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Meaningful futility: requests for resuscitation against medical recommendation

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ABSTRACT

'Futility' is a contentious term that has eluded clear definition, with proposed descriptions either too strict or too vague to encompass the many facets of medical care. Requests for futile care are often surrogates for requests of a more existential character, covering the whole range of personal, emotional, cultural and spiritual needs. Physicians and other practitioners can use requests for futile care as a valuable opportunity to connect with their patients at a deeper level than the mere biomedical diagnosis. Current debate around Canada's changing regulatory and legal framework highlights challenges in appropriately balancing the benefits and burdens created by requests for futile care.

BACKGROUND

Despite over a half century of use, advanced resuscitative measures still occupy a prominent role in public debate about medical ethics. Cases which touch on the cultural and societal conflicts between patients, providers and families continue to generate significant academic commentary and media reaction, as well as judicial and regulatory responses. Unfortunately, these responses do not always help to establish a clear common ground between health professionals and the broader society. One Canadian example, the controversial 2013 Supreme Court ruling *Cuthbertson v. Rasouli*, defined a patient's 'fundamental right' to give or withhold consent when healthcare providers suggest discontinuing life support, resulting in increased provision of potentially inappropriate medical care in cases of disputes regarding end-of-life care. This ethical and clinical reality has established a necessity for further legal clarity in cases not limited to the withdrawal of life-sustaining therapies, as well as greater debate over what principles Canadians want established to ultimately govern disputes regarding potentially inappropriate or 'futile' care. The recent conclusion of the case of Mr Douglas DeGuerre may be a first step in this direction.

Although Mr DeGuerre passed away in 2008, the story of his life and death has echoed through the courts and medical offices of this country over the following 11 years. He died of natural causes, without receiving the heroic resuscitative efforts that he would have wanted—at least as told by his daughter, Joy Wawrzyniak. She is the plaintiff in *Wawrzyniak v. Livingston*, the case decided this August by Justice Peter Cavanagh in favour of Drs Martin Chapman and Donald Livingston, Mr DeGuerre's physicians. Assessing Mr DeGuerre's severe and incurable medical illnesses, they opted to forego cardiopulmonary resuscitation (CPR), which they deemed 'futile'. Their own medical regulators (the College of Physicians and Surgeons of Ontario (CPSO) and its appeal board) eventually disagreed with the doctors' decision, and issued directives forbidding the unilateral imposition of 'Do Not Resuscitate' orders. In the subsequent legal case, however, Justice Cavanagh has found that refusing to offer a medical treatment for reasons of 'futility' does not constitute negligence or malpractice, regardless of whether the CPSO may now consider it professional misconduct. Mr DeGuerre's case, which now appears to be winding down after a decade in regulatory challenges and litigation, offers an opportunity to revisit questions of 'futile care' that have been largely dormant in the literature for several years.

UTILITY AND FUTILITY IN RESUSCITATION TREATMENT DECISIONS

Discussions about treatment wishes and 'goals of care' have become part of our common experience as medicine's technological limits expand. Modern medicine can sometimes reverse conditions that would have meant death even one generation ago. These successes have been accompanied by questions about the appropriateness of aggressive treatments in cases of advanced disease. This debate is often framed in terms of treatment 'futility'—a contentious term which means different things to physicians and to laypeople.

Futility is hard to define in general, especially when dealing with CPR and other extraordinary life-sustaining measures. Early definitions concentrated on the technical effectiveness of resuscitation: futility meant an inability to restore the heartbeat.[1] This definition was often broadened to include the 'immediate prolongation of life' generally: if a patient had a prognosis of only 1 week until death, and resuscitation did nothing to alter the prognosis, then this, too, was futile.[2] This strict technical definition reduces the nature of medicine to the maintenance of physiology, exposing two flaws. First, attempting to define procedures as indisputably 100% physiologically futile is dishonest,[3] since many patients do survive CPR, and predicting a resuscitation's success relies on a balance of probabilities rather than objective certainty. Furthermore, physiological criteria do not account for the personal-emotional dimensions of health critical to the art and practice of medicine.

Unfortunately, trying to formulate more holistic definitions of futility introduces all sorts of subjective value judgements into decision-making. Physicians make assumptions about patient quality of life, and this renders them susceptible to presenting 'values disguised as facts' in proposing a medical

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plan.[4] Values and beliefs obviously play a central role in defining futility,[5] but due to their subjectivity and variability, they are a poor basis for policies and guidelines. For this reason, the stricter physiological definition of futility is often preferred. The American Thoracic Society, for example, recommends the use of the term 'futile' only when a treatment cannot possibly attain a desired physiological goal.[6] This recommendation has changed from the earlier 1991 recommendation, which more broadly referred to 'meaningful survival'.

The physiological definition is enshrined in the CPSO policy that resulted from the DeGuerre case. Physicians in Ontario are to restrict themselves to the strict definition of futility if they decide to unilaterally withhold CPR.[7] CPR, the treatment at stake in Mr DeGuerre's case, is the paradigmatic example of aggressive and possibly futile treatment, and often raises a question: How do we define treatment futility when a treatment is often effective in the strict physiological sense (restoring life) while being almost entirely ineffective in the larger, holistic sense—that is, it does not stop dying, merely delays and prolongs it?

Assessing futility needs to account for treatment benefits and burdens, some of which are subjective and patient dependent.[5] For many patients, CPR provides hope for a delay of death that might give them more time to experience whatever in life seems valuable to them. For families, enabling this delay may be a way of encouraging and accompanying the dying in their last struggle. For society, a presumption 'in favour of life' may be conducive to maintaining a sense of continuing the fight against death.

These are all arguably benefits of resuscitative efforts, independent of the effectiveness of the treatment. Some do not consider even failed CPR to be ever 'futile' at all. Even if there was certainty CPR would fail, this failed attempt might still act as a sort of contemporary 'death ritual' in the modern medical environment.[8] Humans have always had death rituals connected with religious beliefs and broader social values. In our technological society, even 'physiologically futile' resuscitation may have significant value as social ritual for the dying and their loved ones.[9]

Despite this possible personal and social value to CPR, it still seems antithetical to medicine to offer an otherwise 'useless' treatment simply because it makes the survivors feel better—it seems a failure in patient-centredness. This constitutes a possible 'burden' of resuscitation, along with physical suffering imposed on a patient and the costs to the community's healthcare resources—questions of best interests and distributive justice.[10] These burdens need to be weighed against the benefits of treatment, and since both have a significant subjective component, obtaining a clear determination of utility or futility a perilous enterprise.

THE SPECIFIC CANADIAN CONTEXT

The DeGuerre case is not the first case in Canada where a definition of 'futility' has been challenged. In the 2013 *Rasouli* case, the appellant physicians made the claim that a 'futile' treatment was not a treatment at all (for the purposes of obtaining consent to discontinue treatment). Canada's Supreme Court ruled against this position (although it restricted its decision to the relevant Ontario statute), suggesting that even procedures 'not medically indicated' might still be 'treatments' requiring patient input. Whatever the intention, the practical effect of this verdict was to place the aforementioned subjective benefits and burdens over any question of objective effectiveness. This placed patients and substitute decision-makers in the position of adjudicating whether a treatment could be offered or refused—a significant exaltation of patient autonomy over professional judgement.

Following the *Rasouli* case and the resolution of the DeGuerre case at the regulatory level in 2015, Ontario's medical regulators altered end-of-life care policies to respond to the issues raised by these decisions.[11] These policy responses have drawn criticism for their failure to account for the 'burdens' (concerns about patient best interests and distributive justice), and for lionising a concept of patient autonomy that focuses solely on patient-perceived benefits of resuscitative efforts.[10 12] The Supreme Court did not consider resource allocation and distributive justice in the *Rasouli* case.[13] Similarly, in the DeGuerre case, both the CPSO complaint and the subsequent legal case focused on autonomy, communication and the standard of care. Neither case substantively addressed the question of the burdens of 'futile' treatments, and the subsequent regulatory responses have failed likewise to do so.

The discontent stirred by the *Rasouli* decision[14 15] suggests that care providers, policymakers and politicians have failed to productively advance a comprehensive debate about whether and what kind of 'futile' care should be provided at the end of life.

PROPOSALS FOR RESPONDING TO REQUESTS FOR 'FUTILE' TREATMENTS

Ethical guidance on 'medically futile' requests remains vague and elusive. Despite uncertainty, the physician has an obligation to try to do right by their patient. One way to fulfil this duty may be to consider what needs the patient and family are trying to fulfil by making a request for 'futile' resuscitation. Requests for resuscitative measures are often 'masks' for deeper, existential needs, and there may be better ways to fulfil these than through CPR. For example, patients may request 'full code' status out of fear of abandonment in their final illness—the fear that foregoing extreme measures will imply foregoing any and all medical care. Care providers should acknowledge this real and reasonable fear, and make explicit their desire to continue caring for patients, to accompany them in their illness, regardless of what their scope of treatment might be. Likewise, families may request CPR out of a sense of filial duty; making family members a meaningful and valued part of the care team may allow them to fulfil this duty without resorting to means which may be harmful to patients.

This approach may also be beneficial to care providers, who often suffer moral distress as a result of subjecting the dying patient to physically and emotionally traumatic procedures.[9] Providers may feel disempowered to act in the best interests of patients if they are stripped of the ability to make expert decisions, such as when 'full code' becomes a presumptive default that must be offered even against clinical judgement. Recognising that the 'unreasonable request' for CPR may in fact be a surrogate for a different—and reasonable—request for help in meeting an existential need may draw physicians into a compassionate encounter with the patient. Care providers may not understand why a patient or family member refuses to follow the medical recommendation against CPR, but they may certainly understand the fear or sense of duty that can underpin refusals. In an ever more bureaucratised and technocratic medical world, the chasm between patients and those who provide them healthcare may be bridged by seeking to understand each other in these most critical moments of the human experience.

From a policy perspective, there is room to amend the relevant regulatory frameworks in Canada. The most obvious target for

reform is the current CPSO Policy on Planning for and Providing Quality End-of-Life Care.[11] This policy has the practical effect of forcing physicians to tell a patient that CPR will have no reasonable expectation of effectiveness (with any 'benefit' being culturally conditioned), and then asking the patient whether they want it anyways. We would not be the first[1 16] to suggest that this sends a senseless and confusing message that is not helpful to patients.

More broadly, laws and statutes also need change. The legal issues raised by both the *Rasouli* and DeGuerre cases depended on interpretation of Ontario's Health Care Consent Act (HCCA). This act provides no mechanism to limit what medical interventions patients or substitute decision makers (SDMs) can demand[10]—limits which are necessary to appropriately balance patient-perceived benefits with objective personal and societal burdens. Furthermore, many provinces lack legislation similar to the HCCA, or non-judicial dispute resolution mechanisms (equivalent to Ontario's Consent and Capacity Board). Reforms which address these gaps are urgently needed; after the *Rasouli* ruling, Canadian clinical practice is already changing to avoid conflicts and increase the provision of inappropriate care.[12 15]

Courageous leaders are needed to confront this difficult task. It is essential to expand the debate beyond what has been discussed in recent court judgements and to include the multifaceted considerations that affect public opinion and expectations. In establishing limits to 'futile' end-of-life care, legislation and policies will, by necessity, have to be much more explicit about how we value things like cultural and spiritual expectations, and how much financial cost our healthcare system and society at large can practically or morally sustain. This task may be uniquely and exceptionally difficult in Canada compared with other countries (where limits have previously been set) because Canadians generally view access to healthcare services as an absolute and inviolable right.[17]

CONCLUSION

The recent cases discussed are reminders that Canada has no clear consensus on the goals of potentially 'futile' care and treatments. We must consider what needs we are addressing and whether we are addressing them correctly, balancing benefits and costs in a holistic manner. These issues must be addressed both at the bedside and in the broader societal arena.

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