



Medical Futility

A question of care and values at the end of life

BY STUART FOXMAN

In 2012, the College hosted a forum of experts in the end-of-life care field. We asked them what needed to change to meaningfully improve the last months, weeks and days of patients' lives.

The experts describe a current environment where assumptions and misunderstandings – between physician and patient, among specialists and within families – replace informed discussion.

Given that lack of communication appears to be one of the biggest barriers to optimal end-of-life care, we have launched a conversation. What is optimal care and what can be done to achieve it?

This is the last of a five-part series that brings you the views of experts in palliative and end-of-life care, as well as lessons learned from patients' experiences.

We have also taken the conversation online. Please visit us at www.cpsso.on.ca/endoflife and share your thoughts and experiences.



Everyone eventually dies.

Our *Dialogue* series on end-of-life care started last year with a recognition of this simple and stark fact. Throughout this series, we have engaged in conversations with physicians, other health-care professionals and the public about topics as diverse as education and professional development in palliative care, advance care planning, interprofessional understanding and col-

laboration in care, and certifying death at home. Now we come to the last installment of the series: medical futility at end of life.

When the physician, the patient, or the patient's Substitute Decision Maker (SDM) believe that treatment is futile, negotiating care is a delicate balance. It's a process built on respect of the patient and professional values.

Yet what happens when values or goals clash among those providing and receiving care? How can we balance and yet respect differing values simultaneously? And what conversations must society prepare to engage in?

These and other issues relating to medically futile care are the focus of this fifth and final article in this *Dialogue* series on end-of-life care.

What is medically futile care and why is it provided?

While there is no universal agreement on the definition, treatment is generally seen as medically futile when:

- it offers no reasonable hope of recovery or improvement; or
- the patient is permanently unable to experience any benefit.

In these cases, treatments may merely prolong the final stages of the dying process. At a recent conference presentation in Ottawa, Dr. Mervyn Dean, a retired palliative care physician, commented that “there comes a point when you are no longer prolonging life, you're prolonging death.” ►►



Join the conversation

We want to hear from you about your opinions, your experiences.

- When do you think a treatment is medically futile?
- Have you ever provided medically futile care? If so, why?
- Do you think a societal conversation about the allocation of scarce medical resources is needed?
- What lessons have you learned from those experiences when you and a family were not in agreement that care was futile?

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How prevalent is futile care? While it is hard to know exactly, one study of the perceptions of physicians and nurses in the *Journal of Critical Care* suggests that a majority of clinicians believe that their ICUs have provided futile care over the last year.

The most commonly stated reasons for providing such care: family requests, prognostic uncertainty, legal pressures, poor provider-family communication, and the perception that death was a treatment failure.

Rasouli case highlights ethical complexities

The complexities associated with providing medically futile care, and the disagreements that can arise in this context, have been highlighted by the case of Hassan Rasouli.

Mr. Rasouli has been kept alive on a ventilator and feeding tube at

Toronto's Sunnybrook Health Sciences Centre since his brain surgery in 2010. His doctors concluded that there was no therapeutic hope of recovery and recommended that he be taken off artificial ventilation and nutrition and be provided with palliative care until death.

At the centre of this case is the question of whether or not consent is required for the withdrawal of life-sustaining treatment. In Ontario, the *Health Care Consent Act (HCCA)* outlines what constitutes consent and when physicians must obtain consent. In brief, the *HCCA* requires that consent be obtained for any medical treatment, understood as “anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related purpose, and includes a course of treatment, plan of treatment or community treatment plan.”

Mr. Rasouli's wife, acting as substitute decision maker, refused to provide her consent to withdraw life-sustaining treatment being offered to her husband. In doing so, she cited religious beliefs held by her husband, and her contention that his movements indicate minimal consciousness. Mr. Rasouli's wife applied to the court for an order preventing the physicians from withdrawing life support without her consent.

Mr. Rasouli's doctors argued that doctors do not have a responsibility to provide treatment that has

no medical benefit, and that the withdrawal of treatment is not itself a treatment and so does not require consent.

Ultimately, a majority of the Supreme Court of Canada ruled that the withdrawal of life-sustaining treatment in this case falls within the definition of treatment under the *HCCA*, and therefore requires consent from the patient or his/her SDM. As such, physicians do not have the unilateral authority to withdraw life-sustaining treatment.

Writing for the majority, Chief Justice Beverly McLachlin made it clear, however, that patients and SDMs do not have unconstrained rights to receive or insist upon any and all treatments.

Most notably, she states that “this case does not stand for the proposition that consent is required under the *HCCA* for withdrawals of other medical services or in other medical contexts,” thereby limiting the implications of this decision beyond cases such as Mr. Rasouli's.

Jocelyn Downie, a Professor of Law and Medicine at Dalhousie University in Halifax, reflected on the decision in an Impact Ethics blog, calling the decision “a good first step toward reducing uncertainty, conflict, and distress for those who care for, and about, the critically ill in Canada.”

This does not mean, however, that there are no outstanding issues with

respect to medically futile care. Downie, for example, observes that we still need to have a conversation about the allocation of scarce resources in the end-of-life context. And Chief Justice McLachlin acknowledges that “a practical solution that enables physicians to comply with the law and satisfy their professional and personal ethics” may be needed to address the fact that “no legal principle can avoid every ethical dilemma.”

In other words, doctors and other health-care professionals still need to face, understand and address disagreements with their patients or their patients’ SDMs regarding treatment they believe is futile. Much practical work remains in order to appropriately address these disagreements.

Respecting values

Dr. Jonathan Hellmann, a medical advisor in the bioethics department at the Hospital for Sick Children in Toronto, said he hopes that the Rasouli decision “doesn’t change the way we practise.”

In particular, he observes that “we still derive consensus in 99% of the cases” and notes that “legal recourse is the least satisfactory way to resolve these disputes. I don’t want to see more and more hospital committees debate these things.”

His concern is that doctors might start to worry that their opinion no longer counts, and simply defer to



the patient’s wishes or the SDM’s wishes – “That’s the line of least tension, but it’s abdicating our duty. We have to exercise our clinical judgment,” said Dr. Hellman who practised as a pediatrician until last July.

At the same time, the patient or SDM, of course, has to be part of the decision-making. When there is medical futility at end of life, Dr. Hellmann hopes for decisions that are based on “an open expression of values.”

That requires empathy and patience. In studying best practices in palliative care, Rose Steele, RN, PhD, has found that the golden rule is trying to understand the other person’s perspective. She acknowledges that every professional brings his or her own moral, cultural and religious beliefs or val-

ues to the practice. That’s normal, but “we can’t impose these beliefs on others. People will have differing views. Support has to be there for families,” said Dr. Steele, a Professor in the School of Nursing at York University.

When patients or their SDMs struggle with end-of-life care, some doctors take the attitude of “we’re going to get them there.” That’s not quite the correct objective, Dr. Steele suggests. Instead, here’s the better starting point: What is the goal of care for this individual?

One study reported in the *Canadian Medical Association Journal* noted that “initiatives to improve end-of-life care are hampered by our nascent understanding of what quality care means to patients and their families.” Having trust and confidence in the doctors looking ►►

after you emerges as an important element of the physician-patient relationship.

Apart from clinical care, providing quality care at end of life – and negotiating that care – revolves to a huge degree around building relationships and trust.

“You’re going in with an openness, a willingness to learn,” Dr. Steele says. “It’s not about going in and saying ‘this is how it’s to be done’.”

What is the patient or their family feeling? What do they think will happen? What experiences can you share of what to expect? That, says Dr. Steele, “paints a picture for people of things they never imagined.” Maybe then, the goal can then shift from a cure to a pain-free death.

Aligning the relationship

With advances in health care, “societal expectations are enormous,” says Dr. Hellmann, who also teaches at the Joint Centre for Bioethics, University of Toronto.

Many people view technology as the solution to any medical challenge. But there are often unintended consequences that patients or their families may not be aware

of. “Progress,” says Dr. Hellmann, “comes at a cost.” Not just financial costs but, often, the toll on families when the inevitable is prolonged.

Physicians, nurses and other health-care professionals might be aware of this cost even when patients and

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families are not, and some research has suggested that witnessing the prolonged suffering of patients can be very distressing for health-care professionals.

Dr. Steele agrees. Professionals who believe a patient is suffering because treatment is continuing, or feel they’ve failed if the family is not on the same wavelength, can be greatly distressed, she said.

But sometimes the challenge is simply that the patient or family isn’t there yet. “They’re not in denial; they just haven’t processed everything,” says Dr. Steele.

“We have a maxim – move as fast as the slowest member of the group,” Dr. Hellman says. The reality is that patients, families and the health-care team aren’t always on the same page at the same time when care is considered futile.

Dr. Steele concurs, recalling one father whose child was going to die. He said it felt as if the health-care world was going at 100 miles per hour, and he was going at only 10 miles per hour. “Sometimes everything slows down for families, and they can only take in so much at a time,” says Dr. Steele.

She says doctors and other health-care professionals need to “pace” the delivery of information to match where the patient or family is at.

Supporting difficult decisions

When families do make decisions on discontinuing treatment, be aware that the result can be peace or agony. Dr. Steele has studied parents whose child had died after foregoing artificial hydration or nutrition. She says that even when families had come to terms with their decision, “they were often afraid of being judged, by family,

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friends, and sometimes by health-care professionals.”

She describes one family who, with the support of their health-care professionals, decided to take their child home to die. In the meantime, it was important to have nursing care for the child at home. As Dr. Steele recounts, “One nurse came into the home and was aghast. She literally told the parents ‘I can’t believe you’re killing your child.’ Nobody wants their child to die, but in this case, the quality of life was worse.”

Questions of appropriate or inappropriate care are often a matter of perception. At end of life, discussions can centre around likely outcomes. But at any given moment, actions, results and emotions may not be so black and white. Sometimes, “everything can be grey,” says Dr. Steele, “with no right or wrong.”

Societal debate needed

For health-care professionals, what’s a successful outcome at end of life? “When you’ve done as much as possible to help the patient and family feel that everything possible was done,” says Dr. Steele. “And that’s so specific to each individual.”


Another *CMAJ* article, on decision-making around feeding tubes for cognitively impaired seniors, described how SDMs are eager for more of everything – more information on risks and benefits, more details on alternatives, more discussion on implications, more time to make a decision, and more input from other health-care professionals.

In looking at end-of-life care and futility, improvements will hinge on sound institutional policies, greater education (for health-care professionals, patients and families), better training, open communication, and a heightened appreciation for the patient’s and/or family’s beliefs.

When conflicts arise over treatment, physicians need to probe the root reason. Denial? Misinformation? Lack of trust? Differing values? Physicians also need to pay close attention to the mechanics of building consensus and resolving disagreements.

All of these things are true, but end-of-life care also requires something else: an honest societal debate about death, how we allocate health-care resources, responsible treatments, and what it means to live well until life ends. It’s a debate that some say is long overdue. “We are,” states Dr. Steele, “a death-denying society.”

Everyone eventually dies

We all know it, yet, says Dr. Steele, “people think that technology always works, that because we have all these machines, we can keep going forever. People don’t understand the limitations. In the past, all we talked about was cure, cure, cure. Now, we have to have a shift to really raise the issues of death and dying.” 

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