ORIGINAL RESEARCH

A framework for resolving disagreement during end of life care in the critical care unit

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Abstract

Background: End-of-life decisions regarding the administration, withdrawal or withholding of life-sustaining therapy in the critical care setting can be challenging. Disagreements between health care providers and family members occur, especially when families believe strongly in preserving life, and physicians are resistant to providing medically "futile" care. Such disagreements can cause tension and moral distress among families and clinicians.

Purpose: To outline the roles and responsibilities of physicians, substitute decision makers, and the judicial system when decisions must be made on behalf of incapable persons, and to provide a framework for conflict resolution during end-of-life decision-making for physicians practicing in Canada.

Source: We used a case-based example to illustrate our objectives. We employed a comprehensive approach to understanding end-of-life decision making that included: 1) a search for relevant literature; 2) a review of provincial college policies; 3) a review of provincial legislation on consent; 4) a consultation with two bioethicists and 5) a consultation with two legal experts in health law.

Principal Findings: In Canada, laws about substitute decision-making for health care are primarily provincial or territorial. Thus, laws and policies from professional regulatory bodies on end-of-life care vary across the country. We tabulated the provincial college policies on end-of-life care and the provincial legislation on consent and advance directives, and constructed a 10-step approach to conflict resolution.

Conclusion: Knowledge of underlying ethical principles, understanding of professional duties, and adoption of a process for mediation and conflict resolution are essential to ensuring that physicians and institutions act responsibly in maintaining a patients' best interests in the context of family-centred care.

Dramatic technologic advancements over the last 20 years have increased clinician use of, and public expectation of, life-sustaining therapies (LSTs). The aging population, their high prevalence of co-morbidities, and improved medical understanding of how to abate or reverse physiologic abnormalities have led to the administration of LST for patients, who in the past, may not have been candidates for such treatments. Media portrayals of overly optimistic or misleading outcomes from medical interventions can reinforce unrealistic family expectations.[1] In this context, some families adopt a "do everything" attitude, believing that even if a cure is not possible for a critically ill patient, any additional survival time for their loved one, however brief and of whatever quality, is preferable to an earlier death.

As our ability to provide LST has evolved, so has the complexity of decision making at the end-of-life. Critically ill patients are usually unable to make decisions about their own treatment due to an altered level of consciousness, co-morbid conditions, or neurological disabilities related to their age, illness, analgesia or sedation. When patients are incapable of making decisions, substitute decision makers (SDMs) and health care providers engage in developing a management plan. When incapable patients have not previously expressed wishes about treatment while they were competent, decisions are generally made on their behalf to reflect their best interests. However, what constitutes "best interests" from a SDM's perspective may differ from that of the clinicians. These differences may derive from discordant values and beliefs, different knowledge bases and experience, and unique relationships with the patient. Accordingly, it has become increasingly common for conflicts to arise between SDMs and physicians about LST.[2] Indeed, such disagreements are considered to be the main ethical challenge facing Canadians in health care.[3] Families of adult and pediatric patients may engage the legal system to challenge physician's treatment recommendations, and such cases demonstrate that courts are sometimes willing to reject medical opinion.[4-7]

This narrative review outlines the respective roles and responsibilities of physicians, SDMs, and the judicial system in the context of decision-making for incapable persons, and provides a 10-step approach to conflict resolution during end-of-life decision-making that may facilitate this difficult process for physicians practicing in Canada. While this discussion has relevance for end-of-life conflicts in other countries, we restrict our focus to Canadian jurisdictions, as laws and ethical principles differ across the globe, and a global comparison is beyond the scope of this specific review.

Methods

We used a case-based example to highlight the challenges faced by various parties when conflicts arise, and to illustrate a mechanism whereby disagreement during end-of-life decision-making between SDMs and physicians can be resolved.[8] We employed the following comprehensive approach to evaluating the roles and responsibilities of physicians, SDMs, and the judicial system: 1) a search of the medical and health law literature; 2) review of provincial college policies; 3) review of provincial legislation on consent; 4) consultation with two bioethicists; and, 5) consultation with two legal experts in health law. We searched OVID Medline (1950 to Dec 31, 2009) for relevant articles using the search terms: (end-of-life OR best interests OR conflict resolution OR withdrawal of life sustaining therapy OR withholding life sustaining therapy OR consent OR decision making). These terms were combined with terms related to critical care OR intensive care. Reference lists of selected papers were reviewed for additional relevant publications. We used resources from the literature, institutional policies and recommendations through consultation with the bioethicists and legal experts, drawing on personal experience to develop consensus on a 10-step of approach, which we propose as a practical guide to conflict resolution during end-of-life decision-making.

Case Presentation

EJG was a seven month old male infant with severe hypoxic-ischemic encephalopathy secondary to birth asphyxia, who progressed to a permanent vegetative state and ventilator-dependence. All physician and nurse members of the critical care team who cared for EJG concurred that LST was not in his best interest, and recommended the withdrawal of mechanical ventilator support, and withholding resuscitation in the event of cardiorespiratory arrest. EJG's parents, while demonstrating an accurate understanding of his condition and prognosis, disagreed, insisting on continued provision of LST, citing their guiding religious conviction that any life was better than death, their faith in miracles, and their belief that EJG would someday recover completely. Several meetings between attending physicians and family were conducted wherein both parties expressed their expectations and concerns, and the rationale behind their decisions. The institution's bioethicist was consulted to mediate discussions in an attempt to reach consensus on a treatment plan. When it was clear that no agreement on EJG's management plan could be reached, an application was made to the Ontario Consent and Capacity Board (CCB) for an independent review. Given the urgent nature of the submission, the CCB convened a hearing at the hospital within 24 hours, attended by three Board members (a lawyer, a physician and a community representative), two of EJG's treating physicians (with legal representation), EJG's parents (who declined legal representation) and a court-appointed legal representative for EJG. At the hearing, each party was able to offer their positions and reflections regarding EJG's proposed care plan and to question one another. The hearing lasted seven hours, during which time the CCB members were given an opportunity to see EJG at the bedside with the parents. Within 24 hours, the CCB submitted their decision: that EJG's parents did not comply with the principles for SDM as set out in the Ontario Health Care Consent Act.[8] The CCB directed the parents to consent to the physicians' recommended treatment plan. The parents appealed this decision to the Superior Court of Ontario. This hearing occurred three weeks after the original CCB application, and the Court upheld the CCB's decision.[9] The Office of the Public Guardian and Trustee of Ontario was thereafter appointed as the SDM. The treatment team continued to communicate all information with the parents, and shared many aspects of EJG's care with them. The process of withdrawal of LST was described to them in detail, including what to expect following removal from mechanical ventilation, and what measures would be performed to maintain comfort. EJG was then extubated, provided with ongoing palliative care and died peacefully in hospital shortly thereafter, with his family and treatment team at the bedside.

A Framework for Resolving Disagreement

Although LST is traditionally deployed to treat morbidity and delay mortality in the ICU, it is also used to orchestrate end-of-life care. LST can be withheld or withdrawn to help determine prognosis. The tempo of withdrawal of LST influences the method and timing of death. Today, decisions to withhold, provide, or withdraw LST are socially negotiated to synchronize understanding and expectations among family members and clinicians.[10] Operationalizing objective principles for end-of-life decision making is extremely challenging. Debate exists as to which party should have ultimate authority over such controversial decisions for incapable patients – the family members, who have the best knowledge of their loved one's values and beliefs and who will be most impacted personally by these decisions; or the physicians, who have greater knowledge of disease processes, prognoses, and therapeutic options.[11] It is difficult to create guidelines that apply to the wide variety of end-of-life decisions, and approaches vary widely within and among regions. For example in France, physicians maintain the ultimate responsibility for life-support decisions, while in the United Kingdom, the High

Court has overarching authority in decisions regarding children.[12] In Canada, patients and SDMs have considerable discretion in making decisions about their health care, including the right to refuse or forgo a specific treatment.[13]

Regardless of the decision making model, physicians retain professional, ethical, and legal obligations to their patients, and must consider their patients' best interests. Below, we outline the responsibilities of each of the foregoing stakeholders, and the provincial policies and legislation that may guide conflict resolution. Adopting a framework to help resolve disagreements can enhance communication and channel energy towards achieving common objectives. We outline 10 key steps of this approach in Table 1.

Table 1: A 10 Step Approach for Resolving Disagreement Between Legal Substitute Decision Makers and Health Care Providers

1. Ensure clear documentation of the patient's condition, course, and prognosis in the medical chart. Clearly document the impression and recommendations of the attending physicians and each consulting physician, and ensure that there is consensus. A document outlining the impression and recommendations signed by all physicians is helpful. Emphasize what can and will be done for the patient, and not just what will be withdrawn/withheld.

2. Establish whether the patient is indeed "incapable" with respect to the treatment being proposed, and ensure that this finding is clearly documented. Identify the appropriate substitute decision makers (s.20, HCCA).

3. Consult child welfare authorities where the safety of a child is concerned.

4. Conduct interdisciplinary family meetings led by attending physician and attended by the SDMs and other important supportive members of the family, resident, social work and bedside nurse. Clearly document in the medical record all discussions and efforts to achieve agreement between SDMs and health care team

Objectives:

- Explore each parties' understanding of the issues, individual roles and responsibilities, and concerns
- Discuss the patient's prior expressed wishes, if applicable
- Clearly outline the proposed treatment plan and the rationale
- Exhibit respect for the SDMs values and beliefs, ensure that limiting or withdrawal of LST will not lead to abandonment of patient or family
- Focus on the best interests of the patient, acknowledging the difficulties and impact that the family is likely experiencing.
- Offer supportive family services, (e.g., social work, palliative care service, hospital clergy/chaplaincy and the family's community clergy or religious representative)
- Inform the family of an ethics consultation and its purpose

5. Ethics consultation – a multi-phase process:

a. Meeting with clinical ethics committee and medical team - to present the medical perspective of the case, and ensure there is no conflict within the health care team

b. Meeting with ethics committee and family – to present the family's perspective.

c. Meeting of the ethics committee, family and health care team – to negotiate and resolve any conflict between the parties.

When it is clear that no agreement between SDMs and clinicians can be reached, initiate a third party arbitration process:

6. Explore transfer of the patient to a facility willing to provide the treatments requested by the family.

7. Notify the family that while you respect their position and objectives, there is disagreement between SDM and clinicians concerning what is in the patient's best interest. Inform them that a decision cannot be agreed upon, and that the case will therefore be referred for arbitration through an independent third party (e.g., the CCB). Discuss the objective and process of a CCB hearing, and offer them time to seek legal advice or other council.

8. Consult the institution's administration, risk management staff, and legal council. Inform them of the intention to proceed to CCB.

9. Submit an application to the CCB.

10. Up until such time when a decision is made, continue to provide care and LST.

Note:
SDM = substitute decision maker, HCCA = Health Care Consent Act, CCB = Consent and Capacity Board, LST = Life-sustaining therapy.

Responsibilities of the Physician

Physicians bear a responsibility to explore patients' wishes for end-of-life care and to counsel patients and families. When making recommendations about therapy, physicians are guided by three ethical principles – *beneficence* (the provision of treatments based upon the expectation of benefit), *nonmaleficence* (do no harm), and *autonomy* (which accepts that different persons may judge benefits, and even futility, differently).[14] Recommendations to limit LST for individual patients, ideally, should not be influenced by population-based concepts of resource utilization or allocation.

Physicians' communication skills can influence decisions. Perception of poor communication is a common source of conflict between SDMs and clinicians, occurring in up to 50% of cases of end-of-life decision-making, and can result in a patient's or family's perception of being pressured into deciding to withhold or withdraw LST.[15] In contrast, the quality of end-of-life care and family satisfaction is improved by developing trusting relationships and improving dialogue among the physician, the patient and the family.[16,17] Effective communication between family members and SDMs has been shown to enhance medical decision making for the critically ill, improve psychological outcomes and may even lessen the burden of bereavement in these families.[18,19] Furthermore, there is evidence that SDMs value the support they are given, and have empathy for medical staff and the challenges they face during end-of-life discussions.[20] The importance and the quality of SDM-physician communication in the ICU has been the subject of much research and there are several suggested strategies for optimizing communication techniques for physicians, focusing on the style of communication as well as the content, opportunities for and appropriate timing of family conferences.[18,19,21,22] Such crucial decisions require time, presentation of all viewpoints, and assurance that each party fully understands their respective positions and responsibilities. As distinct from their desire to obtain information, a family's desire to participate in actual decision-making should be explored.[23] The SDM should be clearly identified. Meetings with the family and SDMs should begin shortly after (if not before) intensive care unit (ICU) admission.[19,24] Supportive advocates for the patient and family, and/or a family or consultant physician with whom they have a longer standing relationship, may be invited to attend. Discussions should be documented in the patient's health record. Key issues that should be addressed include the family's understanding of the underlying and acute processes, prior expressed wishes of the patient, the therapeutic goals and realistic expectations, emotional distress and potential conflict among family members. One approach to patient- and family-centred decision-making advocates a shared decision-making model that is reassessed over time, can be modified according to the prognosis and certainty of this prognosis, and is responsive to the needs of the family.[18,22] Family members should be given adequate opportunities to speak and time for their deliberations. They should be reassured that the patient will not be abandoned or permitted to suffer, but will be made as comfortable as possible and treated with dignity.[16] SDMs should also be reassured that they have the support and respect of the health care team regarding their ultimate decision on the patient's care, including decisions to withdraw or not to withdraw life support, even in the event of differences of opinions.

Interdisciplinary collaboration and involvement in family conferences are associated with higher patient satisfaction and an improvement in a number of important outcomes in critical care, such as patient survival, length of stay and readmission rates.[25] Routine palliative care, routine ethics consultations, and a proactive communication strategy with families have been advocated to improve the quality of patient- and family-centred care, and reduce the ICU days before death.[26,27] The literature describes some of the models that can be used for ethics and palliative care consultation in the ICU, and the settings in which either type of consultation may be more useful. For example, palliative care aligns more closely with a "Care Provider" model with multi-disciplinary expertise in the comprehensive management of physical, psychosocial, spiritual, and existential needs of patients and their families facing a life-limiting illness; while an "Ethics Facilitation" model is often employed in ethics consultations for enhancing and mediating communication between families and clinicians.[28] Hospital ethics committees should be involved early when there is a concern, as such consultations have been shown to facilitate conflict resolution in some settings, reduce ICU and hospital stay, and limit the use of "non-beneficial" LST.[29] Both ethics and palliative care services clearly play important roles in the ICU, and ultimately the decision on whether consultation to one or both services are most appropriate when conflicts arise will depend on the nature of the case, the expectations and objectives of the SDMs and health care team, and the models of care used by these services at the individual institution.

Responsibilities of the Substitute Decision Maker

When patients are incapable of making their own decisions regarding their health care, SDMs are called on to make these decisions on the patient's behalf. SDMs are often, but not necessarily, family members. An SDM may be a court appointed guardian, or a health care proxy named in an advance directive, or a person named in relevant legislation. In the case of children, parents are typically the SDMs. As SDMs, family members may believe that they are advocating for their loved one by insisting on withholding LST, or alternatively, on initiating LST that may be considered by the physician to be non-beneficial or even harmful. An awareness of the law governing substituted decisions may help to guide both SDMs and physicians.

In Canada, laws about substitute decision-making for health care are primarily provincial or territorial.[30] Consequently, these laws are somewhat variable across the country.[31] Some provinces rely on common law (judge-made) rules pertaining to consent and substitute consent, while others have adopted comprehensive consent legislation.[13] In jurisdictions in which the common law consent rules apply, there may nevertheless be legislation related to substitute decision-making in particular circumstances. Depending on the patient, a wide variety of rules may be relevant to substitute decision-making, including guardianship legislation, mental health legislation and child welfare laws.

In general, whether based on the common law or consent legislation, SDMs must use a *substituted judgment* approach.[13] That is, the SDM must consider what decision the patient would have made for themselves if s/he were competent to do so. Substituted judgment can be based on specific wishes expressed by the patient in advance, as well as on the patient's known values and beliefs. If the patient has provided clear and relevant instructions in a valid advance directive, then the instructions must be followed. This approach seeks to preserve the patient's right to self-determination by placing the patient's own preferences at the center of deliberation (i.e., what would this person have wanted?), recognizing that it is unusual for patients to have clearly articulated their preferences in advance. If it is not possible to make a decision on the basis of known wishes or values and beliefs, the SDM must make the decision most consistent with the patient's best interests.

Some provincial consent laws outline the process of determining "best interest". The Ontario Health Care Consent Act (HCCA) for example, provides direction to SDMs and health care providers regarding consent to treatment, where the definition of treatment includes the withholding or withdrawal of treatment in light of the person's condition.[32] The HCCA describes the circumstances in which consent must be obtained and the principles that the SDM must consider when providing or declining consent for an incapable person. Section 21(1) of the HCCA defines "best interest" based on patient values, beliefs and wishes as well as the probability of success, benefits and risks of a proposed care plan or alternative care plans (Appendix 1).

Spiritual, religious and cultural considerations

Spiritual and religious reasons are often at the heart of a patient's and family's desire to continue LST that is considered medically inappropriate by the treatment team.[33] Many families rely on spiritual resources for guidance during end-of-life decision-making, and clinicians should therefore have an understanding of how withholding or withdrawing LST may be viewed by a particular religion or culture. End-of-life practices vary around the world, and society continues to struggle to identify the circumstances under which LST may be appropriately discontinued or withheld.[34] Various religious laws prohibit any action that intentionally and actively shortens life, but strive to strike a balance between the sanctity of life and the principle of autonomy, and who has the final say during end-of-life decisions.[35,36] Even within a single faith, such as Christianity, major diversities may be encountered.[37] Significant practice variations have also been observed based on the physician's own religious affiliation.[34] Such situations may be confusing to physicians; however, resources are available that outline the various religious traditions and practices as they relate to end-of-life care, and may provide useful insights to help physicians establish what may or may not be permitted when treating terminally ill patients.[38] Local chaplains may also be a helpful resource. It is also important to understand how the specifics of a religion may be practiced outside of the country of origin. For example, under Islamic law, families and guardians are not considered qualified and therefore cannot decide on the application or removal of LST, which is an important difference from practice in North America.[39]

While physicians are not necessarily obliged to provide LST that they consider inappropriate simply because it is demanded on religious grounds by the SDMs, physicians have an obligation to understand the various factors that influence such decisions, and which can only serve to improve communication and minimize conflict. The treatment team should be non-judgemental and open to diverse spiritual beliefs and religious faiths, foster a culture of acceptance and integrate these perspectives when counselling families. Physicians may examine the theological basis of the SDM's decision and explore alternative religious interpretations, in consultation with a religious representative, in order to reach consensus on the appropriate limits to LST.[40] Families often appreciate when their spiritual needs are acknowledged and addressed, and when their community clergy or hospital chaplains are involved.[41] Collaboration between community and hospital religious representatives builds trust and can enhance the spiritual care of a family in crisis, and help the health care team understand the foundation of the family's (as well as their own) moral distress.

Dispute resolution: when consensus cannot be reached

In spite of all of these efforts, SDMs and physicians may not agree on the treatment provided. While physicians are not obliged to provide treatments that they deem inappropriate, the futility of a treatment is not a legal ground for withholding or withdrawing LST. What is a physician's professional obligation when SDMs insist on a treatment considered to be futile? There are several published recommendations on end-of-life decision-making;[14,42] however, there are few resources for Canadian health care providers when clinicians and SDMs are at an impasse.[43]

College Policies and Consent Law

When agreement on a management plan cannot be reached, physicians should seek institutional and legal advice if they have concerns about their obligations, and should familiarize themselves with the Code of Ethics adopted or supported by their professional regulatory body. In addition to the general guidance that can be found in such documents, some provincial colleges have specific practice guidelines or policy statements on decision-making for the end-of-life. Table 2 outlines which Canadian medical regulators have such policies, and briefly summarizes these various policies. For example, the Ontario College of Physicians and Surgeons Policy specifically states that physicians are not obliged to provide treatments that would not be of benefit to the patient; however, it does not endorse unilateral physician decision-making.[44] In contrast, the Manitoba College of Physicians and Surgeons Policy permits physicians to unilaterally withhold or withdraw LST in some circumstances where a consensus cannot be reached.[45] While there is no legislation with respect to unilateral withholding and withdrawal of LST, there are differences in opinion as to whether Canadian law allows unilateral withholding and withdrawal of LST. It has been argued that such decisions violate the strong social commitment to dignity as it is understood and reflected in Canadian law.[46]

TABLE 2: Provincial College of Physician and Surgeons Policies on End of Life Decision Making

Province / Territory	College Policy on End-of-Life decision making	Brief synopsis of policy
British Columbia	No policy, refers to Ontario and Manitoba policies as questions arise	-
Alberta	No policy	-
Saskatchewan	No policy	-
Manitoba	Statement No. 1602. Withholding and Withdrawing Life-Sustaining Treatment[45]	The policy is limited to questions about withholding or withdrawing life-sustaining treatment. It contains guiding principles to assist physicians, including dealing with situations in which the physician offers LST but the patient or proxy decision-maker declines such care, and situations in which the physician concludes that LST is inappropriate, but the patient or proxy disagrees and/ or demands it. It also addresses emergency situations, cardiac arrest and DNR orders.
Ontario	Policy Statement # 1-06. Decision-making for the End of Life[44]	The policy is wide-ranging and deals with many issues involved in end-of-life care, including consent and capacity, advanced care planning, interventions and patient management (including discussion regarding palliative care, CPR and other LST, expected death at home, euthanasia and assisted suicide), conflict management, and organ and tissue donation.
Quebec	Legal, Ethical and Organizational Aspects of Medical Practice in Québec[48] La pratique médicale en soins de longue durée du Collège des médecins du Québec[49]	Originally developed to assist residents in meeting licensing requirements, this was later converted to a document to inform Quebec physicians on the organization of Quebec's health care system and relevant ethical and legal issues. The section on End of Life issues includes discussion of consent and confidentiality in the context of cessation of treatment, euthanasia and assisted suicide, futility and LST, and DNR orders.
New Brunswick	No policy	-
Nova Scotia	No policy	-
Prince Edward Island	No policy	-
Newfoundland	No policy	-
Yukon	*No policy	-
Northwest Territories	†No policy	-
Nunavut	†No policy	-

Note:
LST = life-sustaining therapy, CPR = cardiopulmonary resuscitation, DNR = do not resuscitate.
* Yukon Medical Council.
†Professional Licensing, Dept. of Health and Social Services

When the welfare and safety of a child is concerned, a referral to the child welfare authorities (such as the Children's Aid Society) should be made. SDMs should also be offered access to any mediation, arbitration or adjudication process available within the facility. If the SDM insists on a course of treatment that the physician considers medically inappropriate, the physician is obliged to assist in finding a treatment team who will agree to treat according to the consent given. When all mediation attempts have failed, the physician may apply to a judicial body to challenge the SDM's decision. This option should be considered only after alternative methods of conflict resolution have been exhausted.

Given the variation among Canadian jurisdictions, it is essential that health care providers understand the law in the province or territory in which they practice. In Table 3, we outline which jurisdictions have comprehensive consent legislation, whether or not they have an independent board for arbitrating decisions, and whether there is relevant advance directive legislation. Rules respecting substitute decision-making can also be found in other types of legislation, including guardianship legislation, child welfare laws and mental health laws. In most Canadian jurisdictions, the courts are the site of dispute resolution. In Ontario and the Yukon Territory, consent legislation provides an alternative process through establishing an independent board, whose role includes arbitration when there is disagreement between the treatment team and SDMs with respect to a management plan.

Arbitrating disagreements: The Ontario Consent and Capacity Board

The Consent and Capacity Board (CCB) (www.ccboard.on.ca) is an independent, neutral body created by the provincial government of Ontario under the HCCA, responsible for adjudicating disputes relating to consent to treatment and capacity to make decisions. Currently, Ontario and the Yukon are the only jurisdictions in Canada with a tribunal of this nature. A health care provider may apply to the CCB when there is disagreement between the SDM and physicians on a proposed treatment plan for an incapable patient. The role of the CCB is to determine whether or not the SDMs are providing or declining consent to treatment in accordance with the principles articulated in the HCCA. The CCB is therefore an important resource for health practitioners; not only for resolving conflict but for assisting physicians in determining how to obtain legally valid consent to treatment.[47] In Ontario, applications to the CCB may be considered "collaborative", if seeking direction when capable wishes are uncertain, or to depart from previously expressed capable wishes; or "adversarial", when there is concern that the SDMs are not acting according to capable wishes applicable to the circumstances, or in the best interest of the patient as specified in the HCCA. A pre-hearing may be held to mediate the differences before commencing a formal hearing. The CCB is required to hold a hearing within seven days of an application, but may convene a hearing more quickly depending on the urgency of the situation. The CCB's decision is binding upon the parties, subject only to appeal to the Ontario Court of Justice. If the CCB concurs with the physician, it directs the SDMs to give consent to treatment as proposed by the physician; if the SDMs do not consent, they are removed as the SDMs for the purpose of that decision. The consent is then given in accordance with the CCB's decision by the next ranking substitute decision maker, usually another family member, or the Public Guardian and Trustee if there is no other family.

Conclusion

Disagreements between patients and physicians during end-of-life decision making are not infrequent, and may be influenced by differences in knowledge base, opinions and value systems. Policies for negotiating and managing conflicts about LST are increasingly available at an institutional and provincial level. When physicians and SDMs are at an impasse, an in-

TABLE 3: Provincial Legislation on Consent and Advance Directives[A]

Province	Advance Directive Legislation[B]	Comprehensive Consent Legislation[C]
British Columbia	Representation Agreement Act, RSBC 1996, c.405 Health Care (Consent) and Care Facility (Admission) Act, RSBC 1996, c.181	Health Care (Consent) and Care Facility (Admission) Act, RSBC 1996, c.181
Alberta	Personal Directives Act, RSA 2000, c.P-6	No
Saskatchewan	Health Care Directives and Substitute Decision Makers Act, SS 1997, c.H-0.001	No
Manitoba	Health Care Directives Act, CCSM, c. H-27	No
Ontario	Health Care Consent Act, 1106, c.2, Sch. A Substitute Decisions Act, 1992, SO 1992, c.30	Health Care Consent Act, 1106, c.2, Sch. A Consent and Capacity Board
Quebec	Civil Code of Quebec, SQ 1991, c.64	No
New Brunswick	Infirm Persons Act, RSNB 1973,c.I-8	No
Newfoundland	Advance Health Care Directives Act, SNL 1995, c.A-4.1	No
Nova Scotia	Personal Directives Act, SNS 2008, c.8	No
Prince Edward Island	Consent to Treatment and Health Care Directives Act,[D] RSPEI 1988, c.C-17.2	Consent to Treatment and Health Care Directives Act
Yukon	Care Consent Act, SY 2003, c.21, Sch. B[D]	Care Consent Act, SY 2003, c.21, Sch. B Consent and Capability Board
Northwest Territories	Personal Directives Act, SNWT 2005, c.16	No
Nunavut	No	No

Footnotes:

[A] Provisions relevant to substitute decision-making can be found in other types of legislation, such as guardianship and trusteeship legislation, mental health legislation and child welfare legislation. (e.g. In Alberta, the Adult Guardianship and Trusteeship Act, S.A. 2008, c. A-4.2 contains provisions relevant to “specific decisions” where a substitute decision-maker may be needed)[50].

[B] Advance directive legislation is legislation that permits an individual, while competent, to appoint a proxy decision-maker or to set out instructions as to how health care decisions are to be made if the individual loses capacity to make the decisions him or herself.

[C] Comprehensive Consent legislation means legislation that deals with basic consent thereby ousting the common law. Statutes that deal only with some aspects of consent (e.g. Substitute decision making) are not considered comprehensive consent legislation.

[D] Within / as part of comprehensive consent legislation

dependent review by a neutral board enables the physician to remain focused on the care of the patient (as opposed to taking sides), and may offer new insight to both families and physicians who struggle with such decisions. Our experience is that mutual respect can be maintained between families and physicians when the process is transparent, respectful and sensitive. Knowledge of underlying ethical principles, professional responsibilities and adoption of a framework for mediation and conflict resolution may encourage physicians and institutions to act responsibly, ensuring that the patient’s best interests are addressed while family-centred care is maintained.

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References

1. Diem S, Lantos J, Tulsky J. Cardiopulmonary resuscitation on television: miracles and misinformation. *N Engl J Med* 1996(334):1578-82.
2. Breen C, Abernathy A, Abott K, Tulsky J. Conflict associated with decisions to limit life-sustaining treatment in intensive care units. *J Gen Intern Med* 2001;16:283-89.
3. Breslin J, MacRae S, Bell J, Singer P. and the University of Toronto Joint Centre for Bioethics Clinical Ethics Group. *BMC Bioethics* 2005;6:5.
4. Golubchuk v. Salvation Army Grace General Hospital et al., 2008 MBQB 49 (CanLII)
5. Hunter M. Medical research under threat after Alder Hey Scandal. *BMJ* 2001;322:448.
6. Luce J, White D. A History of Ethics and Law in the Intensive Care Unit. *Crit Care clin* 2009;25:221-37.
7. Priest L. Alberta baby to stay on life support. *The Globe and Mail* Jan 27, 2010.
8. Re E.J.G., 2007 CanLII 44704 (ON C.C.B.).
9. J-G v. Choong (17 October 2007), Hamilton 07-34050 (Ont. Sup.Ct.J.).
10. Cook DJ, Giacomini M, Johnson N, Willms D. Life support in the intensive care unit: a qualitative investigation of technological purposes. Canadian Critical Care Trials Group. *CMAJ* 1999;161(9):1109-13.
11. Inwald D. The best interests test at the end of life on PICU - a plea for a family based approach. *Arch Dis Child* 2007;93(3):248-50.
12. Devictor DJ, Tissieres P, Gillis J, Truog R. Intercontinental differences in end-of-life attitudes in the pediatric intensive care unit: results of a worldwide survey. *Pediatr Crit Care Med* 2008;9(6):560-6.
13. Picard E, Roberston G. Legal liability of doctors and hospitals in Canada. In: Carswell, editor. 4th ed. Scarborough (ON), 2007.
14. Committee on Bioethics, American Academy of Pediatrics. Guidelines on Forgoing Life-sustaining medical treatment. *Pediatrics* 1994;93(3):532-36.
15. Azoulay E, Timsit J, Sprung C, Soares M, Rusinova K, Lafabrie A, *et al.* Prevalence and factors of intensive care unit conflicts: the Conflicus Study. *Am J Respir Crit Care Med* 2009;180(9):853-60.
16. McDonagh JR, Elliott TB, Engelberg RA, Treece PD, Shannon SE, Rubenfeld GD, *et al.* Family satisfaction with family conferences about end-of-life care in the intensive care unit: increased proportion of family speech is associated with increased satisfaction. *Crit Care Med* 2004;32(7):1484-8.

17. Heyland D, Dodek P, Rocker G, Groll D, Gafni A, Pichora D, *et al.* for the Canadian Researchers End-of-Life Network (CARENET). What matters most in end-of-life care: perceptions of seriously ill patients and their family members. *CMAJ* 2006;174(5):627-33.
18. Curtis JR, White D. Practical Guidance for Evidence-Based ICU Family Conferences. *Chest* 2008;134:835-43.
19. Lautrette A, Darmon A, Megarbane B, Joly L, Chevret S, Adrie C, *et al.* A communication strategy and brochure for relatives of patients dying in the ICU. *N Engl J Med* 2007;356:469-78.
20. MIdson R, Carter B. Addressing end of life care issues in a tertiary treatment centre: lessons learnt from surveying parents' experiences. *Journal of Child Health Care* 2010;14(1):52-66.
21. Curtis JR, Engelberg RA, Wenrich M, Shannon SE, Treece PD, Rubenfeld GD. Missed Opportunities during Family Conferences about End-of-Life Care in the Intensive Care Unit. *Am J Respir Crit Care Med* 2005;171:844-49.
22. Truog R, Campbell ML, Curits J, Haas CE, Luce JM, Rubenfeld GD, *et al.* Recommendations for end-of-life care in the intensive care unit: A concensus statement by the American College of Critical Care Medicine. *Crit Care Med* 2008;36(953-963).
23. Curtis J. Communicating about end-of-life care with patients and families in the intensive care unit. *Crit Care Clin* 2004;20:363-80.
24. Glavan B, Engelberg RA, Downey L, Curtis JR. Using the medical record to evaluate the quality of end-of-life care in the intensive care unit. *Crit Care Med* 2008;36(4):1138-46.
25. Baggs JG, Ryan SA, Phelps CE, Richeson JF, Johnson JE. The association between interdisciplinary collaboration and patient outcomes in a medical intensive care unit. *Heart Lung* 1992;21(1):18-24.
26. Campbell ML, Guzman J. Impact of a proactive approach to improve end-of-life care in a medical ICU. *Chest* 2003;123:266-71.
27. Norton S, Hogan L, Holloway R, Temkin-Greener J, Buckley M, Quill T. Proactive palliative care in the medical intensive care unit: effects on length of stay for selective high-risk patients. *Crit Care Med* 2007;35:1530-35.
28. Aulisio M, Chaitin E, Arnold R. Ethics and palliative care consultaion in the intensive care uni. *Crit Care Clin* 2004;20:505-23.
29. Schneiderman L, Gilmer T, Teetzel H, Dugan D, Blustein J, Cranford R, *et al.* Effect of Ethic Consultation on Nonbeneficial Life-Sustaining Treatments in the Intensive Care setting. *JAMA* 2003;290:1166-72.
30. Lahey W. Medicare and the Law: Contours of an evolving relationship. In: Butterworths, editor. *Canadian Health Law and Policy*. 3rd ed, 2007:25.
31. Zuckerberg J. End-of-life decisions: A view from Ontario and beyond. *Europ J Health Law* 2009;16:139-64.
32. The Ontario Health Care Consent Act. 1996;Sections 21 and 37.
33. Brett A, Jersild P. "Inappropriate" Treatment Near the End of Life. *Arch Intern Med* 2003;163:1645-49.
34. Sprung C, Maia P, Hans-Henrik B, Ricou B, Apostolos A, Baras M, *et al.* for the Ethicus Study Group. The importance of religious affiliation and culture on end-of-life decisions in European Intensive Care Units. *Intensive Care Med* 2007;33:1732-39.
35. Sachedina A. End-of-life: the Islamic vies. *Lancet* 2005;366:774-79.
36. Steinberg A, Sprung C. The dying patient: new Israeli legislation. *Intensive Care Med* 2006;32:1234-37.
37. Burbon L, Bosek M. When religion may be an ethical issue. *J Relig Health* 2000;39:97-106.
38. Multi-faith guide for Health Care Professionals at Hamilton Health Sciences. http://www.hamiltonhealthsciences.ca/spiritualcare/.
39. Babgi A. Legal Issues in End-of-Life Care: perspectives from Saudi Arabia and United States. *American Journal of Hospice and Palliative Medicine* 2009;26(2):119-27.
40. Brett A, Jersild P. "Inappropriate" Treatment Near the End of Life. Conflict between religious convictions and clinical judgement. *Arch Intern Med* 2003;163:1645-49.
41. Robinson M, Thiel M, Backus M, Meyer E. Matters of Spirituality at the End of Life in the Pediatric Intensive Care Unit. *Pediatrics* 2006;118(3):e719-e29.
42. Truog R, Cist A, Brackett S, Burns J, Curley M, Danis M, *et al.* Recommendations for end-of-life care in intensive care unit: The Ethics Committee of the Society of Critical Care Medicine. *Crit Care Med* 2001;29(12):2332-48.
43. Decision-making and conflict resolution regarding futility in the use of life support. *Patient Care Manual, 2001*: Sunnybrook and Women's College Health Sciences Centre. http://sunnybrook.ca/uploads/EthLifeSupport2.pdf.
44. College of Physicians and Surgeons of Ontario Policy Statement #1-06. Decision-making for the End of Life; 2006. http://www.cpso.on.ca.
45. College of Physicians and Surgeons of Manitoba. Statement No. 1602

1. Withholding and Withdrawing Life-Sustaining Treatment, 2007. http://www.cpsm.mb.ca.
2. Downie J. Unilateral Withholding and Withdrawal of Potentially Life-sustaining treatment: a Violation of Dignity Under the Law in Canada. *Journal of Palliative Care* 2004;20(3):143-49.
3. Sibbald R, Chidwick P. Best interests at end of life: A review of decisions made by the Consent and Capacity Board of Ontario. *Journal of Critical Care* 2009:In press.
4. Legal, Ethical and Organizational Aspects of Medical Practice in Quebec. *Aldo-Quebec, 2009. http://www.cmq.org*.
5. COLLÈGE DES MÉDECINS DU QUÉBEC, La pratique médicale en soins de longue durée: guide d'exercice. Montreal, Collège des médecins du Québec. May 2007.
6. The Alberta Adult Guardianship and Trusteeship Act. *Chapter A-4.2*, S.A.2008.

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Appendix 1

Health Care Consent Act, 1996, CHAPTER 2, SCHEDULE A (www.e-laws.gov.on.ca)

Principles for giving or refusing consent

21. (1) A person who gives or refuses consent to a treatment on an incapable person's behalf shall do so in accordance with the following principles:

1. If the person knows of a wish applicable to the circumstances that the incapable person expressed while capable and after attaining 16 years of age, the person shall give or refuse consent in accordance with the wish.

2. If the person does not know of a wish applicable to the circumstances that the incapable person expressed while capable and after attaining 16 years of age, or if it is impossible to comply with the wish, the person shall act in the incapable person's best interests. 1996, c. 2, Sched. A, s. 21 (1).

Best interests

(2) In deciding what the incapable person's best interests are, the person who gives or refuses consent on his or her behalf shall take into consideration,

(a) the values and beliefs that the person knows the incapable person held when capable and believes he or she would still act on if capable;

(b) any wishes expressed by the incapable person with respect to the treatment that are not required to be followed under paragraph 1 of subsection (1); and

(c) the following factors:

1. Whether the treatment is likely to,

i. improve the incapable person's condition or well-being,

ii. prevent the incapable person's condition or well-being from deteriorating, or

iii. reduce the extent to which, or the rate at which, the incapable person's condition or well-being is likely to deteriorate.

2. Whether the incapable person's condition or well-being is likely to improve, remain the same or deteriorate without the treatment.

3. Whether the benefit the incapable person is expected to obtain from the treatment outweighs the risk of harm to him or her.

4. Whether a less restrictive or less intrusive treatment would be as beneficial as the treatment that is proposed. 1996, c. 2, Sched. A, s. 21 (2).

37.(1) If consent to treatment is given or refused on an incapable person's behalf by his or her substitute decision-maker, and if the health practitioner who proposed the treatment is of the opinion that the substitute decision-maker did no comply with section 21, the health practitioner may apply to the Board for a determination as to whether the substitute decision-maker complied with section 21.

37.(2) The parties to the application are:
1. The health practitioner who proposed the treatment.
2. The incapable person.
3. The substitute decision-maker.
4. Any other person whom the Board specifies.