Moral justifications for refusing ICU admission

The moral justifications for decision making in the discussion that follows will rely heavily on the moral principles and ethical reasoning proposed by Beauchamp and Childress.8 Briefly, four prima facie moral principles – beneficence, non-maleficence, autonomy and distributive justice – are used as a framework to assist the interpretation of the ethical problem being considered. The principles applied to the ethical problem are then specified or interpreted in their cultural context if necessary. Satisfying all the principles is usually not possible and the importance of each must be weighed or balanced against the others and the relative importance decided. This process may be used to assist the creation of morally justifiable policy or making of individual decisions. While a large body of bioethicists and doctors have adopted this model of ethical justification both for policy making and individual clinical decisions, it has not been universally accepted.9

It is important to realise that not all cases refused ICU admission are refused as a consequence of the need for resource limitation or triage. Based on relatively simple ethical reasoning, three distinct pathways exist for refusal of ICU admission (Fig. 1).

The first pathway is one where the patient, or their surrogate, makes an autonomous, informed decision to decline ICU admission. Intensive care, the provision of life support and inevitable need for rehabilitation are associated with much potential discomfort, pain and suffering. It is necessary to properly inform patients of this potential burden and also of what outcome (survival chances and expected quality of life) intensive care can achieve. Often poor quality of life after intensive care can be expected, particularly when the pre-existing premorbid state is poor.10 The need for this type of discussion is particularly important when the projected outcome is poor enough that there is reason to believe that the patient may consider the burden of ICU care to be such that they would not wish ICU admission. Examples could include painful metastatic malignant disease, or severe irreversible chronic cardiorespiratory compromise. After an explanation of the expected burden and benefits of admission to intensive care, some patients or their surrogates may express a wish not to be admitted. This patient preference not to be admitted is an expression of autonomy and should be respected. The patient or surrogate has thus made the final decision on whether to be admitted or not. This decision should normally take place in situations when the gatekeeper has already decided to accept the patient for intensive care admission and has sufficient resources to provide ICU care, if it is the patient’s wish.
refusal of intensive care admission is one based on futility. In this context futility means that intensive care admission cannot reasonably be expected to alter the patient’s outcome, i.e. no meaningful medical benefit can be achieved. In this situation no good, or beneficence, can be provided to the patient and there is no obligation to provide intensive care. Medically well patients, in whom ICU care will provide little or no extra benefit over ward care, would meet this definition. At the other end of the spectrum of disease, terminally ill patients who may also not reasonably be expected to derive any medical benefit from ICU care should also be refused admission. In fact, given the likelihood of intensive care causing suffering, invocation of the principle of non-maleficence would strengthen the argument for denial of ICU admission.

While the moral issue of futility is reasonably clear, the difficulty with futility is one of practical implementation. It is almost impossible to say with certainty that the outcome of an intensive care admission will not lead to any benefit, either in survival or quality of life. What, in practical terms, is the meaning of ‘cannot reasonably be expected’ to alter the patient’s outcome? Much debate has centred on this issue and but objective criteria have not been universally accepted. It has been suggested that futility could be considered to exist after a process of reaching consensus among medical staff and surrogates is completed, without the need for absolute threshold criteria. Even this approach to dealing with futility is controversial and therefore futility is not frequently used for the justification of refusal of intensive care admission.

The third morally justifiable reason that results in refusal is invoked only when resources are limited and all patients cannot be offered ICU admission because of an absolute deficiency of beds. A choice as to which patients will receive the available beds must be made. In the context of intensive care, triage is the process of prioritisation of patients for admission in the presence of restricted resources.

Different fundamental methods to achieve prioritisation can be considered. Prioritisation or triage can utilise a naturally random process such as ‘first come, first served’ to achieve an egalitarian or ‘equally fair’ chance of ICU admission for all. The American Thoracic Society, for example, recommends that when demand exceeds supply patients should be admitted on a first-come, first-served basis. The desire to achieve maximum utility from the available ICU resources, however, leads some doctors to admit patients preferentially based on the probable magnitude of benefit that the individual could derive from ICU care. The Society of Critical Care Medicine, in contrast to the American Thoracic Society, proposes that the likely benefit derived by an individual patient from the use of ICU resources should be considered as a criterion for prioritisation or triage. In this utilitarian model, patients refused on the basis of triage should be those who will derive insufficient benefit from ICU resources to be given priority to meet the admission threshold. In other words, a patient who will clearly derive more benefit from ICU resources should be given priority over one who will derive less benefit (e.g. lower increment in chances of survival). It is important to note that while triage should be based primarily on the ethical principle of distributive justice, the additional principle of utility justifies prioritisation on the basis of benefit as it maximises the overall gain for the society. Put simply, the society should get more survivors for the same
outlay of ICU resources. Triage as used in this way can allow the resources to be used both fairly and effectively.14,15 Of course, other factors unrelated to benefit such as ethnic origin, race, religion, sex, social status and ability to pay, and age should not be considered as acceptable criteria on which to base a triage decision.16

One argument of the proponents of the egalitarian approach of prioritisation is that benefit is difficult to assess and that this lack of accuracy introduces unfairness.14 While this may be true when differences in likely benefit are marginal, when resources are more severely restricted, as they are in our institution and probably in many parts of South Africa, we believe it is possible to identify benefit more consistently, simply because differences in degree of benefit between those admitted and those refused tend to be substantial. Nevertheless, any form of prioritisation will result in the interests (and rights to autonomy, beneficence and non-maleficence) of the refused individual patients being overridden. For these reasons the justification for triage (usually severe resource limitation) must be overwhelmingly strong, and the triage process fully documented and transparent.

There are enormous practical difficulties when justifying decisions in relation to prioritisation. An example is the necessity to choose between utilitarianism and egalitarianism with the result that two professional bodies chose opposing positions in well considered consensus documents.14,15 To deal pragmatically with these conflicts of principle it has been suggested that focus be placed instead on developing an acceptable process for making these decisions, not heavily reliant on the arguments of moral principles.14 Such a process is intended to allow most, and if possible all, of the relevant parties to agree on what is fair or just. This process has been called ‘accountability for reasonableness’.17 Briefly, this process is made up of four key procedural elements, the first being the need for transparency (all relevant parties, including the public, should have complete access to the decisions and the reasons for the decisions); the second is the use of any rationales that parties can accept are relevant to the fair use of the health resources in question; the third is to ensure that a formal and accessible mechanism should exist for appeals or challenges; and lastly some sort of oversight mechanism, preferably external, should exist to monitor the first three conditions.

Practical decision making

Priority setting in the context of resource allocation is practised at many levels – national, regional and local (within individual hospitals or clusters of hospitals). Decisions at these levels usually determine the macro-allocation of resources and this may profoundly affect the context of frontline triage decisions.16 We will, however, focus on the components of prioritisation or triage that are the primary responsibility of ICU practitioners. Participation in the preparation of institutional guidelines that govern triage decisions is one such responsibility. Institutional guidelines to be followed when making decisions to refuse patients intensive care must be carefully prepared and both the guideline and underlying reasoning supporting the guideline freely available to doctors, nurses, patients and families, administrators and the community at large. A mechanism for appeal or challenge should always be available. The ‘accountability for reasonableness’ process may be particularly useful in assisting the development of guidelines for prioritisation in specific, defined subgroups of patients, and proper implementation of such guidelines should contribute to greater consistency in individual decisions. For example, the method has been successfully used to assist the development of institutional guidelines for the prioritisation of patients with severe head injury to either ongoing ICU life support or limitation of life-support therapy.14 It has also been used as a comparison benchmark to qualitatively evaluate a decision-making process related to a guideline for patient access to neurosurgical ICU beds and assess perceived ‘good’ practice in this context.16

The complexity of disease and heterogeneous nature of general ICU patients, and our lack of quantitative knowledge of ICU outcomes, mean that current institutional guidelines simply cannot be sufficient to define enough specific conditions under which individual patient triage decisions should be made. At best they can provide guidance and provide principles and a process that should be followed in the course of decision making. Although not universally accepted, we propose that triage on the basis of benefit be adopted if resources are critically limited, as it is anticipated that this strategy should lead to a meaningful overall gain in quantity or quality of lives saved for the community.

All individual decisions to refuse ICU admission must be clearly documented in the patient’s records.16,17 The components of the decision must be clearly stated in this documentation. Many recommendations regarding triage have been made, but have generally been made in a piecemeal fashion and are often not followed.16 We therefore suggest the following as essential components of all triage decisions that the physician must assess and document:

- An assessment of the diagnosis, prognosis and outcome.
- A statement of the degree of benefit expected for the patient if admitted, and supporting evidence for this assessment.
- A statement clearly making the decision and identifying it as a triage decision.
- The physician/s responsible for the decision (usually the ICU director or designate, after consultation with
relevant interested parties – see following component).

- A statement confirming that clear communication of relevant factors with the patient/family/other caregivers has taken place – including among others inquiry into the patient’s current and expected quality of life.
- A statement that the decision and reason for that decision has been communicated to the family and relevant caregivers should conclude the documentation.

The prevention of bias when benefit decisions are made is obviously important and therefore it has been suggested that the ICU director be charged with ultimate responsibility for triage decisions as physicians looking after individual patients are likely to have a bias toward securing resources for their own patients. It would appear evident that these factors are used by doctors to determine prognosis and therefore benefit. Ideally prognosis of the patient should be estimated not only if admitted, but also if refused – the difference being an estimate of benefit. Few such data exist to guide triage decisions and most triage decisions are therefore intuitive, based on an experienced clinician’s best guess.

Choosing patients on the basis of benefit requires careful clinical assessment and estimation of prognosis. Factors known to be associated with triage decisions include acute severity of illness, diagnosis, chronic illness status, age, and the success or failure of current medical therapy. It would appear evident that these factors are used by doctors to determine prognosis and therefore benefit. Ideally prognosis of the patient should be estimated not only if admitted, but also if refused – the difference being an estimate of benefit. Few such data exist to guide triage decisions and most triage decisions are therefore intuitive, based on an experienced clinician’s best guess.

The assessment of mortality benefit is usually a priority, but outcome in terms of quality of life benefit should also be considered. Practically, a high absolute mortality in patients admitted to ICU suggests little benefit can be gained by admission. Several studies have attempted to identify such patient groups. For example, patients admitted to ICU for mechanical ventilation after bone marrow transplantation have a poor prognosis (6-month survival of approximately 3%) and even ICU survival rate (18%). It is important for triaging doctors to be aware of objective data that may assist in making more accurate decisions. Although peer reviewed data are likely to provide a more objective assessment of outcome than intuition, they must still be interpreted with care. Data must be carefully assessed to ensure that the reported cohort matches patients about whom decisions are being made, consideration must be made for institutional differences (units specialising in the care of specific diseases may achieve unusually good results, or local therapeutic practice may differ substantially from that of the reporting institution), and care should be taken to ensure that available information is up to date.

Recent data suggest that the outcome of many conditions that previously had a very poor prognosis is improving, and failure to recognise this may lead to inappropriate triage. Some group outcome quality of life data exist in ICU cohorts, but because these data are so limited, accuracy of assessments of benefit in terms of quality of life remains essentially subjective and careful interpretation of the views of the individual patient or surrogate is required.

Acute respiratory failure and triage

Two triage studies have reported rates of refusal of ICU care by diagnostic category. A large proportion of patients refused ICU care (26 - 36%) fall into the category of primary respiratory failure. The results of one study suggested that refusal of admission with the primary diagnosis of respiratory failure may be more likely than refusal with other diagnoses, with the exception of the diagnoses of cardiac arrest and malignancy. Why respiratory failure appears to carry a higher risk for refusal is unclear. Possible reasons may be the impression that primary acute respiratory failure has a poor prognosis, even with ICU care, or that resource utilisation is higher than for other diagnoses.

Certainly recent data from our ICU show that the average length of ICU stay is longer for acute respiratory failure patients than for the rest of the ICU cohort (mean (± SD) of 8 (3) v. 4 (2) days).

In the context of acute respiratory failure requiring ICU admission, several studies have reported the short- and longer-term outcome of chronic obstructive pulmonary disease (COPD), asthma, acute respiratory distress syndrome (ARDS), idiopathic fibrosis, and malignant disease. The outcome in terms of survival for patients with a diagnosis of severe COPD exacerbation requiring ICU admission is surprisingly good – hospital mortality is reported as 6 - 24% and 1-year mortality as 35 - 49%. Recent studies of patients with ARDS requiring ICU admission have reported a hospital mortality of only 25 - 36%. In contrast, the prognosis of ICU-dependent respiratory failure from idiopathic fibrosis is very poor, with hospital mortality of 61 - 87%, and only 1 of 32 patients surviving 16 months in a recent study (90% of ICU cases died a median of 2 months after admission). It must be remembered that these reported cohorts represent patients selected for ICU care and this selected group may have a more favourable outcome than a general cohort of unselected patients with severe acute respiratory failure. Nevertheless, the prognosis of acute respiratory failure, with the possible exception of idiopathic fibrosis and malignancy, seems generally reasonable and by itself should infrequently lead to a triage decision, unless extremely severe resource limitation is evident. ARDS provides a further example of a condition that shows a remarkable improvement in fatality rate over the last 2 decades, and demonstrates how reference to older data could be misleading and lead to inappropriate triage.

Frequently survival is not related directly to the acute
severity of the respiratory failure itself, but rather to co-
morbidities or accompanying organ failure, and ARDS is a typical example of this phenomenon. Survival from ARDS is mainly related to the underlying cause and the presence or absence of organ failure, rather than the severity of gas exchange or chest radiographic changes, and triage decisions should be made on the basis of the most relevant factors. Although opinions have been expressed, publication of data examining outcomes from HIV-related acute respiratory failure in adult ICU patients would be of importance in the southern African setting.

Quality of life after acute respiratory failure is difficult to quantify, partly because it is an individual judgement and partly because few data on the quality of outcomes in ICU cohorts exist. Surprisingly, despite relatively normal lung function test results, recent data demonstrate that role limitation due to physical function limitation is common even 1 year after admission in survivors of ARDS. Similar findings have been noted in older, but not younger, survivors of severe acute respiratory syndrome (SARS). While quality of life outcome data such as this can assist in prognostication and allow better quality information to be provided to patients and family members, good data are currently too sporadic to allow meaningful interpretation to support decision making in the context of resource allocation.

Outcomes when triage is practised

There are data demonstrating that patients are denied ICU admission in several parts of the world and that many of these admission refusals are the consequence of triage decisions. Rates of refusal for resource limitations such as lack of beds, doctors, nurses or equipment in the UK have been reported to be 34% of a referred cohort with refused and admitted mortality rates reported as 46% and 37%, respectively. In Israel 24% of a referred cohort of patients were refused, of whom 63% appear to have been refused on the basis of triage. The corresponding mortality of refused and admitted cases was 46% and 14%, respectively. In France 43% were refused, of whom 35% appear to have been refused on the basis of triage. The corresponding mortality of triaged and admitted cases was 60% and 23%, respectively. In Hong Kong 38% of emergency referrals were refused, of whom 44% were identified as having been refused on the basis of triage using a utilitarian model. The corresponding mortality of triaged and admitted cases was 64% and 37%, respectively. Even adjusted for severity of illness, there was an excess mortality associated with triage out of the ICU in the HK cohort. The excess mortality was also noted to be most marked in patients whose illness was in the mid-range of severity. Those who are relatively well and those who have very severe illness appeared to suffer less excess mortality when triaged out of the ICU, suggesting that if patients in the mid-range of illness could be consistently identified and preferentially admitted overall mortality could be reduced. If a utilitarian approach is to be adopted, further attempts to improve identification of patients who would benefit from ICU should be strongly encouraged.

Cultural factors

Cultural and religious factors are known to influence ethical decision making and attitudes in intensive care medicine. South Africa is a multi-cultural and multi-religious society and individuals may be subject to a clash of values. A detailed discussion of these issues is beyond the scope of this paper; however, an awareness of the influence of such diversity can help to identify causes for conflicting views.

Conclusion

Triage decisions are complex and present both moral and practical problems. The first step is to differentiate reasons for refusal of ICU admission into those based on triage, futility or an autonomous patient decision. This has implications with regard to honesty in communication with colleagues, patients and the public, but also has important practical dimensions. For example, if refusal is commonly a result of triage, then vigorous attempts to increase resources must be made; however, if refusal is commonly decided on the basis of patients’ lack of desire to undergo burdensome ICU care, no further ICU resources are justified. Patient and societal views and expectations can be expected to change with time and if we are not clear about the basis of our decision making, erroneous planning and actions will result.

Triage decisions, like all clinical decisions made on an individual basis, are subject to arbitrary variations. Guidelines that make the decision process explicit and ensure that it is made with due care should help reduce variability of triage decisions. More frequent use of processes such as ‘accountability for reasonableness’ may improve the quality of institutional guidelines and promote consistency of decision making in specific subgroups of patients. Lastly, as professionals we should resist all extraneous influences such as political and economic pressures that have no place in determining rationing decisions.

Triage decisions carry a heavy burden. They are associated with an excess mortality, even after being adjusted for severity of illness following a utilitarian model of triage. It might be expected that an egalitarian model would result in even greater attributable mortality. If a utilitarian model of triage is accepted, preliminary data suggest that patients who benefit most from admission can be identified and therefore strategies could be developed to create admission criteria that would be able to identify these
patients at the time of consultation. Currently, some data exist that support the objective of admitting those in the mid-range of illness severity, but substantially more data demonstrating the real benefit of admission to ICU in a wide range of critically ill patient groups are urgently needed. Given the likely increase in demand for ICU resources in the future, it is essential that strenuous efforts are made to minimise the risk of resource limitation.