



ORIGINAL ARTICLES

Medical futility and end-of-life care

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Acceptance of the concept of medical futility facilitates a paradigm shift from curative to palliative medicine, accommodating a more humane approach and avoiding unnecessary suffering in the course of the dying process. This should not be looked upon as abandoning the patient but rather as providing the patient and family with an opportunity to come to terms with the dying process. It also does not entail withdrawal or passivity on the part of the

health care professional. In addition to medical skills, the treating physician is responsible for guiding this process by demonstrating sensitivity and compassion, respecting the values of patients, their families and the medical staff. The need for training to equip medical staff to take responsibility as empathetic participants in end-of-life decision-making is underscored.

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The 'medical futility' debate must be understood within the context of modernity, which is characterised by an apparently unbridled striving for control, spurred on by ambition and self-importance, with human reason considered the measure of all value. Medicine has become the epitome of this impetus, a technologically driven science. The phenomenon of death is increasingly thought of as an anomaly, an embarrassment – even a scandal.²

Modern people struggle to accept the inevitability of death, and try to muster control over death by medicalising it in order to control it better and to avoid its causes.3 Causes of death are increasingly seen to be preventable. The self-confidence of our technological era could be understood as a defence mechanism against the experience of life's vulnerability, and a mechanism for coping with disability and death. The medical paradigm, with its justification of an all-out war against disease and death in order to achieve utopia for all, has rendered the medical paradigm unsustainable. Medical technology cannot cure or prevent suffering under all circumstances. It may sometimes prolong meaningful life. It is also able to postpone death, sometimes indefinitely, and sustain the organism without improving the underlying condition of disease, creating an illusion of immortality. A modern paradox is that the imperative to eradicate human suffering, which has become a societal priority against the backdrop of a narcissistic impulse to omnipotence,⁴ has itself become a cause of suffering.⁵

We suggest a reconsideration of the original goal of

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April 2008, Vol. 98, No. 4 SAMJ

medicine. Respect and care for the patient, and preservation of the patient's life where possible and desirable, are of the utmost importance, but the main goal is seen not as the prolongation of life, but rather as the relief of suffering. The concept of medical futility has the potential to be of benefit in that it helps to delineate the limitations and boundaries of technological medicine and allows for the acceptance of death as a natural outcome of life and a potential friend. It enables a shift from the focus on curative and often aggressive, potentially harmful approaches, to an acknowledgement of palliative care, enabling issues of quality of life and care to take precedence over an undue and irrational insistence on the idea of the sanctity of life.

Definitions of futility

A *quantitative* definition of the futility of treatment, has been suggested, ⁶ although this has not proved successful. It is based on the probability of a treatment not having the desired effect − if the *p*-value is ≤0.01 the treatment could be considered futile. The *qualitative* definition of futility highlights the chasm between the achievements of an expected goal of treatment and its benefit to the patient. In this context a futile treatment is one that merely preserves permanent unconsciousness or that fails to end total dependence on intensive medical care.

Physicians should differentiate between a therapeutic effect, i.e. one limited to some part of the patient's body (physiological definition of futility), and a benefit that improves the condition of the patient as a whole. Treatment with a therapeutic effect but without benefit to a patient is burdensome and could be labelled futile. The applied concept of futility is that futile means are not ethically indicated, and with few exceptions, should not be provided.

Futile treatment for babies that could apply to all patients has been summarised.⁷ A treatment is futile when it: '1. ... does not alter a person's persistent vegetative state; 2. does not alter diseases or defects that make survival beyond infancy impossible; 3. leaves permanently unrestored a patient's neurocardio-respiratory capacity, the capacity for a



ORIGINAL ARTICLES



relationship, or moral agency; or 4. will not help free a patient from permanent dependency on total intensive care support.'

It has been suggested that treatment should be regarded as futile if it does not achieve its physiological objective. Thus cardiopulmonary resuscitation (CPR) would be regarded as futile if it failed to achieve a heartbeat and circulation, but would not be considered futile, even if the patient subsequently died, if it achieved restoration of circulation or if the patient survived without a chance of enjoying a meaningful quality of life. The authors believe that their physiological definition is superior to the qualitative and quantitative definition in that it avoids a value judgement. This reductionist approach contains a suspicious value judgement, namely that 'when we administer therapy, we care only what happens to the organs, and we do not care what happens to the patient'. 9

Futility needs to be seen in the context of a belief in the good of life. Such belief will affect the choice of a futility threshold.¹⁰

Anti-futility arguments

Ambiguity and relativity of futility

Futility judgements can sometimes be justified, but the concept of futility is 'fraught with confusion, inconsistency, and controversy'. The concept is thought to make sense in some instances, when the treatment has no pathophysiological rationale, e.g. when the patient is not responding, the treatment has already previously been given without success, and further treatment will probably not achieve the goals. These legitimate claims of futility judgements are differentiated from other more general uses of the concept of futility, where the likelihood of success is very small but not zero, i.e. where the goals physicians perceive to be worth while cannot be achieved. In these cases, the patient's quality of life is considered to be unacceptable, or the prospective benefit is deemed not to be worth the resources required.

Determining when treatment becomes futile remains problematic and attempts at quantification of treatment outcome are difficult. Perceptions of futility can range from zero probability of success to simply poor probability. Poor probability needs to be defined, but determining the cut-off point and appointing the judge of this final verdict are both difficult challenges. Confusing the different levels of futility judgement triggers endless, insoluble disagreements between opposing parties.

Value judgements

Futility judgements can slide into 'generalisation of expertise', with physicians illegitimately claiming authority over value judgements that patients should be allowed to make themselves. ¹² Merely employing the specific terminology of futility could cause a physician to decide that a specific treatment is not 'medically indicated', and in this way the value judgement could be masked. 'Futility determinations will

inevitably involve value judgments: a) whether low probability chances are worth taking; and b) whether certain lives are of a quality worth living.' ¹³

Uncertainty in prognostication

Information on the natural history of disease is often lacking and contributes to the complexity of the futility debate. Medical prognostication involves probabilities and should not be simply informal recall of one's previous clinical experience. Rather it should reflect a best estimate derived from review of all valid applicable prognostic studies. Existing predictive models do not seem to have improved the accuracy of physicians' clinical estimates of survival. Therefore professional frustration with a patient's clinical response to treatment and difficulty in accepting the patient's outcome and quality of life could be confused with scientific assessment of the probability of improvement, and lead to labelling of such treatment as futile. Futility judgements could therefore become mistaken rationalisations and projections of feelings of professional inadequacy, failure and guilt.

Futility as the physician's trump card

Anti-futility arguments are often championed by ethicists who fear that physicians may use futility arguments unilaterally, returning to a time when paternalism granted physicians unlimited decision-making power, thereby severely restricting patient autonomy.

Arguments for futility which seem to establish that these fears are warranted have been presented.14 It has been suggested that patients diagnosed with permanent loss of consciousness should be refused medical treatment to prevent demoralised caregivers from being forced to provide care which they believe to be wasteful and futile. A further suggestion has been to change the definition of death to include a diagnosis of permanent unconsciousness. Thus, treatment should be withdrawn after a limited mandatory period of medical treatment for unconscious people, regardless of family objections. The American Thoracic Society¹⁵ seems to have embraced such a conclusion, declaring that treatment should be considered futile 'if reasoning and experience indicate that the intervention would be highly unlikely to result in a meaningful survival for the patient', and asserts that a 'health care institution has the right to limit a life-sustaining intervention without consent'.

Conversation versus paternalism

A model of conversation between patient and doctor has been developed, with the patient encouraged to take a more active, informed position in the therapeutic decision-making process. ¹⁶ However, there could be a danger using the futility concept – some supporters might conclude that they can solve difficult questions without discussing them with the patient or family, relying solely on their professional expertise. The

MJ

April 2008, Vol. 98, No. 4 **SAMJ**









ORIGINAL ARTICLES

physician-patient relationship has frequently been described as a conflicting power dichotomy, which seems unnecessary and undesirable.

Others have suggested that the dichotomy be abandoned in favour of a model of deliberation, where patient and physician interact, share and make the decision together, both parties accepting moral responsibility in arriving at a decision. ¹⁷ According to this deliberative model, no doctor should unilaterally invoke a futility judgement as trump card against a patient's autonomy. Instead, a patient's request for ongoing life-sustaining treatment could serve as a starting point for further exploration and deliberation. A futility judgement can never be a full justification to implement a specific action, since it requires further explanation in terms of values, perspectives and treatment goals. Futility judgements should therefore never end a discussion, but rather serve as a starting point.

Pejorative connotations

Medical futility could pejoratively be misappropriated when it is referred to as the 'futile care concept'. This is a serious misunderstanding. To care for a patient, particularly a dying patient, can never be futile. Whenever an act of caring takes place, it is not futile. Treatment options or goals can become futile, but up to the very end, the patient remains the focus of care.

Discussion

Medical technological advances may obscure the need for human compassion for the dying and their loved ones. The death of a patient is often considered a medical failure and quality of end-of life care is often unsatisfactory for both patients and families.

Compassionate withdrawal of treatment requires moving from a tactical approach and its associated goal, with the physician focusing on individual interventions, to a strategic approach, with formulation of a different treatment goal. This should be the result of discussions with the patient, parents and staff involved. Medical personnel remain active participants and do not have the luxury of naïvely withdrawing from such responsibility. The Western medical paradigm needs to be replaced by a more pluralistic, contextually sensitive paradigm for delivering health care. It can no longer be presupposed that physicians, nurses and patients share a common view of the good of life, or that medical practice will be conducted and framed by Judaeo-Christian principles.¹⁸

The dominance of patient autonomy⁴ has been increasingly challenged and the concept of medical futility is central to such a challenge. There is a growing body of evidence suggesting that 'consistent with the goals of medicine since the time of Hippocrates [that] physicians not only have no obligation to treat – or even present such options to patients and families – when medical interventions cannot produce a sufficient quality of life [such as restoring consciousness and the ability to live without continuous life support], but also that physicians cease behaving professionally if they persist even when no medically valid goal remains'.¹⁹

We suggest that a paradigm shift is necessary within the growing awareness of the limits of medical science's propensity to cure, heal and extend life. Changing from cure-at-all-cost to care-where-cure-is-impossible indicates that there is a need for research and education in quality of end-of-life care. Uncritical acceptance of the advanced possibilities that technology affords medicine may lead to support of the fallacy that cure is effected by prolonging life. On the contrary, the dying process may be prolonged, which may not only prolong suffering but also cause it. Furthermore, empathic caring is sacrificed for treatment based on technological imperatives. Leadership is required to support the ongoing progress of clinical medicine as well as the evolution of our consciousness, which should lead to increased compassion.

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