiding modified rules for ICU admission during global emergencies. EOL: end of life.

extremely low or the health system resources cannot support universal access to ICU. In the latter case, providing patients and families with this information either at admission to hospital or *via* public information campaigns may have some benefit in managing expectations during a pandemic.

Implications for practice

It is clear that using medical criteria alone for decision making on ICU admission at the end of life carries the ethical dilemma of overlooking patient values and preferences [74] or unintentionally making decisions to deny access in times of global emergencies. The role of the physician includes delivering prognostic news sensitively, helping families accept the imminence of death, involving families in decision making when the patient is incapacitated and coordinating healthcare providers in the effective application of end-of-life-care extending to limitations of life-sustaining treatment [75]. This could improve by recognising and effectively using the informal roles of family members as they emerge during crisis situations. These have been identified as Primary Care Giver,

Primary Decision Maker, Family Spokesperson, Out-of-Towner, Patient Wishes Expert, Protector, Vulnerable Member and Health Care Expert [76]. Consultation with them can minimise conflict and facilitate negotiations on prevention of inappropriate ICU admission or interventions. However, this has not been tested in global pandemics and in such situations where decision making needs to be expedited, wide consultation is likely not to be possible.

Conclusions

Perceived inappropriateness of ICU treatments for families and patients is multifactorial, and it involves social constructs beyond the medical rationale. Health service users appreciate consultation on their values and improved communication for shared decisions about ICU admissions and treatments, but their definition of inappropriateness appears to clash with the goal-of-treatment orientation of the medical perspective. Discordance between healthcare provider and healthcare user perceptions and satisfaction with end-of-life management in the ICU continues to be a consistent finding across studies. Much work lies ahead in clinicians'

understanding the family experience and consulting families before ICU admission to reconcile these differences. Admission and discharge criteria specific to emergencies may assist clinicians in allocating resources but is likely to be unpopular with the general population, who might be uncomfortable with explicit proscription formulas for determining access to ICU treatments; they

prefer the clinical judgment of senior clinicians. However, those clinicians should adjust their decision-making approach using a combination of inputs, including patient values, the likelihood of the treatments offered achieving those outcomes, and the competing priorities for the ICU services to ensure scarce resources are diverted to those who both want and would benefit from them.

Suggested answers

1. e
2. e
3. e
4. b
5. d
6. d

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Conflict of interest

None declared.

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