

## LAW, ETHICS AND MEDICINE

## Withholding and withdrawing life support in critical care settings: ethical issues concerning consent

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The right to refuse medical intervention is well established, but it remains unclear how best to respect and exercise this right in life support. Contemporary ethical guidelines for critical care give ambiguous advice, largely because they focus on the moral equivalence of withdrawing and withholding care without confronting the very real differences regarding who is aware and informed of intervention options and how patient values are communicated and enacted. In withholding care, doctors typically withhold information about interventions judged too futile to offer. They thus retain greater decision-making burden (and power) and face weaker obligations to secure consent from patients or proxies. In withdrawing care, there is a clearer imperative for the doctor to include patients (or proxies) in decisions, share information and secure consent, even when continued life support is deemed futile. How decisions to withhold and withdraw life support differ ethically in their implications for positive versus negative interpretations of patient autonomy, imperatives for consent, definitions of futility and the subjective evaluation of (and submission to) benefits and burdens of life support in critical care settings are explored. Professional reflection is required to respond to trends favouring a more positive interpretation of patient autonomy in the context of life support decisions in critical care. Both the bioethics and critical care communities should investigate the possibilities and limits of growing pressure for doctors to disclose their reasoning or seek patient consent when decisions to withhold life support are made.

**REFUSALS, CONSENT AND AUTONOMY: PHILOSOPHICAL BACKGROUND**

In Canada and other Anglo-American jurisdictions, a patient's unequivocal right to refuse medical treatment is well established and is ethically justified by the principle of autonomy, according to which people have a right to self-governance, to act freely in accordance with a self-chosen plan.<sup>3</sup> Control over our body has been taken to be central to the interpretation of autonomy. In the context of end-of-life care, the right to refuse treatment places a recognised limit on interventions by doctors, who must respect refusals even against their best clinical judgement and even if a patient's life is at risk as a result. Patients may thus insist that treatment not be given or be withdrawn, and doctors may be expected to comply. However, the mandate of doctors to respect patient refusals has not been taken to extend to an obligation to secure patient consent to the withholding of treatment. Neither has respect for patient autonomy been taken to mean that we are entitled to every requested medical intervention. In law, the principle of autonomy is taken to bestow a negative right, a right to non-interference. To interpret autonomy positively, by contrast, would arguably entitle everyone to any requested treatment, regardless of medical advisability or competing claims for scarce resources. A positive interpretation of autonomy is therefore often taken to be incompatible with the ethical principles of non-maleficence (do no harm) and justice (distribute scarce resources fairly) and with the practical realities of healthcare provision. The positive obligations that are attached to being a doctor—for example, the duty to provide appropriate care—derive from the principle of beneficence and from professional accountability, not from patient autonomy. It seems, then, that, under the negative interpretation, respect for patient autonomy need play no authoritative part in decisions to withdraw or withhold treatment. That is, the decision to withhold life support can be at the doctor's discretion and need neither be declared to nor negotiated with the patient.

Recent ethics discussions have raised serious doubts about the negative interpretation of patient autonomy and have challenged the received view that a positive interpretation of autonomy would essentially conflict with the integrity of the doctor. For instance, both Biegler<sup>4</sup> and Wreen<sup>5</sup> deny that physician integrity requires limiting patient auton-

Whereas a competent and informed patient's right to refuse medical intervention has been well established in bioethics and Anglo-American law for more than a decade,<sup>1</sup> there is less clarity on the role of patient consent in withholding and withdrawing treatment at the end of life and of the ethical and legal status of patient requests for treatment. In a review of clinical guidance documents for end-of-life decision making in clinical settings,<sup>2</sup> we found an emerging consensus that there is no ethical difference between withholding and withdrawing treatment. However, suggested norms varied on the need for patient input. Most guidance documents declared that doctors are under no obligation to offer treatment they consider futile, but the value-laden notion of futility and the ambiguous meaning of patient autonomy suggest the need for further ethical analysis.

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**Abbreviation:** ICU, intensive care unit

omy to refusals, and argue that patient consent should be required for both withholding and withdrawing treatment at the end of life. According to Biegler,<sup>4</sup> if the fundamental point of the informed consent process is to enhance patient autonomy and prevent harm, the consent process may have relevance to withholding, rather than simply giving, an intervention. Further, he maintains, the consent process is more closely aligned to the concept of positive liberty because it provides patients with options and so supports choice.<sup>4</sup> Biegler thus aligns positive choice of treatment with duties of disclosure and the presentation of options, both of which are considered to be fundamental to physician integrity in therapeutic settings.

Wreen<sup>5</sup> also challenges the alleged incompatibility of physician integrity and positive patient autonomy. If physician integrity is understood to require that interventions be more beneficial than burdensome, he argues, integrity is not necessarily compromised when doctors provide interventions they consider to be medically futile. Burden and benefit are subjective value judgements, and there is no guarantee that doctors' independent assessments of patient values are sound.

### **GUIDANCE DOCUMENTS**

In the context of this debate over the status of patient input into the withholding or withdrawal of treatment, it is worth examining how doctors currently understand the issues and translate them into imperatives for practice. Over the past two decades, several guidance documents have seemed to help doctors and other care providers approach life support decisions in critical care settings. This setting is a special one in which patients can rarely communicate due to their underlying disease, endotracheal tube or drugs that they are receiving. Using a method described in detail elsewhere,<sup>2</sup> we systematically searched and collected 49 published documents that outline the goals of life support or an approach to decision making about life support in the critical care setting. Since this review was conducted, an international consensus statement has also been published on end-of-life care in the intensive care unit (ICU).<sup>6</sup> This set of documents represents the range of prevailing beliefs primarily among healthcare providers (eg, medical associations), and importantly also shapes values and behaviours by promulgating particular approaches to life support care. Although communication with patients and their families is given a high priority in most of the documents, there is a lack of clarity over the decisional status of patients' wishes. There is clarity and consensus, however, over the ethical equivalence of withdrawing and withholding treatment in this context.

### **CONSENSUS OVER ETHICAL EQUIVALENCE**

Of the 49 guidance documents, 29 deal with the ethical equivalence of withholding versus withdrawing life support from acutely ill patients, and 28 of these state they are ethically or legally equivalent acts. Even so, over half of them qualify this position with the suggestion that there are important psychological or social differences between them. A number of these noted non-ethical differences; for instance, psychologically, withdrawal of treatment may suggest patient abandonment<sup>7</sup>; withdrawal of treatment may be perceived as more obviously connected to a hastened death,<sup>7</sup> religious and secular ethical understandings may differ, and call for greater sensitivity in dealing with patients, or perhaps transfer of their care<sup>8</sup>; withholding treatment may be strategically useful in avoiding unnecessary and burdensome interventions<sup>9</sup>; it may, by contrast, be viewed with suspicion by patients<sup>10</sup>; in practice, withholding may be easier for clinicians than withdrawing treatment.<sup>11</sup> Nonetheless, the authors agreed on the question of

ethical equivalence. Rejecting the ethical importance of the action and omission distinction, most authors side with current ethical thinking that the appropriateness of medical intervention must be judged in relation to the purpose and boundaries of medical practice and the professional and ethical integrity of practitioners. The likelihood of patient benefit is key.

### **BENEFIT AND FUTILITY**

As patient benefit has a central ethical role, it is important to understand what counts as benefit and from whose perspective. The documents we surveyed offered a range of definitions and criteria for understanding benefit and futility. Some authors favoured physiological-only analyses of futility; others recognised an ineradicable role for patient values. At the physiological-only end of the spectrum, Orłowski *et al*<sup>7</sup> stated that, "If a treatment is clearly futile in the sense that it will not achieve its physiological objective and so offers no benefit to the patient, there is no obligation to provide the treatment" (p 82). The consensus statement of the Society of Critical Care Medicine's Ethics Committee (SCCM) limits "futile" to treatments that offer no physiological benefit.<sup>12</sup> Snyder and Swartz<sup>13</sup> helpfully distinguish two physiological senses of futility: strict futility, where intervention is virtually impossible for physiological reasons, and physiological futility, where it is reasonably clear that treatment will not preserve a physiological function necessary to preserve life. Winter and Cohen<sup>11</sup> identify futility with the dysfunction of three or more organs. The American Thoracic Society,<sup>14</sup> while offering meaningful survival as a criterion of non-futile care, nevertheless recognises that physiological criteria alone can be sufficient for judging an intervention futile in some cases—for example, in the case of a persistent vegetative state. Braddock<sup>15</sup> defines treatment as futile if it may no longer fulfil any of the goals of medicine, which he lists as to cure, palliate or improve functional status. In all of the above, the assumption is that benefit can be measured without input from patients (although most authors cited do highlight the importance of discussion and disclosure).

Bone *et al*<sup>8</sup> appeal to a broader professional standard. They say, "If general medical opinion considers a particular treatment as futile (not altering the patient's immediate survival nor offering any advantage over alternative treatments) then this alternative need not be performed or even discussed with the patient or his (sic) surrogate." (p 952)

But if, as Biegler<sup>4</sup> and Wreen<sup>5</sup> assert, assessments of benefit are fundamentally subjective, the foregoing definitions must be incomplete. Unless an intervention is infeasible (as in strict futility above), some subjective assessment of its benefit must have a role. A small physiological improvement might seem sufficiently beneficial to a patient, but not to a doctor (or vice versa). Merely postponing an inevitable death might be vital for a patient seeking social, spiritual or any other personal closure, whereas to doctors the deferral of death is not perceived to be beneficial, as the outcome is the same. Proportionality assessments depend on subjective predictions about benefit and harm, which vary with perspective. And even an intervention viewed by a doctor as having a 0% chance of achieving its physiological goal might function and be desired by a patient just in case it might be helpful. Some of the tools we examined recognised this and offered definitions of futility (or understandings of benefit) that encompass more than physiological considerations. For instance, the British Medical Association's position paper (while stopping short of conceding decisional authority to patients) offers three standards: patients' quality of life, the best interests of patients and the proportionality standard (which is usually taken to require a patient's assessment of the balance between benefits and burdens).<sup>10</sup> Virtual hopelessness is offered by Snyder and Swartz,<sup>13</sup> and

refers to a quality of life unacceptable to a patient or other reasonable person. And Ruark *et al.*,<sup>16</sup> adopting a proportionality approach, insist on the priority of the patient's view of the appropriate balance between quality of life and its mere prolongation, and exhort clinicians to diligently avoid making assumptions in this area, especially with patients of different religious or ethnic backgrounds.

## DECISIONAL AUTHORITY

Of the tools that acknowledge the centrality of values, some foreground patient decisional authority. For instance, Snyder and Swartz<sup>13</sup> counsel that doctors should be reluctant to withdraw treatment in the face of family demands for continued treatment and that "Under most current hospital policies and Joint Commission Guidelines, CPR cannot be withheld without the agreement of the patient, or...surrogate" (p 180). Ruark *et al.*<sup>16</sup> assert that the actual authority over the patient never resides with the doctor. Patients alone, or their legal surrogates, have the right to control what happens to them. But most statements on decisional authority are more guarded. The Task Force on Ethics of Society of Critical Care Medicine<sup>12</sup> states that the wishes of an informed adult patient who has the capacity to make decisions should be the primary and most weighty consideration in almost all decisions on treatment, but does not say the decision is the patient's. The British Medical Association<sup>12</sup> recommends that treatment should be continued in cases of disagreement between doctors and patients, but only for a short time (presumably until the patient sees its futility).<sup>10</sup> Most of the documents emphasise the importance of discussions with patients before decision making about withholding or withdrawing treatment, but, as Sjøkvist *et al.*<sup>17</sup> remark, discussion may mean patient request, active participation in the decision making, or merely being informed of the doctor's decision.

Amidst this vagueness about the actual role of the patient, the status of patient preference remains unclear. For instance, according to the American Thoracic Society,<sup>14</sup> although doctors should consider both medical and patient values when making treatment recommendations, they may withhold or withdraw treatment without the consent of patients or surrogates if the patient's survival would not be meaningful in quality or duration, even if the patient has requested intervention. Orłowski *et al.*<sup>7</sup> insist on the permission of the patient before removing a ventilator; yet, they also state that doctors have no obligation to provide useless care or care that violates established community standard of practice. Danis *et al.*<sup>18</sup> in their overview of best practice in the ICU emphasise the importance of communication, of listening well and of taking responsibility for decisions in a way that takes into account the wishes of the patient. Here, it seems, the decisional responsibility still resides with the doctor. Bone *et al.*<sup>8</sup> speak of mutual and voluntary discussions resulting in jointly acceptable decisions. These statements do not suggest that patient consent is required for the withholding or withdrawing of treatment, or that patient autonomy entitles patients to treatment, in large part because critically ill patients can rarely engage in any dialogue about their healthcare. Often proxies are approached to obtain consent; however, this is also problematic because proxies are often unable to accurately reflect the values of critically ill family members.

Should patients (or their proxies) have decisional authority and positive entitlements to desired interventions? Some arguments can be presented in favour of this view. *Prima facie*, patients have a stronger stake in the outcome of end-of-life decisions than doctors and hence ought to have more authority. As Wreen<sup>9</sup> remarks, it is the patient's life to lead, and death to die. A concern with professional integrity cannot

trump that when there is some possibility, however small, of survival, and the patient wants to take it. Furthermore, given that judgements of benefit (and hence harm) have an irreducibly subjective component, for doctors to provide desired medical interventions against their best clinical judgements is not necessarily a violation of integrity. To withhold such interventions, as Biegler<sup>4</sup> notes, may in fact be harmful.

Recent empirical data on how doctors make end-of-life decisions and communicate with patients reinforce the need to require patient input. For instance, Sjøkvist *et al.*<sup>17</sup> report that European practices fall short of compliance despite guidelines mandating discussions with patients or family members regarding end-of-life decisions in the critical care setting. They report a Dutch study in which do-not-resuscitate orders were discussed with only 32% of patients and 32% of family members. Another European study showed that only 57% of doctors discussed do-not-resuscitate orders with the family and only 7% with patients. And although an English ICU study showed a very high (96%) rate of discussion, Swedish practice corresponds to the European practice, despite explicit guidelines from the Swedish Society of Medicine and the National Board of Health and Welfare. A further troubling feature of end-of-life medical practice is documented by Truog *et al.*,<sup>19</sup> who found that several biases affect doctors' decisions on withdrawals. For example, doctors favour terminating recently instituted life support, life support for natural versus iatrogenically induced conditions and more expensive, scarce or more artificial measures.

Are these considerations sufficient to mandate a shift to unilateral decisional authority or positive entitlements for patients in the context of withholding and withdrawing treatment? Three arguments militate against this conclusion. Firstly, even when patient autonomy and integrity of the doctor are rendered more compatible, discomfort remains over the prospect of recognising an obligation to provide harmful or bizarre treatments, as Biegler notes.<sup>4</sup> Furthermore, the principle of justice still operates as a recognised limitation on patient choice, so privileging positive patient autonomy may result in a failure to take responsibility for the fair distribution of scarce resources. And finally, the ideal of unilateral decision making (whether by doctors or by patients) obscures the importance of relationships, both for effective treatment and for the exercise of autonomy. Instead of assigning unilateral decisional authority to one party or the other, we favour a relational model in which doctors have a duty to disclose recommendations for withholding and withdrawal. Patients or their proxies who disagree would have access to appeal procedures such as those in Biegler's due process model, involving other clinicians and ethics committees and the option of transfer. Where the direness of a patient's condition curtails the appeal process, Biegler firmly resists requiring doctors to provide treatments they consider harmful. However, post facto third party reviews would routinely be triggered in cases where the withheld treatment might reasonably have been expected, the patient died as a result or the treatment was withheld after specific deliberation by the healthcare team.

Although favouring Biegler's proposal, we would expand its relational perspective. Many of the guidance documents emphasise the importance of communicating with patients. But increased communication must be accompanied by an understanding of the relevance of non-medical values and the epistemic privilege of patients and family members regarding those values. Improved communication is necessary, but not sufficient, for strengthening patient autonomy. As Sherwin<sup>20</sup> has reasoned, arriving at an autonomous decision is a collaborative activity, in which people rely on particular others in a variety of ways. Patients (or proxies) faced with decisions

about the withholding or withdrawal of treatment should therefore be supported in their morally relevant relationships, and have access to the resources needed for making good decisions. Thus, beyond promoting patients' understanding through good communication, doctors should enhance patient autonomy by ensuring a fully inclusive decision-making environment. This may not be possible in the ICU environment when doctors are caring for critically ill patients who are comatose.

## CONCLUSION

As we have seen in this overview of the guidance documents, notwithstanding changes in ethical thinking on the ethical status of decisions to withhold or withdraw life-sustaining treatment, there remains considerable vagueness regarding the respective decisional weight of patient (or proxy) preferences and the judgement of the doctor in the critical care setting. Clinical guidance documents for life support decisions assert the importance of physician integrity in withholding or withdrawing futile treatments; yet the values content of relevant factors—futility and benefit—suggests that patient consent to withholding or withdrawing treatment might be ethically required from the patients themselves or their proxies. Respect for patient autonomy need not be seen entirely in negative terms (ie, the patient's right to refuse treatment) but may be understood as the provision of options for enhanced choice and the resources to make such choices, a view that is consistent with the current priority given to informed consent. This is not possible without increased attention to communication with family members and other proxies.

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