

Futility

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A story that illustrates a discussion about futility...

This story concerns a patient, a youngish man who has a diagnosis of ALS (or Lou Gehrig's disease.) ALS is fatal, the only real unknown is how long it will take for the patient to die. The patient was a part of a large ALS treatment programme at a major Canadian centre. This centre's ALS treatment programme had a policy (or perhaps a practice) of not offering ventilator support to ALS patients at the end stages of the disease. (Ventilator support would be offered in the earlier stages of the disease with the expectation that the patient would be weaned from the ventilator. Terminal ventilation was not offered.) Well, you can imagine what happened. The patient reached the end stages of the disease and requested (demanded) that he be put on a ventilator. The team refused, "it is against our policy" (practice), they said.

At this stage we held an ethics case consultation, which was attended by most of the staff of the ALS programme and many representatives of the ICU. We are not going to offer a ventilator, said the head of the ALS treatment programme, "no" agreed the head of the ICU, "It's futile."

It is here that I will offer a word or two on the role of the ethicist. Often you can do all that needs to be done by putting your hand up and looking puzzled – or, as in this case, repeating the last word of the previous sentence:

"Futile?"

"Well, yes," they said, "it's futile, it won't cure his ALS."

"No it won't, but will it keep him alive?"

"Oh yes, it will keep him alive."

So, the treatment or intervention, in this case a ventilator, is not "futile", or more precisely, it is not medically futile. It will bring about the effect for which it was intended: it will serve to keep this patient alive. The members of the team understood the power dynamic of the judgment of futility. They knew that the judgment that a treatment was or was not futile was theirs to make, they just misapplied the concept in this case. But the discussion continued.

"We won't put him on a ventilator, it won't do him any good, his quality of life will be awful."

So let us go back to our dynamic of health care decision-making. If a treatment is available and has been offered to a patient the decision about whether or not that treatment is, from the patient's perspective, worth having, is of course, up to the patient. It is up to the patient to decide if the quality of life that would be available with the treatment is something that he or she wants. At the risk of confusing the language a little, the patient has to decide if the treatment is "futile" from his or her perspective. Is there a point to the treatment from the outlook of the person concerned? This, though, is a judgement of "personal futility" not "medical futility." Of course the information that is brought by the care team concerning the experiences of others and their perceptions of the quality of life that would be available with the treatment are very important. In most cases the care giving team will have far greater familiarity with patients who have experience of the treatment concerned and they will know the reports of those patients and they will know what it is like to care for a person under those conditions – this information will be crucial to the patient as she makes her or his decision. However, the care giving team has not lived that experience themselves, and, in any event the authority to make that choice lies with the patient.

So, to go back to our story. We soon established that the decision concerning whether the quality of life with the treatment would be worth having belongs to the patient. But the patient had made his position clear, he wanted the ventilator.

Finally, the head of the ICU said: "That's not what my ventilators are for." Now, perhaps there are other ways of putting this idea, but the concept is crucially important. What the head of the ICU was saying was that he only had a limited number of ventilators. If this patient got one of the ventilators then he would use it for months or possibly years. And then the outcome for that patient would be death. On the other hand if that patient did not use the ventilator for that extended period of time it would be available to help many other people, who could benefit from the ventilator, recover and go home. Given the scarcity of the resource, the head of the ICU wanted to use it in the most productive way he could.

Health care professionals are faced with this type of decision all of the time. Given a scarce resource, how do we share it out – fairly and productively? Given the scarcity of resources, health care resource allocation is a “zero-sum game.” If one person gets “this” then “that” is not available for someone else. This is always and inevitably true. This is one area where the “futility” debate gets confused. A better way of thinking about this issue of resource allocation, rather than “futility”, is to think instead of social “utility.” Is this benefit one that we, as a community, ought, or want to fund? The word “futile,” mistakenly and confusingly in my view, sometimes gets used in this context. Sometimes it is said that a treatment is “futile” if it brings only a very minor benefit, or if the benefit is very unlikely, or if the cost of providing the treatment is somehow disproportionate to any benefits that might accrue. In these cases the treatment is not “medically futile,” though it may well be the case that it is inappropriate, inadvisable or ought not to be offered.

Let’s finish this story with a look at who gets to decide what – and on what grounds. The care giving team, and the physician are responsible for deciding which treatments might be effective, and if those treatments are available they can be offered to the patient. The patient then gets to decide whether or not he or she wants to receive any of those treatments or refuse all of them. But who decides what treatments are available? To go back to our story, who should decide whether or not ventilator support at the end stages of life is something that should be made available to Canadian patients should they want it? Is that the role of the treating physician at the bedside? I would say no. We want physicians at the bedside to be advocates for their patients – to seek the best possible treatment and the widest range of options available. We compromise that advocacy role if we expect the physician at the bedside to be a resource allocator who might have to decide, on value rather than medical grounds, that this patient ought not to receive this treatment because someone else could benefit from it more. The decision that a treatment ought not to be offered to a class of patients (rather than any particular individual) properly belongs to the community. Those who pay for the treatments need to decide what treatments they are prepared to pay for. This should be an informed debate, one that draws on the best evidence, both of effectiveness and cost effectiveness; it should be a compassionate debate, realising exactly what the stakes are, but ultimately it must be a rational debate where people of good will seek and give the best possible reasons and work towards the best possible outcomes.

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