

Making the Decision to Withdraw or Withhold Life Support: Thoughts and Questions

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Abstract

Aim-Background The severity of illness of patients who enter the intensive care unit (ICU) render it a setting where death is common. End-of-life decision-making for the ICU patient has been a hot topic in recent years. This paper presents our comments, concerns and thoughts for making the decision to withdraw or withhold life support in the ICU. What is the optimal approach to such decisions? What are the indications, benefits, and ethical dilemmas of either choice? What is the current preference worldwide?

Methods The databases that were searched included The Cochrane Library Database, Medline, and EMBASE. Articles were also identified through a general internet search using the Google search engine.

Results As a general principle, when the goals of care cannot be achieved with aggressive life-sustaining treatments, it is appropriate to withdraw these treatments and to allow death to occur. However, decisions concerning withdrawal of life support remain one of the most difficult emotional burdens for an ICU team given that these decisions encompass complex emotional and ethical questions that affect patients, family members, and care providers.

Conclusions Doctors must have the conscience or the “courage” to stop a treatment which no longer makes sense, provides no further benefit to the patient, causes discomfort or pain and prolongs the use of limited resources. Doctors are privileged to be able to assist their patients in their final journey through the dying process. As such, they have a duty to ensure that their patients die with dignity. Although doctors may stop active treatment, they must never stop patient care; withdrawal of therapy does not mean withdrawal of care.

Key words ICU; end-of-life decision; withhold; withdraw; life support

Introduction

The severity of illness in patients who enter the intensive care unit (ICU) lends itself to a setting commonly associated with death. Approximately 20% of all deaths in the United States occur after admission to an ICU [1], while approximately 50% of deaths in an ICU occur following the withdrawal or withholding of life support [2].

In spite of great advances in technology and medical knowledge, ICU physicians are well aware that some patients will inevitably die despite their brave efforts. End-of-life decision making for the ICU patient has been a topic of heated debate in recent years, in the knowledge that such practice is common worldwide [3]. As a general principle, when the goals of care cannot be achieved with aggressive

life-sustaining treatments, it is appropriate to withdraw these treatments and to allow death to occur [3]. However, decisions concerning the withdrawal of life support remain one of the most difficult emotional burdens for an ICU team due to the fact that such decisions encompass difficult emotional and ethical questions that affect patients, family members and care providers.

Withholding and withdrawing therapy concepts

Withholding or withdrawing represent the two practices that could be adopted following the decision to limit life-sustaining therapy. Withdrawal of therapy is defined as the removal of a therapy that was initiated in an attempt to sustain life but has become futile and merely prolongs the dying process. Withdrawal usually entails therapies such as mechanical ventilation and administration of vasoactive agents. Withdrawing has been seen as an ‘action’ rather than the passive ‘omission’ of withholding [4]. For example, the immediate consequences of an active decision to withdraw mechanical ventilation in a patient who is unable to breathe spontaneously will not differ from those of a “passive” deci-

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Received 28 Feb 2013; Accepted 26 April 2013

sion not to start mechanical ventilation.

Most physicians have experience with life support withdrawal and greater exposure to ICU patients is associated with more withdrawal experience. This attitude reflects a physician's intended behaviour rather than actual practice while the willingness to withdraw life support does not represent a disposition independent of the context of clinical management. It seems that younger physicians are more likely to withdraw life support and physicians at tertiary care medical centres are more willing to than those in non-tertiary care hospitals [5].

Withholding therapy involves the concept of no therapeutic escalation. Perhaps the most common example of this is the "do not resuscitate" (DNR) or the "do not attempt to resuscitate" (DNAR) order. The vast majority of doctors accept the principal of withholding; were they not to withhold life-sustaining therapies from some patients, ICUs would be full of terminally ill patients with no hope of recovery. The only people to challenge the withholding of therapy are those who hold a very strong religious belief that life must be sustained at all costs.

Decision making variables

Several significant variables could be implicated in a decision to withhold life-sustaining treatments in the ICU. These variables represent patient demographics, severity of illness, comorbidities, diagnosis on ICU admission, ICU admission source, patient's initial response to treatment, baseline quality-of-life assessments, religion, concerns about becoming a burden, and patient and family preferences for life-sustaining treatments.

Ethical conflicts are not uncommon between critical care physicians and nurses involved in end-of-life care. These conflicts can arise as a consequence of multiple factors including physician withdrawal from physical and emotional contact with the patient and family; a feeling among some nurses is that they have more of a moral position because they provide minute to minute continuity of care, and while physicians write instructions regarding end-of-life management, it is the nurses that implement them [6].

Several factors account for the great variability in the end-of-life categories between countries. First and foremost are the different religions and cultures. Religious affiliations have been shown to influence physician attitudes toward withdrawal of life support [5,7]. Research has demonstrated that physicians who are Protestant, Catholic or of no religious faith more readily use withdrawal of life sustaining treatments than those physicians who are Greek Orthodox, Jewish, or Muslim [5]. Second, different cultures among countries adopt diverse approaches; in the United States, the medical model promotes autonomy and self-determination

while in Europe, patient-physician relationships remain somewhat paternalistic [8].

Current questions, possible answers, and future expectations

We wonder whether we have gone too far in recommending that life support be withheld or withdrawn from some patients for whom further care would not be futile and in suggesting that care could be forgone in certain circumstances without the agreement of patients or their surrogates. Furthermore, we always have in mind that as regards our view of limiting care for certain critically ill patients, the majority of physicians feel comfortable with the idea that not all demands upon them must be met and that life need not be supported at all cost. Nevertheless, we have realized that we must be very cautious in exercising our influence over patients to forego life sustaining therapy in the ICU. We argue that physicians do not have a responsibility to provide futile or unreasonable care even if a patient or surrogate insists on it. Our argument is based on the belief that physicians have a professional obligation and a social sanction to provide only therapies that are beneficial, to avoid harm, and to allocate medical resources wisely. We also believe that physicians may misjudge the probability of survival following an intervention and fail to determine what quality of life is acceptable to their patients while the recommendation to limit care may be preceded by a discussion of quality-of-life issues between physicians and patients or their surrogates. Furthermore, we think that recommendations made after these requirements reflect the physician's obligation to seek benefit and do no harm.

In most instances, patients and surrogates accept physician recommendations to limit care if sufficient time is afforded them to consider these recommendations. Nevertheless, on rare occasions, they insist that care be continued and cannot be dissuaded from this position, presumably because they disagree with the prognosis physicians have provided them. When this occurs, our belief is that we should not withhold or withdraw life support on the sole basis of our personal notions of futility, but instead should rely on institutional or multi-institutional futility policies. Although their input is desirable, administrators, even if they are physicians, should not be allowed to impose futility policies that serve primarily to protect the bottom line of their business. Preferably, policies should be developed by physicians, nurses, and other health professionals in concert with patients, community leaders and, when appropriate, participants in managed-care organizations.

What is the quality of life of those patients who are permanently unconscious and totally reliant on medical expertise for even the most basic of bodily functions?

Though the medical progress in supportive therapies that enable organ functions to be maintained while a patient recovers from a serious illness is indeed remarkable, it should be restricted to those who stand to benefit from such therapies, and not be abused to maintain “life” without quality or meaning indefinitely. We argue that withdrawal should be permitted. We consider this practice to be ethically equivalent to withholding, if not more appropriate in some cases. Were the withdrawal of therapy not permitted, ICUs would be full of hopelessly ill patients receiving often costly treatment and, more to the point, of no benefit to them. This process would be against the ethical principles of autonomy, beneficence, non-maleficence, and distributive justice. Furthermore, if withdrawal of therapy is not permitted, this may introduce a degree of hesitation in our actions when time is of the essence. For example, we may hesitate before instituting mechanical ventilation in a patient with acute respiratory failure because we are not in possession of that patient’s full history and the therapy may emerge as futile, and its later withdrawal may be impracticable. However, the slightest hesitation in a patient who stands to benefit from the therapy could make all the difference to their chances of survival. The knowledge that we can withdraw a therapy at a later date could allow the patient to receive timely emergency care.

So what is the optimal approach to such decisions? End-of-life decisions should be made in advance whenever possible. These are difficult issues, and it is often easier to postpone them; however, death should be seen as a natural and necessary process, not as a failure. Our standpoint is that all eventualities should be discussed and covered before they arise. This applies particularly to decisions to withhold therapy because there is often very little time to decide when the situation arises. Preparing for the worst outcome in advance allows everyone time to reflect, to say what they feel, and to be involved in the decision. It is also important that end-of-life decisions are made by the “paternalistic” physician, by consensus, after open discussion involving nurses, the patient - although this is an uncommon situation in the ICU - and the relatives. When patients are not in a position to make an informed decision themselves, relatives must be informed and involved in the discussions, but they should not be the ones to decide. We strongly believe that to ask relatives to make such end-of-life decisions is unacceptable; to burden them with such a heavy responsibility at an already difficult time would be most unfair, particularly given that they possess neither the required medical knowledge nor expertise. In addition, their decision process may be altered by emotive personal reactions and possibly even by personal interest. Any such discussions and decisions should be documented clearly in the patient notes.

We support that enough time must be allowed for end-of-life discussions for the medical and ICU team on one side and for the patient and the surrogates on the other. The gravity of the situation requires that the patient’s family has the time to understand the remaining option and receives transparent, timely, individualized, balanced information that allows them to make a genuinely informed choice among the treatment options or early withdrawal of treatment because of the poor odds of a meaningful recovery. Ideally, such decisions would be made with the patient’s family on the basis of input from clinicians and communicated data concerning overall prognosis.

To achieve this optimal approach, we must first recognize “patient centredness” as an end in itself and a legitimate aspect of health care quality that must be measured and improved. Evidence-based medicine must be combined with preference-based medicine, especially in situations in which evidence fails to provide a clear verdict to guide treatment. In situations involving significant trade-offs between a patient’s quality of life and length of life, quality of care cannot be measured by the rate of death alone; its assessment must also include key information about prognosis, morbidity, and patient preferences.

Over the last decades, there has been growing concern regarding end-of-life care in patients with either advanced cancer or other terminal illnesses. The financial cost, emotional burden, and failed expectations of this situation can take a heavy toll on patients, family members, and society. Longstanding economic constraints, common to all healthcare systems, exert pressure on the need to ration ICU care ethically. Curbing the demand for futile medical services by limiting access to the ICU of patients who are most likely to die has been proposed as a theoretical model to lower expenditures. For example, in patients with a sudden cardiac arrest, their time in the ICU and length of hospitalization is often protracted, thereby incurring high healthcare costs. The prognosis for patients who survive cardiac arrest is often considered dismal, posing the question as to whether they should be admitted to the ICU: costs are expected to be high and benefits are anticipated to be moderate at best. Objective cost-outcome studies, integrating costs and quality-adjusted life years gained are required to determine whether ICU admission constitutes a reasonable use of constrained resources in this patient population. Furthermore, there is a dilemma as to patients surviving hospital discharge with severe neurological deficits (with a GCS score of less than 6 points). What is the quality of life of such a patient? To the best of our knowledge, we cannot judge. On a utility scale from zero (death) to one (perfect health), such patients would definitely not be rated as one but, in all probability, could not be considered as zero either.

An increasing number of healthcare alternatives, such as

home hospice care, have now become available for patients with advanced cancer or other terminal illnesses. These aim at providing less aggressive but more patient-centred care during the last months of life. As an alternative to the more aggressive end-of-life care, hospice care emerges as a more humane and appropriate way of caring for the terminally ill, incurring less cost than traditional care.

Conclusions

In all cases, the patient should be our main concern. However, in futile cases, we have a duty to stop therapy without further delay; to continue mechanical ventilation or extra support in a patient who has no real chances of recovering a meaningful life serves no purpose. Indeed, it should not be commenced if the benefit to the patient is negligible. We strongly believe that we must have the conscience or fortitude to stop a treatment which no longer makes sense, provides no further benefit to the patient, causes discomfort or pain, and prolongs the use of limited resources. As doctors, we are privileged to be able to support our patients throughout their final journey, and ensure that they die with dignity. To cease active treatment is not to cease patient care.

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Παίρνοντας την Απόφαση για τη μη Κλιμάκωση ή την Απόσυρση της Υποστήριξης της Ζωής: Σκέψεις και Διλήμματα

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Περίληψη

Σκοπός Λόγω της σοβαρότητας της κατάστασης των ασθενών που εισέρχονται στη μονάδα εντατικής θεραπείας (ΜΕΘ), αυτή αποτελεί ένα περιβάλλον, όπου ο θάνατος αποτελεί κοινή παραδοχή. Η απόφαση του να τεθεί τέλος στη ζωή κάποιου βαρέως πάσχοντος ασθενούς στη ΜΕΘ αποτελεί σημαίνον θέμα τα τελευταία χρόνια. Η παρούσα εργασία καταδεικνύει τις παρατηρήσεις, ανησυχίες και σκέψεις μας για τη λήψη αποφάσεων σχετικά με τη μη κλιμάκωση ή την απόσυρση της υποστήριξης της ζωής στη ΜΕΘ. Ποια είναι η βέλτιστη προσέγγιση για τέτοιες αποφάσεις; Ποιες είναι οι ενδείξεις, τα οφέλη και τα ηθικά διλήμματα της κάθε επιλογής; Ποια είναι η τρέχουσα αντίληψη παγκοσμίως;

Μέθοδος Οι βάσεις δεδομένων που ερευνήθηκαν περιελάμβαναν την Cochrane Library Database, Medline και EMBASE. Τα άρθρα εντοπίστηκαν επίσης μέσα από μια γενική αναζήτηση στο διαδίκτυο χρησιμοποιώντας τη μηχανή αναζήτησης Google.

Αποτελέσματα Ως γενική αρχή, όταν οι στόχοι της φροντίδας του ασθενούς δεν μπορούν να επιτευχθούν με τις διαθέσιμες θεραπείες, είναι σκόπιμο κάποιος να αποσύρει αυτές τις θεραπείες και να επέλθει ο θάνατος. Ωστόσο, η απόφαση σχετικά με την απόσυρση της υποστήριξης της ζωής παραμένει ένα από τα πιο δύσκολα συναισθηματικά φορτία για την ομάδα ιατρών της ΜΕΘ γεγονός που οφείλεται στο ότι οι αποφάσεις αυτές περιλαμβάνουν δύσκολες συναισθηματικές και ηθικές ερωτήσεις που επηρεάζουν τους ασθενείς, τα μέλη της οικογένειας τους και τους παρόχους υγείας (ιατρικό και νοσηλευτικό προσωπικό).

Συμπεράσματα Οι γιατροί πρέπει να έχουν τη συνείδηση ή το «θάρρος» για να σταματήσουν μία θεραπεία η οποία δεν έχει πλέον νόημα, δεν προβλέπει περαιτέρω όφελος για τον ασθενή, προκαλεί δυσφορία ή πόνο, και παρατείνει τη χρήση περιορισμένων πόρων. Οι γιατροί έχουν το προνόμιο να είναι σε θέση να «βοηθήσουν» τους ασθενείς τους μέσα από τη διαδικασία του θανάτου. Ως εκ τούτου, οι γιατροί έχουν καθήκον να εξασφαλίζουν ότι οι ασθενείς τους να πεθάνουν με αξιοπρέπεια. Αν και οι γιατροί μπορούν να σταματήσουν την ενεργή θεραπεία, δεν θα πρέπει να σταματήσουν ποτέ τη φροντίδα των ασθενών? Διακοπή της θεραπείας δεν σημαίνει απόσυρση της φροντίδας.

Λέξεις κλειδιά ΜΕΘ, απόφαση τέλους της ζωής, μη κλιμάκωση, απόσυρση, υποστήριξης της ζωής

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