As efforts to improve end-of-life care have increased, policymakers and administrators have sought quality measures to evaluate clinicians’ and hospitals’ performance. These efforts are a critical step toward achieving lasting and widespread improvements in care near the end of life.

Quality measures influence policy and practice by serving as the basis for public reporting, reimbursement, and accreditation. In addition, quality metrics endorsed by authoritative organizations carry normative weight: they influence how people define good (and bad) medical care. Therefore, quality measures should be based on strong clinical evidence and should be tightly linked to outcomes that are important to patients or society. Resource allocation considerations may also be relevant in formulating end-of-life quality metrics. However, there is considerable controversy on this point and a detailed discussion is beyond the scope of this commentary.

One metric that has been proposed as a marker of poor end-of-life care is a patient’s death in an intensive care unit (ICU) or within a short period of time (eg, 1 month) after discharge from an ICU. For example, a recent article evaluating the impact of advance directives on the quality of end-of-life care defined “ICU admission in the last month of life” as poor quality end-of-life care. In this formulation, the quality metric is a per-patient determination, in the sense that every ICU death is judged individually to represent poor quality end-of-life care. This per-patient metric is to be contrasted with a population-based metric, which makes no judgments about individual cases and instead evaluates the proportion of a population that experiences the outcomes of interest (eg, 10% of Medicare beneficiaries being admitted to an ICU in the month prior to death).

To inform the current policy debate about end-of-life quality metrics, we will examine whether a per-patient measure of receipt of ICU care in the last month of life should be an end-of-life quality metric. We argue that the per-patient formulation does not satisfy basic requirements of high quality quality metrics and that its use could have unintended negative consequences on the quality of care in ICUs. We summarize what is known about patients’ preferences for care in the context of critical illness and highlight the problems that might arise if this metric, originally proposed as a population-level metric for patients in the very latest stages of advanced cancer, is applied as a per-patient metric to a heterogeneous group of patients with acute critical illness. Finally, we examine the potential to refine the metric to overcome these concerns.

Balancing Competing Preferences

Many Patients Want to Avoid High Intensity Treatment if Dying, But Also Want to Survive if Possible. The main reason given to support the argument that death in an ICU is poor quality end-of-life care is data that indicate home is the preferred site of death for many patients. Although there are some concerns about these data, we think it is reasonable to assume that, all other things being equal, the overwhelming majority of patients do not wish to die attached to invasive life support in a highly technological environment. However, there is another relevant consideration: many patients have a powerful desire to survive if survival with an acceptable quality of life is possible. In the context of acute, potentially reversible critical illness, there is a conflict between the preference for a nonmedical option and the preference to receive treatments that maximize the chance of surviving an acute episode, which may require ICU treatment.

What do we know about how patients balance these competing preferences? The best data comes...
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from a study by Fried and colleagues7 of 226 seriously ill elderly patients. They found that a large proportion of patients were willing to accept ICU care (even at the risk of dying in the ICU) if it increased the likelihood of surviving the acute illness. Preferences varied according to the duration of required ICU care and the likelihood of surviving without functional impairments.7 Using similar methods, Lloyd and colleagues8 found that roughly half of hospitalized patients would accept intensive care if it resulted in a 40% or greater chance of surviving the acute illness.

These data indicate that, for at least some patients, there is a tension between the preference to avoid a technological death and the preference to survive a potentially reversible critical illness. Some patients would judge treatment in an ICU in the face of an uncertain prognosis to be part of a patient-centered care plan, even if they ultimately die in an ICU. Consequently we are concerned that a per-patient quality metric involving ICU admission in the last month of life may not satisfy the fundamental requirement that the metric reflects clear evidence about patient preferences.

Heterogeneous ICU Populations

Patients Who Die in ICUs Often Cannot Be Prospectively Identified as “Dying Patients.” The idea to designate the occurrence of death in or shortly after ICU discharge as a quality metric first arose in the field of oncology.9 The idea was that patients with very advanced solid tumors could be readily identified and generally have a fairly predictable illness trajectory in the final weeks and months. These facts, combined with the reasonable belief that most individuals would prefer not to die in an ICU in the late stages of a terminal disease, led Earle and colleagues9 to suggest that “death in an ICU” for patients with advanced cancer might be a marker of poor quality end-of-life care. We agree that there is potential for this performance measure to be a suitable population-based quality metrics for patients with advanced cancer.

However, there are major problems with generalizing this metric to heterogeneous ICU populations. Many critically ill patients do not have end-stage conditions, nor a clearly fatal illness at presentation. Consequently, the empirical reality is that it is rarely possible to make accurate, prospective (pre-ICU admission) judgments that individual patients cannot survive their acute illness. This poses a serious problem for the quality metric because as the prognostic uncertainty increases, so too does the possibility that ICU care is desired and will be beneficial.

ICU case mix matters tremendously. For example, consider an ICU that admitted 100 patients in a particular month. Assume that 70 of those patients did not have an end-stage chronic condition, preferred ICU care for potentially reversible illnesses, and were admitted with an acute critical illness that carries a roughly 50% mortality rate (eg, septic shock and acute lung injury). If 35 of those 70 patients died in the ICU as would be expected, there is little reason to believe that the simple fact that they died in the ICU indicates their end-of-life care was of poor quality. Alternatively, if the case mix of the ICU was largely composed of patients in the latest stages of a terminal condition, one could reasonably wonder whether they were receiving care consistent with their values and preferences. In light of the known case-mix variability in ICUs, a quality metric that distinguishes between patient-centered and non-patient-centered ICU care near the end of life is needed, rather than one that labels all ICU deaths as poor quality end-of-life care.

The Side-Effects of Labels

Unintended Consequences of Labeling All ICU Deaths as Poor Quality End-of-Life Care. There are at least 2 potential unintended consequences of labeling death in an ICU as poor quality end-of-life care, particularly if hospital reimbursement is linked to
hospital performance on the measure. First, it might create a disincentive to treat patients according to their values and preferences. For example, such a metric might create a bias against admitting patients with acute, potentially reversible illnesses for whom there is a relatively high risk of death. As noted above, many patients would prefer a trial of ICU care in these circumstances, but these patients’ deaths could jeopardize a hospital’s quality rating. Such a metric might also create a bias against transitions to palliative goals of care in patients whose illness progresses after ICU admission or who develop ventilator dependence. Instead, the metric may create a perverse incentive to transfer the patient to a long-term acute care hospital for ongoing disease-focused treatment. For some patients, this would pose a serious threat to patient-centered care. Some may argue that clinicians and institutions are immune to such unintended effects, but the negative impact of public reporting of 30-day coronary artery bypass graft surgery outcomes on surgeons’ willingness to take on high risk cases should serve as a cautionary tale.10

Second, such a metric might create moral distress or negative morale amongst ICU clinicians who are committed to providing high quality care for dying patients. A per-patient metric that adjudicates every ICU death to be a bad death may be interpreted to mean that ICU clinicians’ efforts to care for dying patients are not viewed as important or beneficial by those charged with defining high quality end-of-life care.

Another alternative might be to use the approach that Earle and colleagues’ suggest, which would apply the metric across a population rather than to individual cases. This approach would answer a slightly different question: “What proportion of patients in the population receive ICU care around the time of death?” To create a useful measure, 2 preliminary questions would need to be answered. First, who is the population under study (ie, who is included in the denominator?). Second, given what we know about the case mix and values of the population, what is the appropriate proportion of patients receiving ICU care around the time of death? This, too, would require data that is not routinely collected, but could be acquired using survey methods among a representative sample of the patient population.

We encourage creative efforts to refine this measure and to develop other robust quality metrics to improve end-of-life care for seriously ill patients, regardless of where they receive their care.

Overcoming Limitations

Could the Measure Be Refined to Create an Acceptable End-Of-Life Quality Measure? There are several potential ways to refine the measure to overcome these limitations. First, if the goal was to retain a per-patient metric, the metric would need to be refined to answer the arguably more important question: “Did the care provided match the individual patient’s treatment preferences?” To answer this question, information about individual patient’s preferences would need to be collected. This would require a scale of effort not previously seen for quality measures, but one could imagine ways to gather this information either prospectively through advance care planning efforts or retrospectively through interviews with surrogate decision makers. Each approach poses methodological and logistical challenges.

REFERENCES

