

Review

Ethics roundtable debate: Patients and surrogates want 'everything done' – what does 'everything' mean?

Christopher Doig¹, Holt Murray², Rinaldo Bellomo³, Michael Kuiper⁴, Rubens Costa⁵, Elie Azoulay⁶ and David Crippen⁷

¹Department of Critical Care Medicine, University of Calgary, Calgary, Alberta, Canada

²Department of Critical Care Medicine, University of Pittsburgh, Pittsburgh, PA, USA

³Department of Intensive Care, Department of Medicine, University of Melbourne, Melbourne, Australia

⁴Department of Intensive Care Medicine, Medical Center Leeuwarden, Leeuwarden, The Netherlands

⁵Critical Care Department, Hospital Pró Cardíaco, Rio de Janeiro, Brazil

⁶Service de Réanimation Médicale Hôpital Saint-Louis et Université Paris 7, Paris, France

⁷Neurovascular ICU, Department of Critical Care Medicine, University of Pittsburgh Medical Center, Pittsburgh, Pennsylvania, USA

Corresponding author: David Crippen, crippen+@pitt.edu

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Abstract

Highly complex and specialized care plans sometimes overwhelm the comprehension of patients and families. Many optimistic surrogates of critically ill patients err on the side of desiring that everything be done but with a nebulous idea of what 'everything' entails. Physicians must work closely to educate surrogates as to the benefits versus the risks of treatment. Our roundtable experts ponder the question of whether providers possess the authority to interpret unilaterally the nature of requests for everything.

Introduction

There is always an incentive to use the newest, most interesting medication as soon as possible. There is a perception that new drugs are miracle drugs since they are formulated against the cutting edge of new developments in medicine. Frequently, patients and their families carry out Internet searches for new developments in the field of their interest, and there is much information available. Patients and their families often point out these new developments to their physicians and request they be implemented.

Patients are biased to try anything in hopes of a cure. Physicians have a strong incentive to do everything reasonable for their patients, but not necessarily everything possible. If a new drug is available, even as an investigational tool, there is a temptation to use it. But the wealth of knowledge concerning these treatments differs widely between physicians and patients. We explore the viability of requests for "everything", differences between possibilities and reason and authority to request treatment and to demand it.

The case

A 70-year-old woman with a history of hypertension and deep vein thrombosis on coumadin (warfarin) is admitted to the emergency department (ED) about 1 hour after a syncopal episode and is found to have a small left-sided intracranial hemorrhage. Initially she is hemiplegic, aphasic but arousable, and with stable hemodynamics and ventilation. She is admitted to the intensive care unit (ICU) and given fresh frozen plasma and vitamin K for an international normalized ratio (INR) of 5.6. Her examination findings quickly deteriorate. Another computed tomography scan is performed an hour after admission and it is observed that the intracranial bleed is rapidly increasing in size. Repeat examination reveals no corneals, fixed pupils, and only extension of the left arm in response to painful stimulus. She is intubated and breathes over the ventilator but has no cough or gag reflex. Fresh frozen plasma is infused. Both neurosurgery and neurology consultants agree that the real chances of this patient leaving the hospital alive are nil, and the family is so advised. The patient's husband insists that everything be done. He states that the patient is a 'fighter' and would want everything possible to be done, at least for a while. The family is also willing to pay for the medication out of their own pocket if required.

Recent literature, although early and still in trials, suggests that outcomes for patients with intracranial hemorrhage are improved following administration of recombinant factor VIIa (rFVIIa), and this treatment is routinely used in many centers for treatment of intracranial hemorrhage. However, rFVIIa is expensive and in short supply. It is the opinion of the critical

CPR = cardiopulmonary resuscitation; ED = emergency department; ICU = intensive care unit; INR = international normalized ratio; rFVIIa = recombinant factor VIIa; SDMM = shared decision making model.

care physician that although rFVIIa is one possible option, administering it to this patient would not improve her outcome or, worse, it might convert inevitable death to a vegetative state. However, the critical care physician reminds him that the family wants 'everything' done, and the team must serve that mandate until the family changes their mind and opts for some kind of limitation – 'everything means everything possible'. The critical care physician states his further opinion

that the definition of 'everything' doesn't mean 'everything possible' but in reality means 'everything reasonable', and that the critical care team has the right to interpret care in that light.

Should the family be told that there is more aggressive treatment available but that the team has decided it would not be beneficial to this patient?

The Canadian perspective

Christopher Doig

In Canada medical care follows the traditional principles of medical ethics espoused in the Code of Ethics of the Canadian Medical Association (CMA) [1]. The Code states that one should 'Ascertain whenever possible and recognize [the patient's or surrogate's] wishes about the initiation, continuation, or cessation of life-sustaining treatments'. Canadian courts recognize that life-sustaining medical treatment may be withheld or withdrawn, and that treatment may not always be in a patient's best interests.

What is not defined are limits of autonomy in demanding ineffective or inappropriate treatment. In 1995, the CMA – in collaboration with multiple other health agencies – approved The Joint Statement on Resuscitative Interventions [2]. This guideline recommends that patients be assigned to one of four categories when one is considering whether resuscitative interventions are appropriate (although focusing on cardiopulmonary resuscitation [CPR], resuscitative interventions are more than CPR): patients who are likely to benefit, those in whom benefit is uncertain, those in whom benefit is unlikely, and those who will not benefit. The Statement clarifies that 'These categories can be adapted to ... the care setting and are compatible with policies that establish levels of care or intervention.' The Statement provides guidance on decision making and communication: '... [patients] who almost certainly will not benefit from CPR [or other resuscitative interventions] are not candidates ... and it should not be presented as a treatment option.'

At least two prominent medical ethicists have argued that denying treatment based on the Joint Statement may not be appropriate. Weijer [3], in an editorial on refusing to provide

CPR to patients in a persistent vegetative state, stated 'I believe ... failure of physicians to provide treatment is neither ethically or legally defensible ... Futility bundles uncontroversial cases involving treatment that cannot work with cases involving effective treatment that supports uncontroversial ends e.g. preserving permanent unconsciousness.' Baylis [4] stated that neither the Canadian health care system nor a broad social consensus has conferred upon physicians the authority to make unilateral decisions about futile treatment. Likewise, Picard and Robertson [5], Canadian health law experts, caution that there are 'dangers and problems underlying the concept of medical futility, particularly if ... used to justify the withholding of treatment for socioeconomic and value-laden reasons.'

Although there is apparent incongruence between the CMA's Joint Statement and the opinion of some Canadian experts in ethics and health law, there is no requirement to provide treatments that fall outside standard medical practice. As Weijer and coworkers [6] wrote in their article on inappropriate treatment, there is no obligation to provide treatment that cannot work or is very unlikely to work, or that falls outside the bounds of standard medical practice. Standard medical practice would be defined as one of at least the following: an intervention that is used by at least a respectable minority of experts; one that is licensed by Health Canada's Therapeutic Products Directorate for the specific use; or one that is supported by scientific evidence of safety and efficacy, or for which there is clear evidence that it is not harmful or ineffective. Thus, on the basis of standard care alone, without appeal to medical futility, in Canada, it is my opinion that clinicians would have a sound basis for refusing to provide rFVIIa.

The American perspective

Holt Murray

In this case we are forced to determine what 'everything' means. Families frequently express that they want everything to be done for their loved one. This is, of course, a natural and reasonable request, especially for patients faced with a sudden devastating condition following previously normal

health. The ethical practice of medicine requires that we define 'everything' as 'everything reasonable'.

If this patient were to have stage IVb pancreatic cancer, then distinguishing between everything possible and everything

reasonable would be easier. It would be possible to perform a Whipple procedure; however, this course of action would be far from reasonable or ethical. The patient would be subjected to a procedure with its inherent complications without receiving benefit.

In order to maintain a healthy doctor-patient relationship, patients and their surrogates need to know that the recommendations that they receive will be reasonable and responsible. This case implies that the patient's surrogate desires a therapy that the medical team does not think is indicated. Simply, it would be unethical for the team to provide such a treatment course that is not felt to be medically indicated. This conflict is usually resolved by simple discussion or, in rare cases, by obtaining a third party opinion.

Recombinant medications may revolutionize the way in which medicine is practiced. The high cost of these medications and their limited availability mandate that we use them in a thoughtful manner. rFVIIa may prove to be a very powerful tool in the management of intracranial hemorrhage. To date, the literature is compelling but not definitive. Unfortunately, it is being considered late in the patient's course, when the

likelihood of meaningful recovery has been determined to be nil by all involved parties. In addition to a vanishingly small potential benefit, the patient is at risk for significant harm with her history of recent deep venous thrombosis. Overall, the patient is unlikely to benefit and may acquire harm from the proposed intervention. The scenario presented is very similar to the patient with stage IVb pancreatic cancer; neither the Whipple nor the rFVIIa should be considered reasonable therapeutic options.

The physician has an additional, sometimes competing responsibility. This is a mandate to utilize scarce resources in a responsible manner. Resource allocation decisions are inherently difficult. The more expensive and scarce the resource, the higher the level of evidence we should require before routine use. Although initial reports with rVIIa are encouraging, more data are needed. Consequently, an ethical obligation exists to study and determine how and when to prescribe off-label use of any new drug before it may be considered a local standard of care. We must avoid being seduced by the latest and greatest medication available, and using it before we have sufficient evidence to justify extended off-label use.

The Australian perspective

Rinaldo Bellomo

In my opinion, when dealing with issues such as the one presented in this case, the critical care physician should apply the rule of the five Cs: competence, care, compassion, communication and collegiality.

The first C is paramount. Without the highest level of competence, the others represent inadequate surrogates for what the family and the patient probably want. In this particular case, it is absolutely vital to know the facts and literature in detail before one may consider what to say. rFVIIa has indeed been tested in a multicenter multinational randomized controlled trial [7] and was shown to decrease hematoma enlargement, disability, and 90-day mortality.

However, the trial specifically excluded patients with known recent use of oral anticoagulants and patients with a Glasgow Coma Scale score of 3-5. The 70-year-old woman presented in this case satisfied both exclusion criteria. Thus, there is no evidence to suggest a beneficial effect of rFVIIa in this particular patient. Furthermore, any reasonably competent and experienced ICU clinician would recognize that this patient is irretrievably ill and that the focus of management should change from interventional management to the Cs of care and compassion.

The family should be spoken to in a separate quiet room; they should be given a chance to understand and grieve. They should be consoled by explanations that their beloved

mother/wife/sister/grandmother is not suffering. They should be touched and hugged to show a sense of common humanity and sympathy. If religious, they should be given a chance to involve representatives of their religion. They should be allowed to be at the bedside and offered some privacy (single room/curtains drawn) if they wish to spend some time with their dying relative.

In the appropriate circumstances and with the appropriate family, issues of continued support for another 24-48 hours should be discussed, because this patient might become an organ donor. The possibility of prolonging life until the time of possible brain death for the purpose of organ donation raises important and complex ethical issues. If discussed, the reasons for it should be made explicit and clear and the joint decision fully documented.

I also believe that the C of communication should not only apply to the family but also to colleagues. In my opinion, the care of this patient at presentation to the ED was suboptimal. She presented with a condition that carries a mortality rate in excess of 60% and with an INR of 5.6 [8]. This presentation demands immediate action. In Australia the guidelines are clear; this patient should have received 10 mg vitamin K intravenously, 50 IU of prothrombin complex concentrate, and fresh frozen plasma. This should have been followed, immediately after the initial therapy, by measurement of INR and thromboelastography and further treatment until both

became normal. Because the effect of such treatment might wane with time, frequent monitoring to ensure persistent normalization should continue for at least 24 hours (the time needed for vitamin K to be fully effective). Communication of these concepts to ED physicians is of ethical importance and should occur with the utmost collegiality (the last C) and in a

blame-free manner by means of educational sessions and academic detailing.

To my way of thinking, this is the most important ethical aspect of the case – ensuring better care for the next patient.

The Dutch perspective

Michael Kuiper

Would I, being a critical care attending working in The Netherlands, give a treatment that I am convinced would not improve the outcome for this particular patient, if the family demanded that 'everything done'? If not, should I tell the family about all possible but, in my view, futile treatments available?

Treatment in The Netherlands of this patient would be more or less the same as described in the case report above. I would intubate if it were necessary to protect the airway during the diagnostic period. Awaiting a decision about prognosis, I would treat the coagulation problem; I would also use prothrombin complex concentrate (factors II, VII, IX, and X) to antagonize the effect of coumadin. When the diagnosis of intracerebral hemorrhage is made, I would discuss whether we should admit her to the ICU. If the neurologist, the neurosurgeon, and I are convinced that the chances of recovery are nil, then I would enter into a discussion with the husband and children, and stop treatment then and there in the ED.

So, would I – while convinced of the inevitability of the patient's demise – use a drug for which we have still only limited evidence that it may reduce the volume of the intracerebral bleed and thus improve outcome?

Which ethical principle would help in answering this question [9]? Applying the principle of beneficence and nonmaleficence would lead to the reasoning that treatment with rFVIIa would most likely not benefit the patient, and that – on the other hand – treatment would not harm her, except for the

possibility that she will remain in a vegetative state rather than progressing to death.

Would the principle of distributive justice be applicable? We have rFVIIa readily available in our hospital but it is used under strict supervision of the intensivists. Currently, the hospital and not the patient or insurance company will pay the bill if we use it, and we agreed that we would only use it in cases of otherwise uncontrollable hemorrhage and thus limit its use to an estimated 10-12 patients per year. If I start to use it for other indications, then it may well be possible that I cannot use it for patients who are more likely to benefit from its use.

Then there is the principle of futility. rFVIIa may limit the volume of the intracerebral bleed, but it will not improve the patient's current condition – a condition that is devastating. Because the condition is not reversible with rFVIIa, this treatment may be considered futile.

Autonomy of the patient is not compromised in my view. The husband may see this differently, however, because he has stated his wish that everything should be done.

If the patient is in the ICU, comatose and ventilated, and the husband were to ask me whether there are treatment options, I would answer that we have done everything that could have helped, and that other treatments would not improve her condition. Telling the family about all possible treatments, proven or not, would not in my view lead to a better informed family, but only confuse the situation and increase their suffering. We should instead concentrate our care on the grieving family.

The Brazilian perspective

Rubens Costa

I question whether physicians should cause more stress and dissension within the family by presenting optimistic data gained from different patient populations. With respect to the specific treatment option under discussion, there does not seem to be sufficient evidence to justify widespread use of this new medication on demand. rFVIIa was not developed for use in a clinical situation such as that described in this case. The exclusion criteria for clinical use of rFVIIa could result in disagreements among medical staff, and may even amplify

problems with family decision making if families become aware of them through the popular press.

According to the most recent report in this field [7], the exclusion criteria for use of rFVIIa include a Glasgow Coma Scale score of 3-5 (deep coma); planned surgical evacuation of hematoma within 24 hours after admission; known use of oral anticoagulant agents; and symptomatic thrombotic or vaso-occlusive disease, including deep vein thrombosis,

within 30 days before the onset of symptoms of intracerebral hemorrhage. Furthermore, in that study treatment was given no later than 4 hours after the onset of symptoms. These exclusions negatively impact the statement: '...this treatment [rFVIIa] is routinely used in many centers for intracranial hemorrhage'. In Brazil and many other countries, it is not yet in routine use for the reasons given above.

The US Food and Drug Administration has established a compassionate care program to provide unproven but promising new drugs to patients with life-threatening illness while clinical trials are being conducted. However, this program requires some evidence that the drug has a safe and effective therapeutic profile. That evidence is lacking for this patient's scenario. Here, the attending critical care physician appropriately explores the term 'everything possible' based on the bioethical principle of 'first, do no harm'.

The progression of this patient's devastating disease would not be halted with conventional therapy. Unproven remedies present difficult decisions because there may be little information on safety and effectiveness for this particular scenario. If the physician knew that the unproven drug was as safe and cheap as, for instance, vitamin C, then he probably would not object to its application. On the other hand, if the drug is as potentially dangerous and ineffective, and is very expensive as in the present case, then prudent physicians should refuse to participate in its use.

The prudent physician should endeavor to portray accurately the potential benefit of treatment both honestly and fairly, and in accordance with evidence-based criteria. In this manner, the family can appreciate the medical situation and the options available, and make a clinically beneficial decision. Sometimes family members or surrogates ask for medically inappropriate interventions on the basis of unrealistic optimism. Family members may impose their own values on incompetent patients.

In evaluating family member's requests, physicians must compare the medical risks associated with any intervention to its benefits. In some cases, the medical risks may be so serious that they justify the physician's refusal to provide the requested therapy regardless of the family's optimism.

In this case I believe it is inappropriate to discuss this 'ultra-early haemostatic therapy', as described by Mayer and coworkers [7], with the family. rFVIIa administration would not be appropriate because additional harm could be caused, and there would be very little, if any, benefit at a great cost. We must convey the true perspective to the family and then effectively deal with their psychological and psychosocial issues as best we can. In most similar situations, family members and physicians can negotiate a mutually acceptable plan. In others the risks may be so great or the standard care may be so clear that the physician is justified or obligated to refuse the family member's or surrogate wishes.

The French perspective

Elie Azoulay

After years of heated debate opposing autonomy and paternalism, a model in which decision making is shared with family members – the 'shared decision making model' (SDMM) – is gaining precedence [1]. This model upholds patient autonomy without forcing family members to be involved in decisions that they do not want to make or are not ready to make. The SDMM stands in sharp contrast to paternalism, in which the physician shields the patient, making decisions alone in order to protect the patient and family from the potentially harmful effects of making painful decisions. This model, which emphasizes an active role for surrogates in sharing decisions and discussions, finds its rationale in the five following points. First, the family protects the patient's best interests. Second, relatives are not mere visitors in the ICU; they are the most affected by the nature of any decision, and there is moral justification for surrogate decision making. Third, the SDMM is integrated in a proactive communication approach, in which early and effective information empowers family members and provides them with the ability to understand the patient's situation and to perceive satisfactorily the goals of care. Fourth, qualitative

studies in bereaved families have highlighted the fact that involving relatives in the decisions, if they so wish and if they are supported by the ICU team, can help them to cope with the distress and provide them with opportunities to vent emotions and find meaning in the shift from curative to palliative care. Finally, the SDMM can be a means to prevent ICU conflicts with family members.

In this ethics roundtable debate, the patient is cared for by an ICU team that has identified a situation in which all hope of recovery is lost and life-prolonging treatments become death-prolonging treatments that should be withdrawn or withheld. Before addressing the question asked, we should recall that, like 95% of critically ill dying patients, the patient is incompetent and cannot be part of the decision-making process. Therefore, sharing in end-of-life decisions shifts to the patient's husband (an informal surrogate decision maker). In this situation, concern that curative care may be harmful has been voiced by the ICU team, which then broached the issue with the patient's husband, who indicates that 'she would want everything possible to be done'.

To address the question asked, we must balance the strengths and the risks of telling the family everything. On one hand, anxiety or depression in family members should not be used to justify benevolent paternalism. On the other hand, when family members have not received optimal information, involving them in the decision-making process probably carries a risk for subsequent post-traumatic stress and abnormal grief reactions.

In this situation, I believe that, without asking them to decide, the family should be told that there are more aggressive treatments available but that these options would not be beneficial to the patient. End-of-life decisions are made by communicating openly and often with the family. From the beginning of the decision-making process, the family members should participate by bearing witness to the patient's wishes. Most families accept and understand the need for end-of-life decisions. When this is not the case, negotiations between ICU staff and family may rapidly

put an end to the conflict. Nevertheless, inadequate information or economic restrictions imposed by managed care may lead families to view end-of-life decisions with distrust. This might have led the family to state that they would be 'willing to pay for the medication out of their own pocket if required'.

In case the husband disagrees with the decision to withhold rFVIIa, it is implicitly recommended that physicians refrain from implementing their decision over the objections of the family. On the contrary, physicians should intensify communication with families, initiate a process of negotiation, seek external advice, or show families that the decision is consistent with institutional policies and recommendations issued by learned societies. Along this line, a recent law regulating end-of-life issues in France recommends that surrogates at least be informed of end-of-life decisions. This decision should also be mentioned in the medical chart – a document potentially accessible to family members.

Conclusion

David Crippen

There are two issues here: first whether the physicians have a higher duty to the family's desires than to their clinical intuition; and second whether the family might have legal recourse against the physicians for disregarding their specific desires that 'everything' be done.

This is not a question of the drug's efficacy or a quality of life debate. This is a question of what the term 'everything' means and who is authorized to interpret it. Clearly, the family did not request futile care in the classic sense. They did not ask the physician to drill a hole in the patient's skull and let evil vapors out. They simply asked for the physicians to do 'everything' possible that 'might' improve the patient's outcome – not a guarantee. The available literature does not have to state definitively that rFVIIa has proven benefit. It only has to be demonstrated that the chances of benefit exceed those of potential detriment.

In the array of 'everything', there are many options. Clearly, the option of giving fresh frozen plasma and vitamin K was not working. Had there been absolutely no other options available, then the physicians would have been within their rights to tell the family that 'everything' was being done. However, there were more options. Common sense dictates that a treatment for which the chances of beneficence are greater than those of nonbeneficence, and with acceptable risk comes under the broad rubric of 'everything', as defined by most surrogates in this or similar circumstances.

If the family finds out that not all potential treatments were discussed and that some options were unilaterally withheld, then their response is likely to be anger. In the USA,

contemporary medical ethics mandates that patients and family have much autonomy, and angry families who feel that their autonomy has been compromised seek legal redress much more frequently than do the rest of the global village. This family might sue, not on the merits of the science but because they are angry at having declared their 'wishes' for what they consider reasonable treatment and then finding out that those wishes were not followed. Presumably, they would sue for punitive damages and not wrongful death.

Many attorneys have a mindset for 'righting injustices', and not just compensating those who have suffered damage. The argument would not be based on the merits of rFVIIa as a treatment but on the fact that it is the right of the patient and family to demand it if the potential benefit outweighs the risk and the obligation of the practitioner to provide it. There is no strong precedent in current American law that will protect a physician who unilaterally defies the wishes of the patient or legitimate surrogate in a care plan. Once legal action begins, it is virtually impossible to predict the outcome.

Therefore, it is my opinion that unilaterally withholding all options from family consideration is a dangerous proposition. The family should be informed about all options, and then bright or dark pictures should be painted of some of the options. In the end it is the family's decision, aided by the expert opinions of the physicians.

Competing interests

The authors declare that they have no competing interests.

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