



# Medical, legal and ethical definitions of futility

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## In re Quinlan

70 N.J. 10 (1976)

355 A.2d 647

### IN THE MATTER OF KAREN QUINLAN, AN ALLEGED INCOMPETENT.

The Supreme Court of New Jersey.

Argued January 26, 1976.

Decided March 31, 1976.

On the night of April 15, 1975, Karen Ann Quinlan, aged 22, lapsed into a coma from which she still has not emerged.<sup>1</sup> On September 10, 1975, her father applied to the Chancery division of the Superior Court of New Jersey for letters of guardianship with the express power to authorize “the discontinuance of all extraordinary means of sustaining the vital processes of his daughter. . . .”<sup>2</sup> This request was strenuously opposed by Karen’s doctors, the hospital in which she was being treated, the county prosecutor, Karen’s guardian ad litem, and the state of New Jersey, which had intervened on the basis of a state interest in the preservation of life.<sup>3</sup>

The experts believe that Karen cannot now survive without the assistance of the respirator; that exactly how long she would live without it is unknown; that the strong likelihood is that death would follow soon after its removal, and that removal would also risk further brain damage and would curtail the assistance the respirator presently provides in warding off infection.

It seemed to be the consensus not only of the treating physicians but also of the several qualified experts who testified in the case, that removal from the respirator would not conform to medical practices, standards and traditions.

The further medical consensus was that Karen in addition to being comatose is in a chronic and persistent "vegetative" state, having no awareness of anything or anyone around her and existing at a primitive reflex level. Although she does have some brain stem function (ineffective for respiration) and has other reactions one normally associates with being alive, such as moving, reacting to light, sound and noxious stimuli, blinking her eyes, and the like, the quality of her feeling impulses is unknown. She grimaces, makes stereotyped cries and sounds and has chewing motions. Her blood pressure is normal.

Karen remains in the intensive care unit at Saint Clare's Hospital, receiving 24-hour care by a team of four nurses characterized, as was the medical attention, as "excellent." She is nourished by feeding by way of a nasal-gastro tube and is routinely examined for infection, which under these [26] circumstances is a serious life threat. The result is that her condition is considered remarkable under the unhappy circumstances involved.

We thus arrive at the formulation of the declaratory relief which we have concluded is appropriate to this case. Some time has passed since Karen's physical and mental condition was described to the Court. At that time her continuing deterioration was plainly projected. Since the record has not been expanded we assume that she is now even more fragile and nearer to death than she was then. Since her present treating physicians may give reconsideration to her present posture in the light of this opinion, and since we are transferring to the plaintiff as guardian the choice of the attending physician and therefore other physicians may be in charge of the case who may take a different view from that of the present attending physicians, we herewith declare the following affirmative relief on behalf of the plaintiff. Upon the concurrence of the guardian and family of Karen, should the responsible attending physicians conclude that there is no reasonable possibility of Karen's ever emerging from her present comatose condition to a cognitive, sapient state and that the life-support apparatus now being administered to Karen should be discontinued, they shall consult with the hospital "Ethics Committee" or like body of the institution in which Karen is then hospitalized. If that consultative body agrees that there is no reasonable possibility of Karen's ever emerging from her present comatose condition to a cognitive, sapient state, the present life-support system may be withdrawn and said action shall be without any civil or criminal liability therefor on the part of any participant, whether guardian, physician, hospital or others.<sup>[11]</sup> We herewith specifically so hold.

We repeat for the sake of emphasis and clarity that upon the concurrence of the guardian and family of Karen, should the responsible attending physicians conclude that there is no reasonable possibility of Karen's ever emerging from her present comatose condition to a cognitive, sapient state and that the life-support apparatus now being administered to Karen should be discontinued, they shall consult with the hospital "Ethics Committee" or like body of the institution in which Karen is then hospitalized. If that consultative body agrees that there is no reasonable possibility of Karen's ever emerging from her present comatose condition to a cognitive, sapient state, the present life-support system may be withdrawn and said action shall be without any civil or criminal liability therefor, on the part of any participant, whether guardian, physician, hospital or others.

**INDEXED AS: CARTER v. CANADA (ATTORNEY  
GENERAL)**

**2015 SCC 5**

File No.: 35591.

2014: October 15; 2015: February 6.

Present: McLachlin C.J. and LeBel, Abella, Rothstein,  
Cromwell, Moldaver, Karakatsanis, Wagner and Gascon JJ.

Section 241(b) of the *Criminal Code* says that everyone who aids or abets a person in committing suicide commits an indictable offence, and s. 14 says that no person may consent to death being inflicted on them. Together, these provisions prohibit the provision of assistance in dying in Canada. After T was diagnosed with a fatal neurodegenerative disease in 2009, she challenged the constitutionality of the *Criminal Code* provisions prohibiting assistance in dying. She was joined in her claim by C and J, who had assisted C's mother in achieving her goal of dying with dignity by taking her to Switzerland to use the services of an assisted suicide clinic; a physician who would be willing to participate in physician-assisted dying if it were no longer prohibited; and the British Columbia Civil Liberties Association. The Attorney General of British Columbia participated in the constitutional litigation as of right.

The trial judge found that the prohibition against physician-assisted dying violates the s. 7 rights of competent adults who are suffering intolerably as a result of a grievous and irremediable medical condition and concluded that this infringement is not justified under s. 1 of the *Charter*. She declared the prohibition unconstitutional, granted a one-year suspension of invalidity and provided T with a constitutional exemption. She awarded special costs in favour of the plaintiffs on the ground that this was justified by the public interest in resolving the legal issues raised by the case, and awarded 10 percent of the costs against the Attorney General of British Columbia in light of the full and active role it assumed in the proceedings.

*Held:* The appeal should be allowed. Section 241(b) and s. 14 of the *Criminal Code* unjustifiably infringe s. 7 of the *Charter* and are of no force or effect to the extent that they prohibit physician-assisted death for a competent adult person who (1) clearly consents to the termination of life and (2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition. The declaration of invalidity is suspended for 12 months. Special costs on a full indemnity basis are awarded against Canada throughout. The Attorney General of British Columbia will bear responsibility for 10 percent of the costs at trial on a full indemnity basis and will pay the costs associated with its presence at the appellate levels on a party-and-party basis.

Insofar as they prohibit physician-assisted dying for competent adults who seek such assistance as a result of a grievous and irremediable medical condition that causes enduring and intolerable suffering, ss. 241(b) and 14 of the *Criminal Code* deprive these adults of their right to life, liberty and security of the person under s. 7 of the *Charter*. The right to life is engaged where the law or state action imposes death or an increased risk of death on a person, either directly or indirectly. Here, the prohibition deprives some individuals of life, as it has the effect of forcing some individuals to take their own lives prematurely, for fear that they would be incapable of doing so when they reached the point where suffering was intolerable. The rights to liberty and security of the person, which deal with concerns about autonomy and quality of life, are also engaged. An individual's response to a grievous and irremediable medical condition is a matter critical to their dignity and autonomy. The prohibition denies people in this situation the right to make decisions concerning their bodily integrity and medical care and thus trenches on their liberty. And by leaving them to endure intolerable suffering, it impinges on their security of the person.

The prohibition on physician-assisted dying infringes the right to life, liberty and security of the person in a manner that is not in accordance with the principles of fundamental justice. The object of the prohibition is not, broadly, to preserve life whatever the circumstances, but more specifically to protect vulnerable persons from being induced to commit suicide at a time of weakness. Since a total ban on assisted suicide clearly helps achieve this object, individuals' rights are not deprived arbitrarily. However, the prohibition catches people outside the class of protected persons. It follows that the limitation on their rights is in at least some cases not connected to the objective and that the prohibition is thus overbroad. It is unnecessary to decide whether the prohibition also violates the principle against gross disproportionality.

The appropriate remedy is not to grant a free-standing constitutional exemption, but rather to issue a declaration of invalidity and to suspend it for 12 months. Nothing in this declaration would compel physicians to provide assistance in dying. The *Charter* rights of patients and physicians will need to be reconciled in any legislative and regulatory response to this judgment.

First Session, Forty-second Parliament,  
64-65 Elizabeth II, 2015-2016

## STATUTES OF CANADA 2016

### CHAPTER 3

An Act to amend the Criminal Code and to  
make related amendments to other Acts  
(medical assistance in dying)

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#### ASSENTED TO

JUNE 17, 2016

BILL C-14

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#### Consent to death

**14** No person is entitled to consent to have death inflicted on them, and such consent does not affect the criminal responsibility of any person who inflicts death on the person who gave consent.

#### **2 The Act is amended by adding the following after section 226:**

##### **Exemption for medical assistance in dying**

**227 (1)** No medical practitioner or nurse practitioner commits culpable homicide if they provide a person with medical assistance in dying in accordance with section 241.2.

*medical assistance in dying* means

**(a)** the administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death; or

**(b)** the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death.  
(*aide médicale à mourir*)

### **Eligibility for medical assistance in dying**

**241.2 (1)** A person may receive medical assistance in dying only if they meet all of the following criteria:

- (a)** they are eligible — or, but for any applicable minimum period of residence or waiting period, would be eligible — for health services funded by a government in Canada;
- (b)** they are at least 18 years of age and capable of making decisions with respect to their health;
- (c)** they have a grievous and irremediable medical condition;
- (d)** they have made a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure; and
- (e)** they give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care.

### **Grievous and irremediable medical condition**

**(2)** A person has a grievous and irremediable medical condition only if they meet all of the following criteria:

- (a)** they have a serious and incurable illness, disease or disability;
- (b)** they are in an advanced state of irreversible decline in capability;
- (c)** that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and
- (d)** their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.

### **Reasonable knowledge, care and skill**

**(7)** Medical assistance in dying must be provided with reasonable knowledge, care and skill and in accordance with any applicable provincial laws, rules or standards.



# Defining medical futility

- *futtile* – a container with a wide mouth and a narrow vase, from which water drawn from the Vesta would immediately spill
- Medical futility- A treatment that (per a physician's determination) offers no therapeutic benefit to the patient
- the probabilistic nature of medicine and the value judgments inherent in evaluating any probability problematize attempts to define “futile” care (Truog et al, 1992)
- Futility must be defined in terms of the futility of achieving specific ends (“Futility in relation to what?”)
  - Medical utility: Is treatment worthwhile to the individual?
  - Economic utility (rationing): Is the benefit worthwhile to society?

Shneiderman et al:

- Defined futility as a conclusion of common-sense notions and widely accepted statistical assumptions about acceptable levels of probability

Two broad conceptions of futility:

- Quantitative (physiological) futility: Care that produces no effect
- Qualitative futility: Care that produces an effect, but offers no benefit

### **Quantitative futility**

- Care that produces no physiological effect at a given level of probability (Veatch and Spicer)
- Hastings Center: physicians may withhold or withdraw care that is determined to be physiologically futile
- e.g. surgery for diffusely metastatic cancer
- Does not solve issue of benefit vs. effect of therapy (e.g. mechanical ventilation sustaining life in a comatose patient with unresolvable brain injury)
- Fails in the face of medical uncertainty: probability  $\neq$  certainty

## **Qualitative futility**

- Care that produces effects the physicians perceive to be of no benefit
- e.g. mechanical ventilation in a comatose patient with diffuse anoxic injury, CPR in a patient with diffuse metastatic lung cancer
- Presumes (and allows) a physician to make a decision in the best interest of her patient (the “perpet[ual] prisoner in the Intensive Care Unit”)
- Stell: “nested” ends for diagnostic and therapeutic efforts—value is dependent upon the expected or possible end result

## **Qualitative futility**

- Normative futility: a judgment of medical futility made for a treatment that is seen to have a physiologic effect but is believed to have no benefit
  - e.g. life-maintaining interventions for a patient in a vegetative state

**Conversely:** qualitative futility conflicts directly with established notion of patient autonomy: based on *physician perception*

- *Who decides that a treatment will not achieve its goal? Who decides the goal?*

## Is this Futility?

- A treatment that will achieve its goal <1% of the time with minimal risks to the patient and at small cost.
- A treatment that will achieve its goal <1% of the time with very high risks to the patient and at small cost.
- A treatment that will achieve its goal <1% of the time with very high risks to the patient and at very high costs.

Patient  $\leftarrow \rightarrow$  Physician  $\leftarrow \rightarrow$  Health System  $\leftarrow \rightarrow$  Society

## **The Tensions**

1. Inevitability of death and illness
2. The limitations of scientific medicine
3. The ends of medicine
4. The availability of resources
5. Socio-religious and cultural Issues
6. Conflict of interests

What makes a treatment “unethical”?

- Patients could pursue treatment towards ends for which medical treatment should not be employed
- The treatment could violate a particular physician’s personal (or personal understanding of her professional) ethics
- The treatment could not be the best use of society’s scarce health care resources

What makes a treatment “unethical”?

- Patients could pursue treatment towards ends for which medical treatment should not be employed
  - Persistent vegetative state (PVS)
  - Survival with severe deficits
  - Survival with moderate deficits (i.e. chronic pain)
- The treatment could violate a particular physician’s personal (or personal understanding of her professional) ethics
  - Abortion
  - Craniectomy for dominant hemisphere stroke
- The treatment could not be the best use of society’s scarce health care resources



# Futility and the legislature

## Amendment to Virginia Health Care Decision Act (VA-HCDA Section 2990)

- “Nothing in this article shall be construed to require a physician to prescribe or render medical treatment to a patient that the physician determines to be medically or ethically inappropriate.”

## Amendment to Maryland Health Care Decision Act (MD-HCDA Section 5-611)

- (a) Ethically inappropriate treatment is not required.
- (b) Medically ineffective treatment not required.
  - Medically ineffective treatment defined as “to a reasonable degree of medical certainty, a medical procedure will not (1) Prevent or reduce the deterioration of the health of an individual; or (2) Prevent the impending death of an individual.”

- Both statutes provide for transfer of the patient when physicians determine that the requested treatment is inappropriate
  - *What to do if an accepting alternative physician/institution willing to provide the requested treatment cannot be identified?*
- In the absence of an alternative, both the VA-HDCA and MD-HDCA require physicians to offer treatment that are necessary to prevent death

Veterans Health Administration policy:

- Cannot write a DNR order without a patient's or surrogate's consent
- A physician may withhold or terminate CPR based on bedside clinical judgment

## Texas Advance Directives Act (1999)

- Allows a health care facility to discontinue life-sustaining treatment ten days after giving written notice if the continuation of life-sustaining treatment is considered futile care by the treating medical team
- No reporting clause in the current statute
- Dr. Robert Fine (Office of Clinical Ethics, Baylor Health Care System):
  - 974/2922 Ethics committee consultations for cases concerning medical futility
  - 65 letters stating agreement with the attending physicians that treatment should be withdrawn
  - 27 cases in which treatment was withdrawn
  - 22 patient died receiving treatment while awaiting transfer

#### Key Provisions for Resolving Futility Cases under the Texas Advance Directives Act.\*

1. The physician's refusal to comply with the patient's or surrogate's request for treatment must be reviewed by a hospital-appointed medical or ethics committee in which the attending physician does not participate.
2. The family must be given 48 hours' notice and be invited to participate in the consultation process.
3. The ethics-consultation committee must provide a written report detailing its findings to the family and must include this report in the medical record.
4. If the ethics-consultation process fails to resolve the dispute, the hospital, working with the family, must make reasonable efforts to transfer the patient's care to another physician or institution willing to provide the treatment requested by the family.
5. If after 10 days (measured from the time the family receives the written summary from the ethics-consultation committee) no such provider can be found, the hospital and physician may unilaterally withhold or withdraw therapy that has been determined to be futile.
6. The patient or surrogate may request a court-ordered time extension, which should be granted only if the judge determines that there is a reasonable likelihood of finding a willing provider of the disputed treatment.
7. If the family does not seek an extension or the judge fails to grant one, futile treatment may be unilaterally withdrawn by the treatment team with immunity from civil and criminal prosecution.

\* The list is adapted from Fine and Mayo<sup>1</sup> and Okhuysen-Cawley et al.<sup>2</sup> The full text of the law is available at <http://tlo2.tlc.state.tx.us/statutes/docs/HS/content/htm/hs.002.00.000166.00.htm>.

# Legal understandings of medical futility (US)

## **In Re Helga Wanglie 1991**

- 85yo W
- 14 December 1989 mechanical fall resulting in broken hip
- Complicated post-operative course resulting in an irreversible persistent vegetative state
- Ventilator-dependent
- Husband refused advise to support withdrawal of futile care
- Petition to replace guardian filed by Steven B. Miles
- Decision: Ms. Wanglie and her estate best served by appointment of Mr. Wanglie as her guardian

# Legal understandings of medical futility (US)

## **In Re Baby K 1993/1994**

- Born in October 1992 with anencephaly
- Medically stabilized at birth, family informed of diagnosis and prognosis
- Medical team recommended supportive care (warmth, nutrition, hydration) and DNR
- Ms. H refused DNR and asked that mechanical breathing assistant be given
- At 2<sup>nd</sup> readmission, hospital brought a declaratory judgment action to determine whether the hospital was required to continue delivering care that it deemed medically and ethically inappropriate

# Legal understandings of medical futility (US)

## **In Re Baby K 1993/1994**

- US District Court for Eastern District of VA—mother found to be appropriate decision-maker for Baby K
- Fourth Circuit affirmed decision
- Mother's constitutional and common-law rights as parent to make medical decisions
- Presumption in favor of life

# Legal understandings of medical futility (US)

## **In Re Jane Doe 1991**

- 13yo girl with irreversible coma with no hope of “meaningful recovery”
- Parents disagreed as to de-escalation of care or DNR
- Court disagreed with physician concerns that continued treatment would be “abusive and inhumane”—move away from “paternalistic view of what is ‘best’ for a patient” and toward principle of individual autonomy
- Fundamental right of parents to direct medical treatment for their children
- Presumption in favor of life



# Legal understandings of medical futility (Canada)

[2013] 3 R.C.S.

CUTHBERTSON c. RASOULI

341

**Brian Cuthbertson and  
Gordon Rubinfeld** *Appellants*

v.

**Hassan Rasouli, by his Litigation Guardian  
and Substitute Decision-Maker,  
Parichehr Salasel** *Respondent*

and

**Consent and Capacity Board,  
Euthanasia Prevention Coalition,  
Canadian Critical Care Society,  
Canadian Association of Critical Care Nurses,  
Advocacy Centre for the Elderly,  
ARCH Disability Law Centre, Mental Health  
Legal Committee, HIV & AIDS Legal  
Clinic Ontario and Evangelical Fellowship  
of Canada** *Interveners*

INDEXED AS: CUTHBERTSON v. RASOULI

2013 SCC 53

File No.: 34362.

2012: December 10; 2013: October 18.

Present: McLachlin C.J. and LeBel, Fish, Abella,  
Rothstein, Cromwell and Karakatsanis JJ.

ON APPEAL FROM THE COURT OF APPEAL FOR  
ONTARIO

**Brian Cuthbertson et  
Gordon Rubinfeld** *Appelants*

c.

**Hassan Rasouli, représenté par sa tutrice à  
l'instance et mandataire spéciale,  
Parichehr Salasel** *Intimé*

et

**Commission du consentement et de la capacité,  
Coalition pour la prévention de l'euthanasie,  
Société canadienne de soins intensifs,  
Association canadienne des infirmiers/  
infirmières en soins intensifs, Advocacy Centre  
for the Elderly, ARCH Disability Law Centre,  
Mental Health Legal Committee, HIV & AIDS  
Legal Clinic Ontario et Alliance évangélique  
du Canada** *Intervenants*

RÉPERTORIÉ : CUTHBERTSON c. RASOULI

2013 CSC 53

N° du greffe : 34362.

2012 : 10 décembre; 2013 : 18 octobre.

Présents : La juge en chef McLachlin et les juges LeBel,  
Fish, Abella, Rothstein, Cromwell et Karakatsanis.

EN APPEL DE LA COUR D'APPEL DE L'ONTARIO

R is unconscious and has been on life support since October 2010. The physicians responsible for R's care believed that he was in a persistent vegetative state, that all appropriate treatments for his condition had been exhausted, and that there was no realistic hope for his medical recovery. In their opinion, continuing life support would not provide any medical benefit to R and may cause harm. They sought to remove his life support and to provide palliative care until his expected death. S, R's wife and substitute decision-maker ("SDM"), refused to provide her consent and applied to the Ontario Superior Court of Justice for an order restraining the physicians from withdrawing R from life support without her consent as required by the *Health Care Consent Act, 1996*, S.O. 1996, c. 2, Sch. A ("HCCA"), and directing that any challenge to her refusal of consent be made to the Consent and Capacity Board ("Board"). The physicians cross-applied for a declaration that consent is not required to withdraw life support where such treatment is futile, and that the Board has no jurisdiction to decide these issues.

**Purposes**

**1** The purposes of this Act are,

- (a) to provide rules with respect to consent to treatment that apply consistently in all settings;
- (b) to facilitate treatment, admission to care facilities, and personal assistance services, for persons lacking the capacity to make decisions about such matters;
- (c) to enhance the autonomy of persons for whom treatment is proposed, persons for whom admission to a care facility is proposed and persons who are to receive personal assistance services by,
  - (i) allowing those who have been found to be incapable to apply to a tribunal for a review of the finding,
  - (ii) allowing incapable persons to request that a representative of their choice be appointed by the tribunal for the purpose of making decisions on their behalf concerning treatment, admission to a care facility or personal assistance services, and
  - (iii) requiring that wishes with respect to treatment, admission to a care facility or personal assistance services, expressed by persons while capable and after attaining 16 years of age, be adhered to;
- (d) to promote communication and understanding between health practitioners and their patients or clients;
- (e) to ensure a significant role for supportive family members when a person lacks the capacity to make a decision about a treatment, admission to a care facility or a personal assistance service; and
- (f) to permit intervention by the Public Guardian and Trustee only as a last resort in decisions on behalf of incapable persons concerning treatment, admission to a care facility or personal assistance services. 1996, c. 2, Sched. A, s. 1.

## CONSENT TO TREATMENT

### **No treatment without consent**

**10** (1) A health practitioner who proposes a treatment for a person shall not administer the treatment, and shall take reasonable steps to ensure that it is not administered, unless,

- (a) he or she is of the opinion that the person is capable with respect to the treatment, and the person has given consent; or
- (b) he or she is of the opinion that the person is incapable with respect to the treatment, and the person's substitute decision-maker has given consent on the person's behalf in accordance with this Act. 1996, c. 2, Sched. A, s. 10 (1).

### **Opinion of Board or court governs**

(2) If the health practitioner is of the opinion that the person is incapable with respect to the treatment, but the person is found to be capable with respect to the treatment by the Board on an application for review of the health practitioner's finding, or by a court on an appeal of the Board's decision, the health practitioner shall not administer the treatment, and shall take reasonable steps to ensure that it is not administered, unless the person has given consent. 1996, c. 2, Sched. A, s. 10 (2).

### **Elements of consent**

**11** (1) The following are the elements required for consent to treatment:

1. The consent must relate to the treatment.
2. The consent must be informed.
3. The consent must be given voluntarily.
4. The consent must not be obtained through misrepresentation or fraud. 1996, c. 2, Sched. A, s. 11 (1).

### **Informed consent**

(2) A consent to treatment is informed if, before giving it,

- (a) the person received the information about the matters set out in subsection (3) that a reasonable person in the same circumstances would require in order to make a decision about the treatment; and
- (b) the person received responses to his or her requests for additional information about those matters. 1996, c. 2, Sched. A, s. 11 (2).

**Meaning of “substitute decision-maker”**

**9** In this Part,

“substitute decision-maker” means a person who is authorized under section 20 to give or refuse consent to a treatment on behalf of a person who is incapable with respect to the treatment. 1996, c. 2, Sched. A, s. 9.

The *HCCA* codifies and builds upon the common law of consent in Ontario. It is designed to give effect to the principle of patient autonomy — a principle with deep roots in our common law — that permits a patient to refuse medical treatment, no matter the consequences. The scheme of the Act ensures that when treatment is proposed, doctors, substitute decision-makers and the Board are all bound by the patient's known wishes, if clear and applicable. This is true for all treatments; there are no special provisions for end-of-life scenarios.

However, the *HCCA* does not permit a patient to dictate treatment. Neither the words nor the scheme of the Act contemplate a patient's right to stop a doctor from withdrawing treatment that is no longer medically effective or is even harmful. Such an extension of patient autonomy to permit a patient to insist on the continuation of treatment that is medically futile would have a detrimental impact on the standard of care and legal, ethical, and professional duties in the practice of medicine. The role of patient autonomy must be balanced with the physician's role, expertise, and advice. As well, there are a myriad of important interests, such as the integrity of our health care system, at stake.

As with the *HCCA*, the common law does not entitle a patient to insist upon continuation of treatment; it does not require a patient's consent to the withholding or withdrawal of treatment. Even in those cases in which the court has intervened to prevent doctors from unilaterally withdrawing or withholding treatment, the courts did not conclude that consent was required. Rather, in those cases, the courts ordered an injunction pending trial. Other courts have explicitly concluded that consent is not required for the withdrawal of treatment and that it is not appropriate for a court to interfere with medical doctors acting unilaterally and professionally in the best interests of a patient.

As with the *HCCA*, the common law does not entitle a patient to insist upon continuation of treatment; it does not require a patient's consent to the withholding or withdrawal of treatment. Even in those cases in which the court has intervened to prevent doctors from unilaterally withdrawing or withholding treatment, the courts did not conclude that consent was required. Rather, in those cases, the courts ordered an injunction pending trial. Other courts have explicitly concluded that consent is not required for the withdrawal of treatment and that it is not appropriate for a court to interfere with medical doctors acting unilaterally and professionally in the best interests of a patient.

In many typical doctor-patient relationships, the fiduciary obligation and the standard of care will likely overlap or resemble one another. However, in the end-of-life scenario where ongoing life support is futile, the foundation and ambit of a doctor's fiduciary duty would be a useful and appropriate conceptual paradigm to supplement the standard of care and address the broader best interests of the patient. These obligations should require doctors to undertake a certain process for resolving important questions in the end-of-life setting by including a role for the family or substitute decision-maker; providing notice and a thorough and accommodating process for determining the condition and best interests of the patient; and, where they are of the opinion that life support for a patient should be withdrawn, exploring alternative institutions willing to continue the treatment. Ultimately, if a doctor is satisfied that treatment is futile, he or she may discontinue treatment notwithstanding the wishes of the patient or family, provided they have followed these consultative processes and considered the patient's best interests.

Where, as here, a family member or a substitute decision-maker disagrees with the medical practitioner's decision to withdraw life support, that person may apply to the court to challenge the physician's decision. In reviewing whether a physician is acting within the professional standard of care, the court should determine whether the life support has any chance of being medically effective and whether withdrawal of the treatment is in the best interests of the patient. This necessarily includes consideration of the patient's wishes, values and beliefs, in addition to the broad mental and physical implications for the patient's condition and well-being. However, in making that determination, the continuation of life is not an absolute value. The ultimate decision whether to withdraw life-sustaining treatment must respect the medical or physical consequences of withdrawal or continuation of life support, and also the personal autonomy, bodily integrity, and human dignity of the patient. A doctor cannot be required to act outside of the standard of care and contrary to his or her professional duties.

In this case, the application judge made no factual findings about the patient's condition and effectiveness of any treatment, and the patient's diagnosis has been subject to change. The matter should therefore be remitted to the Ontario Superior Court of Justice, so that it may make the necessary findings of fact, and to determine whether the withdrawal of life support is in accordance with the standard of care and the best interests of the patient.

# Challenges since *Rasouli*

- University of Montreal Hospital v. WL
- In re SL



# The Ethics of Futility

- What are the goals of medicine?
- What defines meaningful human existence?
- Do we demean ourselves by allowing another being to exist in a state of physical despondency?

“Patients in the United States have a well-established right to determine the goals of their medical care and to accept or decline any medical intervention that is recommended to them by their treating physician. But do patients also have a right to receive interventions that are not recommended by the physician?”

Brody: four reasonable justifications for physicians' decisions to withhold futile treatments

- 1) The goals of medicine are to heal patients and to reduce suffering; to offer treatments that do not achieve these goals subverts the purpose of medicine
- 2) Physicians are bound to high standards of scientific competence; offering ineffective treatments deviates from professional standards
- 3) If physicians offer treatments that are ineffective, they risk becoming “quacks” and losing public confidence
- 4) Physicians are justified in risking harm to patients only when there is a reasonable chance of benefit; forcing physicians to inflict harmful procedures on patients makes them “agents of harm, not benefit”

The right of a patient to demand a treatment is limited by the need for physicians to provide care that meets high ethical, clinical, and scientific standards.

- Physician autonomy is a necessary for physicians to be moral agents

What constitutes professional integrity?

What is the responsibility of professional expertise?

What is expected of the compact of physicians with society?

# The Procedural Approach

Council on Ethics and Judicial Affairs (AMA) 1999

- “objectivity in unattainable” when defining futility
- Best approach is to implement a “fair process”
  - Extensive deliberation and consultation in an attempt to reach resolution
  - Efforts to transfer care to a physician willing to comply with the patient’s wishes
  - If transfer cannot be accomplished, then care can be withdrawn or withheld, even though “the legal ramifications of this course of action are uncertain”
- The preventive-ethics approach
  - Primary care physicians must take responsibility for discussing decisions about futile treatment with patients before clinical circumstances call for such decisions

- “[M]edical futility is the unacceptable likelihood of achieving an effect that the patient has the capacity to appreciate as a benefit.” (Schneiderman, *Bioethical Inquiry* 2011, 8: 123)
  - Patient: *patiens*, πάσχειν (pathkei) = one who suffers
  - Healing: *sanitatem*, ἰάομαι (iaomai) = to make whole
- Ethical duty to avoid unnecessary harm
- Ethical duty of proportionality (advising a patient toward a therapy with minimal gain at the risk of severe harm is malpractice)
- The duties of medicine are to alleviate suffering restore health—not to prolong life
- Medical decisions and treatment are *never* value-neutral: they are ethical acts
- Struggle to protect and enable patient autonomy while avoiding futile interventions
- Need to maintain compassion while assisting patients with difficult and often dire decisions
- **How do we negotiate instances in which patient and physician autonomy cannot be reconciled?**

## **Persistent barriers to reaching consensus on futility**

- Communication hindered by mistrust
- Belief system that is irreconcilable with precepts of medicine
- Fundamental difference in values (What is unwarranted suffering? What is an undignified death?)
- Patients' views about care before they are sick may be quite different from their views when they are acutely ill
- Medicine is unable as a field to reach consensus regarding first principles
- Is futility an objective entity?

## **Conclusion**

- Futility encompasses uncertain but very real territory in medical practice
- The courts have broadly favored patient autonomy and appreciated the finality of decisions that result in death
- The ethics of futility are intertwined with the ethics of doctoring
- Patient autonomy and medical ethics are not always reconcilable

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