Medical Futility Is Not A Futile Ethical Principle

Dr Katherine Hall
Clinical Lecturer, Bioethics Research Centre

Medical futility has a credibility problem – at least amongst ethicists. To practising clinicians the concept of medical futility may appear relatively simple and straightforward, but it has been called 'dangerous', 'fatuous and detrimental to good decision-making', and 'ethically and morally unsound and legally imprudent'. There have been calls for the term futility to be abandoned totally. The criticisms are many: that futility lacks an exact definition; that it is falsely objective; that it confuses moral with scientific reasoning. Moreover, it is said to be imprecise, with varying success rates, between 0 to 13 per cent of treatment attempts having been defined as futile by different doctors. It has uncertain legal status and implications. Some fear that it will be, and is being, used to justify widespread unilateral and paternalistic decision-making by doctors when patients should be involved. And it is feared that this trend will be encouraged by the ever-increasing need to restrain health care spending and reduce medical costs.

However, despite the criticisms, medical futility is an ethically and medically sound principle. The following two hypothetical case histories are used to illustrate both the problems and a solution for this threatened medical and ethical principle.

Case 1

The first case is of Mrs S., a thirty-five year-old, previously well woman. She is admitted to hospital following an eight-hour history of headache, fever, rash and neck stiffness. When seen in A & E she has low blood pressure unresponsive to intravenous fluid therapy. ICU is contacted and she is admitted to the unit. Urgent tests confirm the diagnosis of meningococcal septicaemia. Despite intravenous antibiotics, further fluids and blood pressure support with drugs (inotropes), she pursues a relentlessly downhill course over four hours with persistent and unresponsive low blood pressure. It is debated amongst her doctors whether a change of inotropic agents, or the addition of a third inotrope may be beneficial. However, given the clinical context and her unresponsiveness to treatment, it is decided that any such change or addition would be futile. Two hours after the discussion, Mrs S. dies.

In this case, the health care team has appealed to the concept of medical futility to justify their decision. This is relatively non-problematic. I would view it as a legitimate and appropriate use of medical authority. It is not expected that physicians seek patient or family consent for these sorts of decisions, although the case may certainly, and I think often should, be discussed with the patient or family. Such decisions are based on medical fact and experience, and form an expert decision. It is a use of medical authority that is sanctioned by society and a recognition of the training and skill invested in those individuals who make these decisions. That is what specialist colleges and registration boards are all about. They are the overt expression of this social sanction.

Case 2

The second case, Mr T., is a seventy-eight year-old man who is admitted to a general medical ward for terminal care, having been diagnosed with lung cancer with secondary masses six months earlier. Given his medical diagnosis, and the known poor outcome of CPR in the context of metastatic carcinoma, his health care team designate him as not for resuscitation. In their opinion the therapy would be futile. The patient notices a black dot has been attached to his ward chart. He finds out from a fellow patient that this means he will not be treated if he has a cardiac arrest. On hearing this he becomes very agitated and demands to see his medical team. He tells them he realises that he is dying, but he wants to be resuscitated if it becomes necessary, as a daughter whom he has not seen for five years is flying from England and is due in five days. After he has seen her and they have said their goodbyes, he is quite happy that they do not give him CPR. He would in fact be angry if they did not let 'Nature take its course.' The DNR order is removed until this later date.

Although the health care team also used the concept of futility, this second case is not nearly as straightforward as the first. Here the health care team has followed a similar decision-making path to that followed by the first. In both cases, the team recognised that their patient was dying. Both recognised that the treatment under consideration – a new inotrope in the first case, and CPR in the second – was not going to change the ultimate outcome. But the thinking went astray. In the second case, the decision-making process was not sufficient to take all the factors into account. Looking at it from the patient's point of view, there was a very good reason why CPR was anything but futile. The second health care team defined and used the principle of medical futility in precisely the same fashion as the first – something like 'Medical futility is futile medicine and only a doctor can decide what is futile medicine'. Given this definition, the patient was given no opportunity to enter discussions as to the appropriateness of the DNR order. The patient's opinion was viewed as being neither necessary nor a legitimate part of the decision-making process. Involving the patient would not even have been discussed or considered. The team only became aware of the problem with this view when the patient requested to see them, after accidentally discovering their decision. In other words, this preconceived and circular definition of futility immediately excludes the patient from any right to participate in the decision-making process. Yet this definition of futility and its use in the decision-making process, which appeared legitimate and non-problematic in the first case, caused considerable distress in Mr T. Even the most hard-core paternalistic health professional, in the face of that distress, might at least pause to consider what went wrong before labelling Mr T. 'difficult' or 'demented'.

A Solution

There is a solution to the problem illustrated by the two case histories. When using the term medical futility, one must always ask the question, 'Futile in relationship to what?' In other words, futility must always be defined in relationship to a goal. What was the goal that was being considered in the first case? It was whether or not a change in inotropic support would improve Mrs S.'s cardiovascular instability. In other words, it was the predicted physiological effect of a therapeutic manoeuvre that was deemed futile. This is what has been called physiological futility. That is, an intervention or treatment is deemed futile if it fails to produce a desired physiological change. Apart from containing it a value judgement of sorts, in deciding what the desired physiological change might be, this is a relatively value-free and objective term. Physiological futility relies on the knowledge and expertise of the health care team, who are using this term in their decision-making, for accuracy in its application. In other words, if the team has inaccurate or inadequate knowledge of the uses or effects of a particular intervention, physiological futility will acquire a degree of inaccuracy. This inaccuracy will arise solely from within the health care team – from deficiencies in knowledge from the members who comprise the team, or from deficiencies in medical knowledge generally. The inaccuracy does not arise from failing to include the patient in the decision-making process. Nor does it arise from a lack of understanding, appreciation of or empathy with the patient or the patient's life goals. In other words, it is a bona fide medical judgement. It is the type of judgement society expects medical professionals to make.

Under this judgement of physiological futility, health professionals can legitimately refuse requests for physiologically futile treatment. An example of this is the patient who demands antibiotics for what is almost certainly a viral infection. A physician is under no compulsion to provide therapy that will not bring about a desired physiological change – in this case, the reduction in symptoms and the quicker resolution of a viral infection. It is this definition of futility which has been used in international guidelines for the withholding and/or withdrawal of medical treatment. However, it is a very narrow definition and there are many occasions when decisions are made which fall outside this definition. For example, in New Zealand, treatment in intensive care units is sometimes withheld or withdrawn, not at the point where the treatment of a patient's illness has become physiologically futile, but at an earlier stage, where judgements of benefit are being brought into play. It is when judgements of benefit occur, that the real problems with the concept of futility arise.

When Mr T.'s medical team decided to place a DNR order on him without his consent or knowledge, they were acting as if they were making a decision based on physiological futility. But this was not correct. The desired physiological outcome of CPR is the effective restoration of heartbeat, circulation and respiration. At present, there are no reliable predictors available to assess for which patients CPR is futile in this strict physiological sense, other than the duration of CPR once it has started. The decision was made in reference to a different goal – that of hospital discharge. Studies have shown an extremely poor (virtually nil) hospital discharge rate in patients with metastatic carcinoma who have an in-hospital arrest. This is not the same as physiological futility, and any decision would include a judgement of benefit which goes beyond a physiological response, and which could be termed 'relative futility'.

Relative futility

According to relative futility, an intervention or treatment is deemed futile if it fails to produce an outcome which is beneficial to the patient. Not only is it relative to a goal, but it is also relative to a person – the patient. It is a subjective term – and this subjectivity is constructed in relation to an individual patient and is based on her/his thoughts, feelings, hopes and dreams. In other words, all those attributes of individual personhood which could be laid to one side when considering physiological futility, now take centre stage when considering relative futility. In order to correctly understand what is relatively futile for a particular patient, the medical team must obtain some knowledge and understanding of what makes that patient a *person*. A degree of empathy with the patient is necessary for several reasons. In decisions made with the patient's participation and consent, a degree of empathy is more likely to ensure that the information most relevant for that particular patient is discussed. In situations where the patient is unable to participate in such discussions, for example when unconscious, an empathetic understanding of who that patient is as a person can allow better decisions to be made on the patient's behalf.

Suppose, for the sake of argument, it is known in Mr T.'s case that CPR would be physiologically futile. The decision to withhold this treatment could be made without his consent. Several ethicists hold the view that there is no obligation to offer physiologically futile therapy. Nor is there any obligation to seek the patient's consent for this non-provision. It is suggested that attempting to gain consent may even send an invidious mixed message: 'If the therapy is truly useless, why then are they asking for my consent not to have it?' could be the thought set up in a patient's mind. However, this does not mean that it is appropriate for the medical team to make this decision without informing the patient of it. As in the case of Mr T., the patient may surreptitiously find out the decision and become distressed. In Mr T.'s case the medical team should explain that CPR will not be performed because it will not succeed in restoring his heartbeat, circulation and respiration. It is essentially a matter of pot-luck whether his daughter will arrive in time.

In the context of Mr T.'s case, CPR is not an example of physiological futility, but of relative futility. It is deemed relatively futile therapy because it is defined relative to the probability of Mr T. ever leaving hospital; a probability of nil or something very close to it. But Mr T. has no argument about his chances of leaving hospital or his ultimate prognosis. He does not disagree or deny he is dying. As the case history described, he would be angry if his carers interfered with the natural course of events at a later stage. But at this juncture, with his daughter on her way to see him, it is extremely beneficial to him to live through the next few days. Relative to this goal of survival for five more days, CPR no longer can be categorised as 'futile'. Failure to involve the patient in the decision-making would mean this vital information would never become known to the health care team. When judgements are based on 'relative futility', it is essential that the patient be involved.

This does not solve all the problems regarding futility. What are the limits to a patient's requests for relatively futile therapy? For example, is an octogenarian entitled to renal dialysis? It is certainly not physiologically futile therapy, and the patient could easily argue that it was not relatively futile either, as it would keep her alive when she would otherwise certainly die. At some level, restraints must be placed on what is allowed as relatively futile care. This leads on to another problem with medical futility – the issue of resource allocation and health care rationing. The necessity for these restraints is economic – no health system can afford to provide all possible therapies to all those who request or benefit from them. The market mechanism is one way of defining those limits, but in a highly unjust fashion. A minimally adequate level of health care needs to be defined, including definitions of relative futility that go beyond individual values. Social judgements as to what is medically reasonable must underpin individual requests for treatment, just as social judgements underpin the concepts of medical expertise and rightful medical authority. It may be that these social judgements, regarding what is relatively futile, are based on group probabilities, such as not treating anyone who falls into a group with a predicted mortality of 99 per cent. Current scoring systems can be applied to group predictions, with some reservations. They may provide a means of reaching a societal definition of what is medically reasonable. Those treatments that do not receive the sanction of society, perhaps because the cost of treatment is viewed as excessive, or the benefit received is marginal, could be termed medically unreasonable – but they are not futile.

The confusion and criticisms in bioethics over medical futility have arisen because the term has been used in various clinical situations to denote physiological futility, relative futility and medical reasonableness. For the sake of clarity, it would be wise to restrict its usage to situations where it means physiological futility. A clear sense of the relevant differences between the uses of the term 'futility', the respective roles and ethical limits on physician authority and patient autonomy, and the importance of decision-making processes need to be appreciated and remembered when at the bedside.

The Bioethics Research Centre holds a list of supporting references for Dr Hall's article.

Reader's Views

Dear Editor

Please find attached a press release from North Health Ethics Committee regarding its decision to approve in March 1996 the treatment of two children with Canavan Disease by gene therapy.

In March this year, North Health Ethics Committee Y approved an application to treat two children with Canavan Disease by gene therapy. Following the granting of that approval two children who had been brought from the United States by their parents underwent gene therapy surgery at Auckland Hospital. The Committee's decision was subsequently the subject of some debate, most notably criticism by Professor Alastair Campbell in an article published in the *Listener* in June 1996.

The principal thrust of the criticism made against the Committee's decision was that the children involved were too young to give informed consent to the experimental procedures, and the Committee ought not to have relied upon the parental consent given on behalf of the children.

The Committee's decision was subsequently supported in a letter written by Dr David Seedhouse, Director, Research Unit for the Ethical and Legal Analysis of Health Care, and Professor Garth Cooper of Auckland University to the *Listener* in response to its article. Subsequently, the Committee commissioned Mr Ron Paterson, Senior Lecturer in Health Care Law at Auckland University, and Peter Skegg of the Faculty of Law of Otago University, to review the Committee's decision, and its decision-making process.

Mr Paterson and Professor Skegg carried out a comprehensive review of the Committee's handling of the application lodged by Professor Matthew During, and the objections subsequently levelled at the Committee's decision to approve the gene therapy application. In carrying out their review, Paterson and Skegg, both experienced lawyer-ethicists, examined the application and all of the information which was before the Committee at the time the decision was made, together with the current National standard for Ethics Committees and the Ethical Guidelines and relevant case law in New Zealand and overseas.

Paterson and Skegg concluded that there is no ethical requirement that children should have independent representation at Ethics Committee hearings held to consider applications seeking ethical approval for experimental treatment procedures. Paterson and Skegg were satisfied that the Ethics Committee complied with all relevant Standards in granting their approval to allow the gene therapy trial to proceed. Paterson and Skegg also determined that there was no legal requirement that children should have independent representation at an Ethics Committee hearing to determine whether ethical approval should be given to therapeutic research procedures for which their parents have given informed consent.

In coming to their conclusions, Paterson and Skegg noted that the New Zealand courts

> 'even in the context of withdrawal of life support for an incompetent patient with no prospect of recovery ... have been prepared to rely upon "good medical practice", subject to the concurrence of family and an ethics committee (with no requirement that the patient be independently represented before the committee) rather than requiring court approval ...'.

Paterson and Skegg concluded that the gene therapy application was appropriately handled by the Ethics Committee; that the parents of the children involved gave a valid consent to what they understood to be a potentially beneficial procedure and that there was no legal or ethical requirement for the children to be independently represented.

It is interesting to now see that the opinions expressed by Paterson and Skegg are consistent with those expressed by Judges of the English Court of Appeal in the recently reported *Baby T* case.

Ann Howard
Secretary
Ethics Committees