

End-of-life Care: Challenges and Obligations in Setting Limits to Life-sustaining Therapy

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Abstract

It is now generally accepted that the withholding or withdrawal of interventions that serve only to prolong the dying process is appropriate. Setting limits to life-sustaining therapy are now common practice. However, making such decisions can be challenging. They are also not uncommonly a source of disagreement between the physician and the patient or surrogate. The potential for strained patient-physician relationship can be mitigated by patient-centred, goal-specific care with its emphasis on effective communication, a sense of timing and attention to the various dimensions of the illness experience.

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Introduction

A patient with recurrent stroke disease and severe pneumonia did not respond to the previous courses of antibiotics. The medical team decided to switch to another broad-spectrum antibiotic. The consultant in-charge informed the medical officer and ward registrar to “speak to her relatives, inform DIL (Dangerously Ill List) and discuss DNR (Do Not Resuscitate) status with them”. The medical officer duly met the family.

A previously active 75-year-old man was admitted with a brainstem stroke. He had a myocardial infarct in the ward and was intubated. Inotropes were required to maintain his blood pressure. He developed nosocomial chest infection and was ventilator-dependent. He remained unresponsive. One week into intensive unit care, the medical team met his daughter to discuss further management.

For many of us, the above scenarios are all too familiar. Some time in the course of caring for a terminally ill patient, it may become apparent to the clinician that further intervention may only prolong the dying process. Many questions relating to the extent of intervention may arise. Decisions must be made with regards to resuscitative efforts and the use of therapy, such as haemodialysis, chemotherapy or surgery. Even the decision to withhold or withdraw less invasive treatments, such as antibiotics, transfusion and parenteral hydration, in those with advanced life-challenging illnesses may not be any easier.

Challenges in Setting Limits to Life-sustaining Therapy

“Palliative care affirms life and regards dying as a normal process, neither hastens nor postpones death.”¹

Many clinicians will have encountered situations when they had to evaluate the appropriateness of life-sustaining efforts and to discuss this with patients and/or their families. Making these decisions would be more straightforward if we know when an intervention is futile, if we are aware of patients’ preferences, if we have their trust and society, as a whole, can afford the interventions in question. However, this is clearly not the case.

Futile Care: Can We Define It?

The futility concept has been used to claim authority in decision-making independent of patient’s choice. However, to determine that treatment is futile involves value judgements of 2 types. Firstly, the treatment will not have any consequence that is beneficial for the patient. Secondly, the likelihood of benefit is too remote to make the intervention worth taking.

Who, then, is the judge of beneficence? The qualitative definition proposed by Schneiderman et al² considers treatment that merely preserves permanent unconsciousness or that fails to end total dependence on intensive medical care as futile. Turning to the goals of medicine, Schneiderman et al argued that “medicine has the effect to produce a whole lot of effects – none of these is a benefit

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unless the patient, has at the very least, the capacity to appreciate it”.³ To maintain patients in a persistent state of unconsciousness or preoccupation with illness is considered an act of futility. Therefore, if the best outcome physicians can achieve is to keep the patient perpetually in the intensive care unit, the treatment should be regarded as futile. Some extend this to treatment that does not enable a patient to be discharged from hospital. Under such circumstances, it has been argued that such care need not be offered and if present, withdrawn. It is apparent from the aforementioned that what constitutes medical benefit is subjective. In addition, is good only limited to the medical or organic sphere? How about the psychological, social and spiritual dimensions? Would “buying time” for relatives to turn up at the bedside or to come to terms with the patient’s illness, or for patients to reach a symbolic birthday be considered a benefit? How do we view time given for families to accept an impending loss? Would allowing care that may be considered futile normally, be deemed beneficial if it meets an emotional need? To be congruent in such decision-making requires that the values held by the patient or surrogate are similar to, or at least respected by, the physician. It also demands an empathetic relationship between the physicians and patients (or surrogates), whose affective responses, such as denial or guilt, may lead them to insist on treatment goals that are not achievable.

Furthermore, how certain are we of our ability to gauge prognosis accurately? The 1 in 100 guiding principle is widely touted.² Hence, futility exists when a physician concludes (either through personal experience, experiences shared with colleagues or consideration of empirical data) that, in the last 100 cases, a medical intervention has been useless. Other than the cases of “physiological futility”, this has been found to be impractical and far from the reality that clinicians practise in. Prognostication is an imprecise science and even “objective” systems of prognostication (such as APACHE⁴ and the Palliative Prognostic Index⁵) at best provide accurate prognostication for groups and can only be used as adjuncts in discussions with individual patients. They are not solutions to the problem of defining the level at which a treatment might be called futile.

In a recent study,⁶ 41 intensivists completed a questionnaire which posed grounds for withdrawing or withholding therapy in 10 clinical test cases. There was marked variability in end-of-life decisions, with >30% of respondents choosing extremes of care in 5 out of 10 cases. Another study⁷ in Canada also illustrated similar diversity in decision-making at the end of life. An ethnographic study⁸ carried out in various centres in the United States and New Zealand demonstrated that end-of-life care varies according to the administrative model. These studies do not give comfort to cynics of our ability to judge the futility of care and to practise it in a consistent manner.

Patient Choice: Do We Know It?

Central to patient-centred care is awareness of patients’ needs and preferences. In a Canadian study⁹ conducted amongst seriously ill patients, 90% of patients preferred to be consulted on decisions with regards to end-of-life issues. Despite this, only 36% had discussed end-of-life issues with their doctor. Using cancer disclosure rates as a surrogate,^{10,11} this figure can be assumed to be lower in the local population. By the time such decisions become crucial, the decision-making capacity and competency of patients are often in doubt. In the absence of clear patient preference, families are often the accepted proxies. This is clearly far from ideal as many studies^{12,13} have demonstrated poor agreement between patients and their surrogates over the use of life-sustaining measures at the end of life.

In addition, information is not always conveyed in a manner that can be understood by patients and their families. A study by Murphy¹⁴ in a chronic care setting found that only 10% of patients have DNR orders, implying that 90% wished to be resuscitated in the event of collapse. However, when the approach was changed from determining if the patient wanted to be resuscitated to discussions about the role, likelihood of success and invasive nature of resuscitation, the residents overwhelmingly rejected cardiopulmonary resuscitation.

Trust: Do We Have It?

Most end-of-life discussions with patients or surrogates are not contentious. However, disagreements do sometimes arise. Why would patients and physicians disagree over limits of care?

Mistrust of the physician or healthcare system breeds disagreement. The rising tide of malpractice claims¹⁵⁻¹⁸ suggests that physicians have lost the treasured relationship of years past. Perceived limitation of care based on ethnicity and social standing may lead patients to demand more aggressive therapy. In addition, stories about how patients recovered when intervention was deemed “futile” add to the suspicion when doom is forecast. Moreover, patients or their relatives may be in a state of denial and disbelieve what has been said, turning instead to another doctor, alternative therapy or religious miracles. Finally, the tendency for physicians to hedge their bets may give rise to misunderstandings. Physicians are afraid to be wrong. So we learn “never to say never”. When a physician says “there is only a very small chance that she will survive”, what relatives may hear instead is that “there is small but possible chance that she may survive”. This has led Lantos¹⁹ to say that if we mean that a treatment will offer no benefit, we should say so.

Resources: Can We Afford It?

Conflicts over perceived futile treatment take on added

significance when scarce resources are at stake. Arguments about providing something that does not cost much such as amoxycillin for a patient in the terminal stages of carcinoma of the lung with fever, are interesting, but not compelling. There will be greater angst in allowing ventilatory support for a patient with hypoxic encephalopathy in order that her family may come to terms with her illness and eventual death. Clearly, we cannot deliver any care that the patient demands or hopes for. Motivated by a sense of social responsibility, we may be forced to make difficult decisions and to limit costly interventions. In providing care to a patient who has little chance of having what we judge as a meaningful life, we may have used resources that could have been more beneficial to others.

Time is also a resource that we are often hard pressed to provide. Even as the healthcare system is pressured to be efficient and cost-effective, we cannot deny that caring takes time. It is seemingly easier and more efficient to write a prescription of diazepam than to listen to the wife of a dying patient talk about her grief. Yet, we know that setting time aside to talk and listen to her is the compassionate thing to do.

Physicians' Obligations in Setting Limits to Life-Sustaining Therapy

We are now in the post-Quinlan²⁰ era. Setting limits to life-sustaining therapy has become common practice. Surveys in North America showed that most deaths in intensive care units follow a deliberate, considered decision to withhold or withdraw some form of life-supporting therapy.^{21,22} Through a process of balancing the various ethical principles of beneficence, non-maleficence and justice, physicians should arrive at a decision of what interventions would fall within the standard of care with its attendant duty to disclose.²³ Where uncertainty exists, opinions of colleagues and peers should be sought.^{6,24} Most families are open to setting limits on intensive care, and most discussions on withdrawal or limiting interventions do not become acrimonious. However, there are occasions when differences in opinion occur. Some physicians even acknowledge to performing the "slow code", or have actually stopped such treatment, in spite of the patient's or surrogate's request to the contrary.^{25,26}

How do we avoid such situations? How do we ensure that the relationship between the patient or surrogate and us is one characterised by trust and respect? The key here is patient-centred, goal-specific care, and it involves effective communication, a sense of timing and attention to the various dimensions of the illness experience.

Effective Communication

There are 4 areas of focus when discussing the limits of life-sustaining therapy.

The first area involves *treatment planning*, when the emphasis of discussion should be on the goals of care rather than the treatment. Physicians often ask patients and families if they want cardiopulmonary resuscitation, artificial ventilation or haemodialysis with little or no attention to the goals these interventions may or may not serve. In the first scenario described at the beginning of this review, an example of treatment-focused discussions may be: "Your mother is currently very ill. If she develops breathing difficulties, do you want us to put her on a respirator?" Discussions phrased in such a manner may invite various unintended responses: "Of course, you are a doctor. You are supposed to help her". In the second scenario, a discussion on the discontinuation of life support may precipitate a response such as: "You want me to pull the plug?" Intervention options offered without making clear the possible outcomes may confuse, support illusions of unachievable goals and place undue pressure on the patients or surrogate decision-makers.

In goal-specific discussions, the aims would be to identify what outcomes specific interventions would achieve and which would be desirable for the patient. For example, aggressive intervention may, at best, mean that the patient is discharged in a severely disabled state requiring assistance in all aspects of life. The family may deem the outcome as undesirable and, therefore, reject the interventions that accompany such a choice, choosing instead comfort measures only. On the contrary, if the family accepts the possibility of such an outcome, they may request for aggressive intervention. In the first scenario mentioned earlier, this would mean intensive care unit management with mechanical ventilation. In the second scenario, a tracheostomy will be required. Even if the desire is to sustain life, the burdens of intervention (such as the pain of continual mechanical ventilation and the risk of tracheostomy) may not be acceptable, with life-sustaining therapy ultimately rejected.

The second area involves *participatory decision-making* between the healthcare team and the patient (or surrogate) as opposed to the dichotomy of patient autonomy and physician paternalism. The patient-doctor relationship is not a relationship between equals. Just as we have moved away from the era of unilateral decision-making, we must view patient autonomy in its proper perspective. Firstly, the doctrine of informed consent does not give patients and their families the right to choose any treatment they want. What it does is to offer patients a right to choose between (or request) treatment interventions that fall within the standards of care. Secondly, physicians have been entrusted with the responsibility of making clinical judgements. This elevates them above the role of a technician following orders or a waiter offering a menu. The physician provides information about the patient's diagnosis, the differential

consequences of alternative treatments and the uncertainties pervading these assessments. The patient or surrogate articulates personal choices or wishes that may be affected by the treatment choices. Crucial to patient-centred care is the physician's understanding of the motivation of patients and families. Together, they arrive at an agreement about what health-related outcomes ought to be pursued and what interventions should be employed to achieve them.

The third area involves *surrogacy*, and the aim here is to direct surrogates to make decisions based on what the patient would have wanted. Sixty per cent to 70% of seriously ill patients are unable to speak for themselves when decisions to limit treatment are contemplated.^{27,28} Locally, few people have completed advance medical directives. Living wills and value statements are new concepts even in countries that are advocating their use.

Physicians need to advise surrogate decision-makers on how to base their decisions. In order of preference, decisions should be made on the basis of the patient's previously stated wish, inferences based on patient's known values or life goals, or the patient's best interest as judged by weighing the benefits and burdens of treatment. By helping surrogate decision-makers aim for the first 2 standards (substituted judgement), the physician can lessen the burden in making judgements of this nature. Therefore, when the decision is to limit care, the change in perspective from "giving up" to "letting go" because this is "what the patient would have wanted", makes it a little easier to bear emotionally.

The last area involves *aiming for a therapeutic conversation*. Clinicians who conduct such discussions must learn to identify and address emotions faced by families and patients at the end of life. The art of interlacing factual statements and questions with those that explore the patients' or relatives' feelings aims to bring the conversation from the level of sharing of information to a higher plane characterised by empathy.

To the son who has just agreed with the doctors to withdraw life support from his father, one might add: "I appreciate that this is not easy for you"; to a patient who has just been told that further surgery would not help, one can say: "How do you feel about what I have just said?"

We begin to empathise when we aim to know our patients and to pay attention to their concerns and feelings. Such communication with patients and their families can be therapeutic. For Peabody,²⁹ getting to know the patient was a major element in the practice of medicine.

A Sense of Timing

A sense of timing is helpful in determining the most opportune time to break bad news, to allow healing before revisiting a difficult topic and to practise advance planning in competent patients. A patient who insists on aggressive

care may not have the same opinion later on in the course of the illness. A relative who was very suspicious of the intention of the physicians in limiting care may be won over subsequently as he witnesses the care of the gravely ill patient. Where uncertainty or differences in opinion exists, the physician should have the flexibility to offer a time-limited trial of therapy. At review, a withdrawal of therapy can proceed if the patient does not improve.

Patients and families arrive at decisions to withhold or withdraw life-sustaining therapy through a social process that has cognitive, affective and interpersonal dimensions.³⁰ Certain milestones indicate progress, such as acceptance of imminent death and that recovery is not likely, willingness to discuss transfer to a hospice and acknowledgement of grief. We need to be aware that each individual deals with these various aspects at their own rate and we need to keep pace with them through timely disclosure of information, discussion of management and exploration, and meeting of psychosocial and emotional needs.

Attention to Various Dimensions of the Illness Experience

Attention should be paid to the various dimensions of the illness, including the physical, psychological, social and spiritual aspects. Patients need reassurance that limiting life-sustaining treatment does not mean limiting care. Control of symptoms is paramount. In the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment, almost half of the patients who were able to respond reported pain with 15% reporting moderately severe to extremely severe pain.³¹ Other symptoms, such as anxiety, depression, delirium, dyspnoea and fatigue, are also common. Protocols for withdrawing technologies have been suggested to minimise patient's distress.³²⁻³⁴ Psychological and social needs should also be addressed. This is best accomplished in the context of a multidisciplinary team involving social workers, staff trained in bereavement support and pastoral staff.

Conclusion

In few other areas is the need to combine the practice of medical science, knowledge of medical ethics and embodiment of medical humanities more crucial than in the care of the dying patient. At such times, the challenge for physicians is to balance appropriate and compassionate care with a respect for the choices and wishes of patients and their relatives. Though aggressive interventions and palliative care are not mutually exclusive, the decision to limit life-sustaining therapy should never be construed as abandonment. Improvements in communication, a sense of timing and meticulous attention to the various dimensions of the illness experience are likely to have a notable impact on improving end-of-life care.

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