



LAW COMMISSION OF ONTARIO
COMMISSION DU DROIT DE L'ONTARIO

BALANCING THE INTERESTS OF PATIENTS, SUBSTITUTE DECISION-MAKERS, FAMILY AND HEALTH CARE PROVIDERS IN DECISION-MAKING OVER THE WITHDRAWAL AND WITHHOLDING OF LIFE-SUSTAINING TREATMENT

Improving the Last Stages of Life

April 2017

Commissioned by the Law Commission of Ontario

Prepared By:

James Downar, MDCM, MHSc (Bioethics), FRCPC

Laura Hawryluck, MD, MSc (Bioethics), FRCPC

Alexi Wood, JD

Susan Brown, MA

Joy Richards, RN, PhD

Robert Sibbald, MSc

Jennifer Gibson, PhD

Csilla Kalocsai, PhD

The LCO commissioned this paper to provide background research for its “Improving the Last Stages of Life” project. The views expressed in this paper do not necessarily reflect the views of the LCO.

ACKNOWLEDGMENTS

We would like to express our gratitude to all of the stakeholders who volunteered their time and contributed to the work presented in this report, including members of the University Health Network's Patient Partner Program, as well as members of Ontario's legal community.

ABSTRACT

This report aims to address some of the challenges around decision-making and conflict resolution regarding the withdrawal and withholding of life-sustaining treatment, including cardiopulmonary resuscitation (CPR), for patients with serious illness who are nearing the end of life. This subject poses difficulties for patients, substitute decision-makers (SDMs), and health care providers alike, and has been increasingly under the spotlight as a result of two recent high-profile cases in Ontario. This paper discusses the current legislative framework in Ontario and the challenges and conflicts that arise when decisions are being made with patients and SDMs. We explore the perspectives of different stakeholders about current mechanisms of conflict resolution, and we propose potential changes to the legislative framework and dispute resolution mechanisms that, from the clinical perspective, could result in improved patient care at the end of life.

Table of Contents

EXECUTIVE SUMMARY	1
I. REVIEW OF LAW AND POLICY	5
A. Definitions.....	7
B. Ontario’s HCCA	9
C. Case Law Prior to <i>Rasouli</i>	15
D. The <i>Rasouli</i> Decision.....	15
E. Case Law after <i>Rasouli</i> : <i>EGJW v MGC</i>	19
F. Policies and the College of Physicians and Surgeons of Ontario	20
G. Other Provincial Statutes.....	22
H. Case Law in Other Canadian Jurisdictions	24
I. United Kingdom	31
J. Summary and Conclusions.....	35
II. MEDICO-ETHICAL CONCEPTS AND STAKEHOLDER PERSPECTIVES.....	36
A. Shared Decision-Making: the Prevailing Model within the Health Care Community for Treatment Decisions Nearing the End of Life	37
B. The MSOC for Life-Sustaining Measures at the Bedside in Ontario.....	39
C. The Therapeutic Imperative and the Idea of CPR as a “default” option	41
D. How do Patients view Decisions about CPR?	45
E. How do Substitute Decision-Makers view decisions about CPR and Life-Sustaining Measures?.....	47
F. How do Physicians and Health Care Providers view Decisions about CPR and Life-Sustaining Measures?	48
G. How do Members of the Legal Community View Decisions about CPR and Life-Sustaining Measures?	50
H. Summary and Conclusion	54
III. MECHANISMS FOR DECISION-MAKING AND CONFLICT RESOLUTION	55
A. How do we currently balance the standard of care with the importance of consent?	55
B. What are Alternative Models of Dispute Resolution?.....	59

C. How can we discuss this Issue Constructively among Stakeholders?	61
D. Summary and Conclusion	61
IV. ISSUES AND SUGGESTIONS	62
Appendix A – Qualitative Research Methods and Data	67
A. Qualitative Research Methods	67
B. Data and Results	68
ENDNOTES.....	87

EXECUTIVE SUMMARY

This report aims to address some of the challenges around decision-making and conflict resolution regarding the withdrawal and withholding of life-sustaining treatment, including cardiopulmonary resuscitation (CPR), for patients with serious illness who are nearing the end of life. This subject poses difficulties for patients, substitute decision-makers (SDMs), and health care providers alike, and has been increasingly under the spotlight as a result of two recent high-profile cases in Ontario. This paper discusses the current legislative framework in Ontario and the challenges and conflicts that arise when decisions are being made with patients and SDMs. We explore the perspectives of different stakeholders about current mechanisms of conflict resolution, and we propose potential changes to the legislative framework and dispute resolution mechanisms that, from the clinical perspective, could result in improved patient care at the end of life.

Two recent events have put new life into an old debate in Ontario around the use of CPR and life-sustaining treatments in caring for patients at the end of life: the decision of the Supreme Court of Canada in *Cuthbertson v. Rasouli*,¹ and the revised policy of the College of Physicians and Surgeons of Ontario's (CPSOs) on *Planning for and Providing Quality End-of-Life Care*.² When physicians feel that CPR and life-sustaining treatments should be withheld or withdrawn because they cannot help and may cause suffering, but the patient or substitute decision-maker disagrees, who ultimately gets to make the decision and on what basis should that decision be made?

In this report, we attempt to provide a framework for understanding and answering this broad question. We undertook the following steps to do so:

1. We reviewed the existing ethics, clinical, and legal literature to explore relevant definitions, jurisprudence, legislation, policies and frameworks used in Ontario and elsewhere.
2. We summarized and expanded on the completed work of the authors, and conducted new qualitative research to gain the perspectives of all relevant stakeholders, including patients, substitute decision-makers, physicians, and lawyers that represent patient and substitute decision-makers who have appeared before the Consent and Capacity Board (CCB) on some core considerations:
 - a. The roles of the medical standard of care and consent in decision-making in these circumstances.

b. How stakeholders perceive the medical standard of care, and what it means if treatments fall outside of it.

3. We synthesized the major issues raised in the two steps above, and considered some of the potential (and existing) legal and ethical policy options that might address these issues and establish the best means of balancing the need to respect patient values with the need to respect the medical standard of care.

The report is organized into sections that reflect these steps. In Section 1, we review existing law and policy relevant to this topic. In Section 2, we consider some important medico-ethical concepts and stakeholder perspectives, including the results of qualitative research conducted specifically for the purpose of this report. In Section 3, we describe and critique some of the existing mechanisms for decision-making and conflict resolution in Ontario and other jurisdictions. Finally, in Section 4, we identify key points and concerns raised in the previous three sections, and suggest approaches to address these concerns.

We acknowledge that the perspective of the paper reflects the professions of the authors – namely physicians and ethicists. We have attempted to supplement this perspective by conducting qualitative research involving lawyers and family members to balance the analysis and recommendations.

As a general comment, we feel that it is unlikely that we will ever develop a “perfect” model for decision-making and conflict resolution around these decisions, or even one that everyone will find acceptable. This issue involves multiple complex clinical, emotional, cultural and philosophical considerations, and we should always expect some disagreement among health providers, patients, SDMs and families who seek to find a balance among these considerations.

The law has provided some clarity for approaching decisions about withdrawal or withholding of life-sustaining treatment, but large gaps and “gray areas” remain. Case law is helpful at times but heavily dependent on specific statutes and the facts of each case, which limits broad interpretation of any one decision.

“Shared Decision-Making” is a model that is commonly promoted as a way to reach decisions that respect patient’s values within the clinical realities of their specific situation and, if necessary, to resolve disagreements. In practice, however, this can be difficult if patients or their SDMs lack sufficient information and insight about the

severity of advanced illness and the likely effectiveness of treatment options. Similarly, shared decision-making is challenging if a patient's SDM does not know or is unable to represent the patient's values effectively in the specific clinical context, or if health care teams are unwilling to elicit patient values, to communicate treatment options clearly for patient or SDM understanding, or to define a clear medical standard of care (MSOC).

In this paper, we define the MSOC as all treatment options, which have a reasonable potential to either cure, stabilize an illness and/or alleviate pain and distressing symptoms, based on scientific knowledge, evidence based medicine and clinical experience. These treatments may be individual in nature or form part of a treatment plan with multiple treatments. These treatments are those that a reasonably prudent physician could offer (propose) to a patient who comes seeking medical help, and are grounded in medical knowledge and science alone. Simply put the MSOC delineates what can reasonably be expected to help (i.e. benefit) a patient without exposing him or her to a disproportionate risk of harms and side effects.

The MSOC is a component of a broader concept: that of the "medical standard of practice." The medical standard of practice includes all the professional, legal and ethical aspects of medical practice that have been clarified by statute, case law and the policies of provincial medical regulatory colleges. These concepts include the requirements for consent, and the physician's recommendations among available treatment options based on both the science of medicine and the unique nature of the patient's wishes, values and state of health.

The distinction that we have drawn between the MSOC and the medical standard of practice is one that we will use in this project to ensure clarity. Our goal is to explore the tensions between the desire to obtain consent and the desire to use only treatments that can help more than they harm.

Notwithstanding such complexities, we claim that patients, SDMs, and health care providers share an interest in making treatment decisions that respect both patient values and the MSOC, and in taking steps to improve how shared decision-making is accomplished in practice. Incremental improvements in multiple aspects of our process of decision-making and dispute-resolution could lead to a dramatic improvement in outcomes for all stakeholders. This would be more realistic than seeking to adopt radical changes.

The aim of our project was to better appreciate the balance of interests of all stakeholders – patients, substitute decision-makers, and health care providers – in decision-making over the withdrawal and withholding of life-sustaining treatment. The project involved a legal and policy analysis, a review of the literature, and qualitative research with SDMs and members of the legal profession. In our suggestions for policy and practice change, we have tried to avoid generic or ubiquitous recommendations (e.g. “promote advance care planning” or “better communication”) that can be found in other reports addressing broad limitations in end-of-life care. We have made suggestions to address four key issues related to balancing patient, SDM, and health care provider interests in decision-making about the withdrawal or withholding of life-sustaining treatment.

A complete treatment of all identified issues and their corresponding suggestions is found at Section 4, “Issues and Suggestions.”

I. REVIEW OF LAW AND POLICY

In this section, we will review some of the key laws and policies that affect decisions about the withholding and withdrawal of life-sustaining measures, both in Ontario and in other jurisdictions around the world.

Statutory law, case law and policies across Canada have addressed some legal issues that arise in end of life care. The issues that have come before the courts have centered mainly on issues of capacity, consent, substitute decision-making and withholding and withdrawal of life support. Statutes across the country have focused on the requirements and standards for consent, substitute decision making and advance care planning and, though the actual terminology can vary from province to province, the creation of powers of attorney for personal care or health care to respect a patient's wishes should he or she become incapable, including in cases where he or she develops a life-threatening illness. It is Canadian case law that has clarified specific aspects of substitute decision-making and the requirements for consent to treatments and treatment plans being proposed by physicians to such critically ill patients. In turn statutes and case law have been incorporated into health care policies – at the level of the provincial colleges of physicians and surgeons, and within hospitals themselves.

The right to self-determination – the right of a capable person to decide among the available treatment choices exactly what treatments he or she wishes to undergo – is a basic and long recognized right in Canadian law. This right to self-determination (and the related ethical principle of autonomy) underpins the importance of the legal constructs of capacity and consent, including the patient's right to voluntarily accept treatment based on information disclosed by a physician that also takes into consideration significant aspects of the patient's situation and treatment goals.

In *Fleming v. Reid*, the leading Court of Appeal ruling on this issue in Canada, Robins JA clearly stated how:

with very limited exceptions, every person's body is considered inviolate, and, accordingly, every competent adult has the right to be free from unwanted medical treatment. [...] It is the patient, not the doctor, who ultimately must decide if treatment – any treatment – is to be administered.³

In Ontario, the legal requirements for capacity are defined by the *Health Care Consent Act* (HCCA or “the Act”) in s. 4.⁴ To have capacity to make health care decisions in Ontario, a person must have the ability to understand information relevant to making a decision about the treatment, and have the ability to appreciate the reasonably foreseeable consequences of a decision or of not making a decision. In the event of a person being incapable, the need to protect this fundamental right to self-determination has resulted in the construct of substitute decision-making wherein another person (generally but not always someone close to the patient who knows what is important to him or her) makes decisions on his or her behalf. While physicians have a responsibility to offer treatments that may help a person in need, consent from a capable patient or, in the event of incapacity, his or her SDM is required before any treatment can be given. It is only in an emergency situations, situations that are narrowly defined, that treatment can be given without consent and only if consent cannot be obtained. Even in an emergency, if the physician has reason to believe the patient would not want the treatment that is required, the treatment cannot be administered.⁵

The treatments that a physician can offer to cure, stabilize or alleviate the symptoms of an illness are those that have the potential to help more than they harm, for all treatments have risks and side effects. Physicians have an ethical, professional and legal obligation to avoid deliberately harming patients. It is the MSOC that attempts to preserve this balance between medical benefits (the ethical principle of beneficence) and harms (ethical principle of non-maleficence). However, if disagreements arise, and a patient or his or her SDM questions the medical standard of care and requests treatment his or her physicians states falls outside of it, what carries more weight in resolving the conflict: the right to self-determination or the MSOC? It is this question that this research project will seek to explore and to which it will seek to propose potential solutions.

The goals of this section are to:

- A. discuss the current state of the law in Ontario by looking to the statutory provisions of the HCCA, including an overview of the law as it stands in Ontario after the Supreme Court of Canada’s ruling in *Cuthbertson v. Rasouli*
- B. review the CPSOs guiding policy on *Planning for and Providing Quality End-of-Life Care*, and

- C. look to other jurisdictions in Canada and the United Kingdom to see alternative forms of analyzing the legal roles of consent and the medical standard of care and medical standard of practice in the context of end-of-life care.

A. Definitions

Before discussing the state of the law in Ontario and in other jurisdictions it is crucial to define a few concepts: the MSOC, medical standard of practice, consent, and substitute decision-making.

In Canada, provincial statutes themselves do not define the MSOC. The definition of the MSOC arises instead from case law, the law of negligence, and refers to an objective standard that a reasonable, prudent physician would be expected to exercise in a given situation. As explained in the case of *Crits v. Sylvester*,

Every medical practitioner must bring to his task a reasonable degree of skill and knowledge and must exercise reasonable care. He is bound to exercise that degree of care and skill which could reasonably be expected of a normal, prudent practitioner of the same experience and standing.⁶

However how does another physician know what a reasonable prudent physician in her situation would do? To answer this question, the law turns to medical experts of similar knowledge, skill, and who practice in similar settings.

Conflict at the end-of-life considered in this project is not an issue about negligence, but rather one of appropriateness. In other words, it's not about which treatments constitute sub-standard care – or even how those treatments are provided. Rather, the conflict in question is about who has the final say over specific elements of end-of-life decisions. To this end, it is more useful to consider the medical terminology that helps define when something is appropriate or not – that of “medical indication.” Physicians use the term “medical indication” to help define what the ultimate purpose of a particular intervention is.

The purposes of medicine are to attempt to cure reversible illnesses when possible; to stabilize an acute deterioration; to optimize quality of life if cure is not possible; and always, to alleviate pain and distress. These purposes are known as medical benefits.⁷ Treatments that fall within the standard of care aim to yield one of these benefits while seeking to minimize potential side effects or harm.⁸ The MSOC should therefore be

defined as all treatment options, which have a reasonable potential to cure, stabilize an illness, and/or alleviate pain and distressing symptoms, as based on scientific knowledge, evidence-based medicine, and clinical experience. These treatments may be individual in nature or form part of a treatment plan with multiple treatments. These treatments are those that a reasonably prudent physician could offer (propose) to a patient who comes seeking medical help, and grounded in medical knowledge and science alone. Simply put, the MSOC delineates what can reasonably be expected to help (i.e. benefit) a patient without exposing him or her to a disproportionate risk of harms and side effects.

The MSOC is part of a broader concept: that of the medical standard of practice. The medical standard of practice includes all the professional, legal and ethical aspects of medical practice that have been clarified by statute, case law and the policies of provincial medical regulatory colleges. These concepts include the requirements for consent, and the physician's recommendations among available treatment options based on both the science of medicine and the unique nature of the patient's wishes, values and state of health.

The distinction that we have drawn between the MSOC and the medical standard of practice is one that we will use in this project to ensure clarity, as our goal is to explore the tensions between the desire to obtain consent and the desire to use only treatments that can help more than they harm.

Many professional societies have issued statements about a physician's obligation to offer only treatments that they feel would "benefit" the patient.⁹ However "benefit" is not usually further defined. Some professional societies state physicians should avoid providing treatments that will only have negative outcomes – restating the historical principle that physicians should not cause avoidable harm.¹⁰ In ethics these concepts are known as beneficence and non-maleficence. Thus, policy statements that define the MSOC tend to focus on the understanding that treatments should be "beneficial" to patients and, correspondingly, that health care providers should avoid providing treatments that would have negative outcomes in each particular situation.

Whether in in case law, policy, or in medical literature, the description of the MSOC can include either the narrowly defined MSOC, or the MSOC as inclusive of the medical standard of practice. When reading a ruling or an article it is important to avoid confusion by understanding and clarifying how the term "MSOC" is being used. For example, in the case law, the MSOC could include the act of obtaining consent to

treatment. This review of the state of the law will focus on the legal aspects of consent and the tensions that may arise between the need for consent and the desire to respect the MSOC in end of life situations. For the sake of clarity and in view of our purposes we will maintain the distinction between MSOC and medical standard of practice as described in the previous paragraphs. As we have outlined above, the MSOC will therefore be narrowly defined as evidence-based treatments grounded in science and clinical experience that a reasonably prudent physician would offer a patient in need.

B. Ontario's HCCA

Before understanding the state of case law and interpretation, it is helpful to review the relevant parts of the HCCA, especially the definition of "treatment." This was a central issue in *Rasouli*, the recent Supreme Court of Canada decision on end-of-life care decision making which will be discussed in detail below.

Looking to the definitions provided, the HCCA defines treatment as "anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related purpose, and includes a course of treatment, plan of treatment or community treatment plan."¹¹ Under HCCA s. 2(1), a "plan of treatment" means a plan that:

- (a) is developed by one or more health practitioners,
- (b) deals with one or more of the health problems that a person has and may, in addition, deal with one or more of the health problems that the person is likely to have in the future given the person's current health condition, and
- (c) provides for the administration to the person of various treatments or courses of treatment and may, in addition, provide for the withholding or withdrawal of treatment in light of the person's current health condition.

The HCCA also states that no treatment can be provided without consent unless the situation is an emergency. Section 11(1) of the *HCCA* sets out the requisite elements of consent:

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.

The requirement that consent be informed is further outlined in HCCA sections 11(2-3):

- (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.

...

- (3) The matters referred to above in subsection (2) are:
 1. The nature of the treatment.
 2. The expected benefits of the treatment.
 3. The material risks of the treatment.
 4. The material side effects of the treatment.
 5. Alternative courses of action.
 6. The likely consequences of not having the treatment.

The inclusion of the “withholding and withdrawal of treatment” in the statutory definition of a treatment plan and, therefore the need to consent to the withholding and withdrawal of treatment, was clarified by the Supreme Court of Canada in *Rasouli*, which will be discussed below.

The HCCA also includes provisions with respect to an emergency situation. This is narrowly defined in s. 25(1) as a situation in which a person is “apparently experiencing severe suffering or is at risk, if the treatment is not administered promptly, of sustaining serious bodily harm”. The HCCA further specifies limits on when the emergency provisions apply. This is to ensure limited infringements on the right to self-determination while allowing physicians to provide treatment in a way that promotes a philosophy that “errs on the side of life” when decisions need to be made very quickly. The legislation reads as follows:

- 25. (2)** Despite section 10, a treatment may be administered without consent to a person who is incapable with respect to the treatment, if, in the opinion of the health practitioner proposing the treatment,
- (a) there is an emergency; and
 - (b) the delay required to obtain a consent or refusal on the person’s behalf will prolong the suffering that the person is apparently experiencing or will put the person at risk of sustaining serious bodily harm.

(3) Despite section 10, a treatment may be administered without consent to a person who is apparently capable with respect to the treatment, if, in the opinion of the health practitioner proposing the treatment,

- (a) there is an emergency;
- (b) the communication required in order for the person to give or refuse consent to the treatment cannot take place because of a language barrier or because the person has a disability that prevents the communication from taking place;
- (c) steps that are reasonable in the circumstances have been taken to find a practical means of enabling the communication to take place, but no such means has been found;
- (d) the delay required to find a practical means of enabling the communication to take place will prolong the suffering that the person is apparently experiencing or will put the person at risk of sustaining serious bodily harm; and
- (e) there is no reason to believe that the person does not want the treatment.

Should a patient become incapable of providing consent to treatment, HCCA s. 21 describes the framework for substitute decision-making:

(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.

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.

The framework requires SDMs to make decisions consistent with the patient's previously expressed capable wishes where they apply to the patient's current circumstances and, if these aren't known, to make decisions in the best interests of the incapable patient. The definition of "best interests" in s. 21(2) includes considerations such as whether the benefits of treatment outweighs the risk of harm, whether the treatment is likely to improve the person's condition or well-being and other factors that might be considered by health care providers in terms of the MSOC.

Such MSOC considerations, when included in the definition of best interests, may inadvertently set up tensions between the values and beliefs held by the patient and the MSOC itself. This arises in part over which components of the "best interests" standard for decision-making are to be given more weight in the event of conflict between patient values, their well-being, and the applicable medical risks and benefits.¹² Professor Sneiderman has argued that medical considerations should be paramount,¹³ while Professor Gilmour maintains that patient values and beliefs should be the chief considerations.¹⁴ In other words, is it patient values or MSOC considerations that are paramount if the list of the components of best interests appear to conflict?

This discussion is additionally informed by the statutory purpose defined in the HCCA. Section 1 of the Act states:

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.

The purpose of the *HCCA* is therefore not to define the MSOC. It is to outline the required legal framework of consent and decision-making once a treatment has been offered by a physician that, in accordance with medical science and knowledge, has the potential to help a patient and therefore fall within the MSOC. Accordingly, if one starts from the premise that best interests as outlined in *HCCA* s. 21(2) are only engaged after a physician, after careful consideration, offers treatment or plan of treatment options that have the potential to provide greater medical benefit than harm to an incapable patient, it would be up to the SDM to choose among these treatment options – ones that fall squarely within the MSOC. The choice would then be made according to previously patient's beliefs and wishes that may not have been directly applicable to his or her current situation. This approach would not create any tension between values/beliefs and the MSOC as the situation would be similar to that of a capable patient choosing among treatment options that fall within the MSOC in accordance with his or her values and treatment goals. There is therefore no conflict between patient values and the MSOC itself as the best interest standard would then ask the SDM to consider issues of differences in potential medical benefits and risks among treatments within the MSOC.

The tension between the MSOC and patient wishes/values perceived by Sneiderman and Gilmour in the wording of the best interests standard in the Act (i.e. in its inclusion of concepts that are also used to defined the overarching MSOC itself in its wording) would only arise if physicians don't first consider what potential medical benefits can be achieved by medical science, decide which treatments actually do fall within the MSOC and proceed to offer these treatment options. Best interests would then ask that a choice be made within the MSOC – not that there be a choice between values and the MSOC. In other words, the wording of best interests in the HCCA only creates a conflict if the MSOC (the medical science) itself is *only* considered after patient values: if treatments are deemed to fall within the realm of patient choice based on their values *alone without* considering what medical science can or cannot achieve. Still the inclusion of MSOC considerations in the definition of best interests without clear clarification in the HCCA that such consideration of medical benefits and harms are engaged to facilitate decision making and choice among treatments that fall *within* the overarching MSOC has resulted in confusion and discussion.

The HCCA further outlines the functions of the Consent and Capacity Board (CCB) in several circumstances, including where the incapable patient's wishes are unclear; where there is a need to depart from these wishes; where there is a need to appoint or terminate a representative; and where questions arise as to whether the SDM is meeting his or her legal obligations with respect to making decisions on behalf of an incapable patient. The CCB is a tribunal mechanism created through the HCCA that effectively has the power to determine whether the requirements for substitute decision-making are met. For example, the refusal by an SDM to consent to the withdrawal of life-sustaining treatments may be overruled by the CCB if the decision does not comply with the requirements for substitute decision-making under the HCCA.

We argue that considerations important to the MSOC are included in the definition of "best interests" under HCCA s. 21(2)(c) as they are listed as factors SDMs must take into consideration in decision-making on behalf of an incapable patient (e.g., the risks and benefits of treatment). The CCB, by extension, must therefore consider some MSOC issues in its deliberations of whether the SDM have met their legal requirements when providing or refusing consent to proposed treatment options. The HCCA itself, as discussed above, has created confusion and discussion among legal experts¹⁵ and health care teams who, in our experience, are also unclear in clinical practice as to how patient wishes and values interact with these considerations of the MSOC in the determination of best interests, particularly as the HCCA does not define any hierarchy with respect to the relative importance of such considerations. This means that if it is

not clarified that “best interests” are only engaged after a physician determines which treatments will be offered to the patient, if a treatment is requested by an SDM based on his or her perceptions of the patient’s wishes and beliefs, yet the treatment would cause more harm than benefit and would fall, in the physician’s opinion, outside the medical standard of care, the weight that should be provided to such considerations in determining “best interests” is unclear in the current wording of the HCCA. It is here that the Supreme Court of Canada attempted to provide clarity in its decision regarding *Rasouli*.

C. Case Law Prior to *Rasouli*

The most cited case about end of life care in Ontario (other than *Rasouli*, which went to the Supreme Court) remains that of *Scardoni v. Hawryluck*.¹⁶ In that case the patient, an elderly woman with advanced dementia, required repeated admissions to the ICU for aspiration pneumonia despite having a tracheostomy and a percutaneous feeding tube. The physicians sought consent to a treatment plan that included no re-admission to the ICU and a “No CPR” order in the event of a cardiac arrest. The patient’s SDMs, her daughters, refused to provide consent to the treatment plan. The case remains seminal in the clarity it provides in two regards: first, that the standard of substitute decision-making is one of “correctness” rather than “reasonableness;” second, that “best interests” are determined by considering the wishes and values of the patient even if somewhat vague in nature; and third, that the meaning of “well-being” in the HCCA means “more than [sustaining] mere life itself... and to include considerations such as a person’s dignity levels and pain.”¹⁷ The ruling did not address how to factor in considerations of the MSOC in determining best interests.

Subsequently in *Children's Aid Society of Ottawa-Carleton v. MC* (2008),¹⁸ the courts ruled on the matter of a child apprehended at birth by the Children's Aid Society (CAS) with an intracerebral bleed and congenital heart abnormality for whom the treating physicians recommended palliative care. The child’s mother (his SDM) did not return to the hospital and the court authorized the CAS to consent to palliative care, ruling that the best interests of a child, where appropriate, can require “refraining from invasive treatment or withdrawing medical treatment other than palliative care.”¹⁹

D. The *Rasouli* Decision

The *Rasouli* decision is the only Supreme Court of Canada case that specifically considers some of the issues of the tension between MSOC and consent that this project seeks to

address. After surgery to remove a brain tumor at Sunnybrook Health Sciences Centre in Toronto, Mr. Rasouli developed a severe brain infection, which left him in a minimally conscious state and dependent on life support. His physicians felt that he had no further chance of recovery and recommended withdrawing life support. However, as an observant Shia Muslim, Mr. Rasouli's wife, his substitute decision-maker, felt that it would be contrary to his religious beliefs to have life support withdrawn and refused to consent to stopping these treatments. The conflict could not be resolved and ultimately was heard by the Supreme Court of Canada. The physicians argued that removing life support from Mr. Rasouli did not constitute "treatment" under the definition provided by the *HCCA* because life support now fell outside the MSOC since it was not providing him with any medical benefits. Since life support was therefore not a treatment under the Ontario *HCCA* (as it served no medical purpose), they argued that consent to stop it was not needed. Mr. Rasouli's wife's position was that consent to withdraw life support was required.

The Rasouli decision was apparently intended to be narrow in scope; it was largely a statutory interpretation about the definitions of "treatment" requiring consent contained in the *HCCA*. Writing for the majority, Chief Justice McLachlin noted that "keeping the patient alive and forestalling death, life support arguably falls within 'therapeutic' and 'preventive' purposes listed in the definition of 'treatment'" as defined under s.2 of the *HCCA*.²⁰ The Court also stated that "inclusion of life support in that definition is also generally supported by the objects of the *HCCA*, by providing consistency with respect to consent, by protecting autonomy through the requirement of consent, and by providing a meaningful role in the consent process for the SDM."²¹ Moreover, the Supreme Court stated that life support served a "health-related purpose" under the Act and therefore consent was required to withdraw it.²²

One of the questions considered in *Rasouli* was the distinction between this "health related purpose", which would require consent because of its inclusion in the definition of "treatment" in s. 2 of the Act, and the concept of "medical benefit" more generally. Medical benefits define, as discussed above, the MSOC in that only treatments that have the potential to offer some medical benefits (in other words that can help a patient by curing or stabilizing the illness and/or alleviating its pain and symptoms), greater than their potential to cause harms, fall within the MSOC. We argue that only treatments that fall within the MSOC are offered to patients in an ideal health care system—to protect patients from the harms of medical interventions that cannot help them. The Court distinguished a 'health-related purpose' as described in the Act from 'medical benefit' in the following ways:

The concept of “medical benefit” is a clinical term used by physicians to determine whether a given procedure should be offered to a patient. This clinical term has legal implications for the physician’s standard of care. If a treatment would be of medical benefit to the patient in this sense, the physician may be required to offer that treatment in order to comply with his standard of care. Whether a given treatment offers a medical benefit requires a contextual assessment of the patient’s circumstances, including the patient’s condition and prognosis, the expected result of treatment for that patient, and any risks of treatment for that patient: A.F., at para. 44.

*The concept of “health-related purpose”, by contrast, is a legal term used in the HCCA to set limits on when actions taken by health practitioners will require consent under the statute. Treatment is “anything that is done” for one of the enumerated purposes (therapeutic, preventive, palliative, diagnostic and cosmetic) or “other health-related purpose”. Under the HCCA, only acts undertaken for a health-related purpose constitute treatment, and therefore require consent. The concept of health-related purpose in the HCCA does not interfere with a physician’s professional assessment of whether a procedure offers a medical benefit. **Its only function is to determine when the actions of health care practitioners require patient consent.***

[...]

In summary, withdrawal of life support aims at the health-related purpose of preventing suffering and indignity at the end of life, often entails physical interference with the patient’s body, and is closely associated with the provision of palliative care. Withdrawal of life support is inextricably bound up with care that serves health-related purposes and is tied to the objects of the Act. By removing medical services that are keeping a patient alive, withdrawal of life support impacts patient autonomy in the most fundamental way [emphasis added].²³

The Court held thus that, in order to alter the “plan of treatment,” and withdraw life support, Mr. Rasouli’s doctors required consent from his substitute decision-maker, or permission from the CCB.

The *Rasouli* ruling also provided the following guidance regarding the role of the MSOC in decision-making: Chief Justice McLachlin stated that “[t]here has been no trial on the standard of care in this case”²⁴ and further commented, in the context of the “best interests” analysis in the HCCA that:

...this review of s. 21(2) [of the HCCA] reveals that although a patient’s beliefs and prior expressed wishes are mandatory considerations, there is no doubt that the medical implications of a proposed treatment will bear significant weight in the analysis.²⁵

As a result of the Supreme Court's ruling in *Rasouli*, there is a need to obtain consent from the patient, or the patient's substitute decision maker, before withdrawing life support. Consent is required to withdraw such treatments even in situations where the physicians have determined that the continuation of such treatments would fall outside the MSOC as they would offer no medical benefit. If there is a conflict between an SDM and health care provider, Ontario physicians can refer the case to the CCB. For physicians the issue in similar situations is whether life support falls within the MSOC, yet the Court ruled that consent is required and the CCB is to adjudicate in the event of intractable conflicts. We argue, unless the statute is clarified as we have discussed above and will elaborate on now, that the CCB, in its evaluation of whether the standards of substitute decision-making are being met in terms of determining the patient's "best interests," therefore effectively now has the power to rule either that the MSOC (as outlined in s. 21(2)(c) of the HCCA) is more important than the incapable person's wishes and values as perceived by his or her SDM (as outlined in s. 21 (2) (a) and (b)), or conversely, it could rule that the patient's wishes and values are more key to substitute consent or its refusal than the MSOC considerations outlined in the Act.

We claim that while the letter of the law would not permit the CCB to adjudicate whether treatment falls within the MSOC, the wording of HCCA s. 21(2)(c) as part of the "best interest" test to include the very factors that form the basis of the assessment of whether a treatment falls within the MSOC for a patient does give the CCB the ability (intended or not) to effectively adjudicate that wishes and beliefs outweigh the MSOC. Effectively this could mean that the CCB can rule that patients have a "right" to treatment outside the MSOC based on their SDM's interpretation of their wishes and beliefs. However, the "best interests" test is supposed to only be engaged once different treatment options are being offered, in other words once the physician has determined what treatment choices fall within the MSOC. Therefore the concerns regarding the unintended (non-statutory) powers of the CCB in adjudicating that wishes and beliefs trump the MSOC can be seen as unfounded. There is confusion among legal experts and, in our experiences, within clinical practice as we have discussed. While the CCB presumably only has a role in determining substitute consent or its refusal for treatments that fall within the MSOC, the ruling in *Rasouli* was that life-sustaining treatments could not be withdrawn without consent—whether or not such treatments fell outside the MSOC as was the physicians' position before the Court. Hence the CCB, as a result of the *Rasouli* ruling which aimed, as the Court has stated to respect the "critical interests" and the role of the SDM in such decisions and required consent,²⁶ can now weigh the role of wishes and beliefs and adjudicate if these "trump" the MSOC

in conflicts over withdrawal (and, likely in view of the wording of the Act, though not tested in case law, the withholding) of life-sustaining treatments.

In clinical practice, therefore, the question of how factors relating to the MSOC and wishes and values are to interact in decision-making is unclear and confusing to physicians and SDMs.

E. Case Law after *Rasouli*: *EGJW v MGC*

Since the Supreme Court's ruling, legal arguments in a subsequent case in Ontario have been made that *Rasouli* stands for multiple, and possibly conflicting, propositions. In *EGJW v. MGC*,²⁷ the Health Professions Appeal and Review Board (HPARB) was called on to determine if a critical care physician had acted improperly when, prior to *Rasouli*, he entered a "Do-Not Resuscitate" (DNR) order in a patient's record, in the belief that cardiopulmonary resuscitation fell outside the MSOC for this particular patient. This order was in contravention of the wishes of the patient's SDM, who had previously communicated her desire for resuscitation to a resident physician. A DNR order is an order to withhold CPR in the event of a cardiac arrest. A DNR order, in practice, is often written with the consent of a patient, but it has also been written in situations when the attending physician felt that CPR would fall outside the MSOC because it would not benefit the patient. In recent years since this case, the DNR order has been replaced with a "No CPR" order in some institutions for clarity.

In September 2008, the patient was admitted to the emergency department at Sunnybrook Health Sciences Centre with sepsis from peripheral vascular disease in both legs. Both legs were amputated above the knees, but following the operation his condition began to deteriorate. The consulting ICU physician, in view of his multiple conditions (comorbidities) and his current state of health, wrote a DNR order on his medical record. The patient's condition worsened quickly and he died later that day. The patient's daughter, his substitute decision-maker, did not consent to the DNR order and believed in the event of a cardiac arrest he would be resuscitated based on prior discussions she had had with the treating medical team. A complaint was made to the CPSO and a hearing held by the Complaints Committee ("the Committee"). The Committee determined that the physician acted reasonably because the DNR order was appropriate since treatment that is non-beneficial does not have to be provided.²⁸ On appeal, HPARB's initial ruling returned the matter to the CPSO with the request that the HCCA and existing policies be considered.²⁹ In the second hearing the Committee ruled the placement of a DNR order was in accordance with the HCCA and existing policies

since any attempt to resuscitate would only cause suffering and death was inevitable. Once again this was appealed to HPARB, at which time the *Rasouli* ruling had been released. On this second occasion, the HPARB ruled that writing the DNR order was a change in the treatment plan, which would require consent under the HCCA.³⁰

The issue under review by the CPSO and the HPARB in *EGJW v. MGC* was not whether resuscitation would fall under the MSOC; the issue was whether consent is required to withhold (in effect to not offer) CPR, where CPR would fall outside the MSOC.³¹ This issue was not the one at stake in *Rasouli*, which concerned the withdrawal of life support. Illustrating the confusion as a result of the *Rasouli* ruling, counsel for the both the SDM and the physician relied on *Rasouli* in support of their client's position.³² The confusion around the application of *Rasouli* apparent in *EGJW* persists: the literature³³ and subsequent case law demonstrate that health care providers, substitute decision-makers, lawyers and others continue to struggle with understanding the law surrounding the withdrawal and withholding of treatment in end of life situations.

F. Policies and the College of Physicians and Surgeons of Ontario

In Canada, all health care related policies whether at regulatory or health care facility levels, must be in accordance with statute and case law, and ideally would offer guidance to physicians regarding the role of the MSOC and consent in decision-making. Few provincial policies have been able to do so until the CPSO released its guiding policy document, "Planning for and Providing Quality End-of-Life Care" in September 2015.³⁴ The CPSO policy clearly acknowledges that there may be situations where in the physician's opinion CPR should not be provided, including but not limited to where:

- CPR will almost certainly not resuscitate the patient,
- the patient's quality of life will be extremely poor should they survive, or
- there are no further treatment options for the patient's underlying illness.³⁵

However, the policy also says that physicians cannot make a unilateral decision to not to perform CPR. If the physician is of the opinion that CPR should not be offered this must be discussed with the patient or SDM. In the event of a disagreement, a No-CPR order cannot be written without consent even if resuscitation would fall outside the MSOC. In other words, the CPSO recognizes that in a physician's opinion, there may be situations in which CPR should not be offered, but it mandates that physicians effectively obtain consent to apply what they believe to be the MSOC. For although the CPSO policy does

not use the term “MSOC,” by stating that there are situations in which physicians would opine that CPR should not be provided and then going on to defining these situations, the CPSO effectively does outline and create MSOC considerations in its policy.

In subsequent amendments in June 2016,³⁶ the CPSO clarified that there is “a narrow set of circumstances in which CPR need not be provided: instances where the patient's condition would prevent the physiologic goals of CPR from being achieved.” These situations are very narrowly defined and describe “instances where the patient's condition would prevent the physiologic goals of CPR from being achieved” in that oxygenated blood could not be delivered to the heart and brain. While the amendments “provide an important clarification of the policy position, while maintaining important policy content to ensure that no-CPR orders cannot be unilaterally written by physicians and that physicians engage in conflict resolution when there is disagreement regarding a no-CPR order,”³⁷ the situations defined in the amendment are, in clinical practice, rare and very narrow in nature in that they describe irreversible situations where death is not only imminent but also inevitable.

The CPSO’s policy also outlines processes to minimize and resolve conflicts in which physicians must:

- Communicate clearly, patiently, and in a timely manner information regarding:
 - The patient’s diagnosis and/or prognosis;
 - Treatment options and assessments of those options;
 - Availability of supportive services (e.g., social work, spiritual care, etc.); and
 - Availability of palliative care resources.
- Identify misinformation and/or misunderstandings that might be causing the conflict and take reasonable steps to ensure that these are corrected and that questions are answered;
- Offer referral to another professional with expertise in the relevant area and facilitate obtaining a second opinion, as appropriate;
- Offer consultation with an ethicist or ethics committee, as appropriate and available;
- Where appropriate, seek legal advice regarding mediation, adjudication or arbitration processes that are available; and
- Take reasonable steps to transfer the care of the patient to another facility or health-care provider as a last resort and only when all

appropriate and available methods of resolving conflict have been exhausted.³⁸

Though policies are not binding, they do inform what can be expected by administrative bodies like the CCB and the courts. The CPSO's policy does emphasize the importance of quality end-of-life care, and the clarity it provides will improve understandings about the MSOC. However, in our view, the policy will most likely also result in more patients receiving CPR at the end of life when resuscitation would fall outside of the MSOC in the opinion of the physicians it regulates.³⁹ The policy states physicians should seek, when appropriate, legal advice regarding mediation, adjudication and arbitration processes however the policy provides no guidance on which process is best suited, nor does it consider whether such processes are responsive to the needs of patients, SDMs and health practitioners in such circumstances.

G. Other Provincial Statutes

Across Canada, the fundamental principle that consent is needed prior to the administration of treatment has been stated in a number of statutes in various provinces,⁴⁰ unless the situation is an emergency.⁴¹ In some provinces, these principles are found in mental health legislation,⁴² court appointed guardianship legislation,⁴³ or legislation concerning advance care planning mechanisms.⁴⁴ To the extent that the statutes do not explicitly state these principles, case law such as *Fleming*⁴⁵ and *Malette v. Schulman*⁴⁶ provide a framework. British Columbia's *Health Care (Consent) and Care Facility (Admission) Act* (HCCCFAA)⁴⁷ and Prince Edward Island's *Consent to Treatment and Health Care Directives Act* (CTHCDA)⁴⁸ is the only health care consent legislation to codify elements of consent similarly to Ontario's HCCA. These elements largely parallel one another as each statute states consent must be related to the proposed treatment and must be informed, voluntary and not obtained through misrepresentation or fraud.⁴⁹

Most provinces across Canada have statutes specific to consent in the health care context or that address advance care planning and substitute decision-making. Most of this legislation incorporates definitions of "treatment", "treatment plan", "health care", or "health service" that are similar to concepts that are defined in Ontario's HCCA.⁵⁰ British Columbia, Saskatchewan, Manitoba, Nova Scotia and Prince Edward Island use very similar language to define treatment and health care and incorporate the concept of treatment plan into their definitions. In Alberta, the *Health Information Act* defines "health service" instead of treatment and, in our view, this definition is in some ways

clearer as a “health service” is provided to an individual for any of the following purposes:

- (i) protecting, promoting or maintaining physical and mental health; (ii) preventing illness; (iii) diagnosing and treating illness, (iv) rehabilitation;
- (v) caring for the health needs of the ill, disabled, injured or dying, but does not include a service excluded by the regulations.⁵¹

The definition of “health service” does not specify a distinction between treatment, treatment plan or course of treatment as seen in the HCCA and avoids reference to a “health related purpose” through the use of more specific terminology. While the similarities between provinces outweigh differences, the differences in statutes that do exist are important and may be a source of confusion for physicians, patients, SDMs, lawyers and others as any conflicts that arise with respect to the need for consent may result in different rulings across the country should they require adjudication if the ruling is ultimately based on the provincial statute. This has been seen after the *Rasouli* ruling which due to its interpretation of the HCCA has resulted in some confusion as to how and whether it applies across Canada.⁵²

No provincial statute besides that of Ontario mentions withholding and withdrawal of treatment in any of its definitions of health care, health services or treatment plan.

Statutory frameworks place considerable emphasis on a patient’s right to self-determination and have provisions to ensure this right is protected and that consent or refusal of consent may be provided by a substitute decision-maker even if the patient loses capacity to make decisions on his or her own. Some statutes state that consent or refusal of consent given when a patient is capable is not invalidated by any subsequent development of incapacity.⁵³ When statutes dealing with substitute decision-making are considered, some variation exists around who can act as substitute decision-makers, and different limits are placed on the decisions that can be made on behalf of an incapable patient. But there are many similarities, in particular that an SDM must act in accordance with the individual’s wishes if they are applicable to the circumstances and are possible to comply with and otherwise, SDMs must act according to what would be in the individual’s best interests as stipulated by statute.⁵⁴ As a general principle, with the exception of emergency situations, treatment cannot be provided without consent. Even in emergency situations, if a physician has reason to believe the patient would not have consented to a specific treatment, that treatment cannot be provided. In general,

this holds true across Canada, though such provisions may not be codified in all provincial statutes with respect to emergency treatments of incapable patients.⁵⁵

No statutes in Canada explicitly address the role of the MSOC when conflicts arise because a patient or an SDM requests “treatment” or refuses to consent to the withholding or withdrawal of treatment that a health care provider believes to fall outside the MSOC.

H. Case Law in Other Canadian Jurisdictions

Prior to the Supreme Court of Canada’s *Rasouli* decision, jurisdictions (mainly outside of Ontario) had grappled with the question of whether a refusal of treatment constitutes a form of treatment and therefore requires consent. Jurisdictions have also struggled to determine whether treatment needs to be provided when it falls outside the MSOC but is nonetheless requested by a patient or the patient’s SDM. The cases above provide some guidance with respect to the resolution of conflicts in end-of-life care, and in particular those conflicts involving the provision of CPR and life support. The cases were adjudicated on specific facts and in view of the statutes in the provinces in which they arose. A review of some of the key cases will be provided here. Since *Rasouli* did not resolve all the issues that arise in end-of-life care, these additional cases help build an understanding of how statutory definitions, issues of consent, and the MSOC have been adjudicated across Canada. Overall, at law, it is not clear whether life-sustaining treatments can be withheld or withdrawn without consent if they fall outside the MSOC.

The province that has dealt most often with these issues is Manitoba. In *Child and Family Services of Manitoba v. R.L.* (also known as the *Lavallee* case),⁵⁶ a three-month-old infant was physically abused by his parents and as a result was in a persistent vegetative state. His physicians wanted to place a DNR order on his medical record but his parents refused consent to such an order.⁵⁷ The initial application was heard before Cummings P.J. who ruled that under s. 25(3) of the *The Child and Family Services Act*, the court “had jurisdiction under the section to authorize a negative as well as a positive treatment plan and, being convinced by the medical evidence that non-resuscitation was in the best interest of the infant, granted the order sought.”⁵⁸ Twaddle J (for the Court of Appeal) found there is “no legal obligation on a medical doctor to take heroic measures to maintain the life of a patient in an irreversible vegetative state” and “the only fear a doctor need have in denying heroic measures to a patient is the fear of liability for negligence in circumstances where qualified practitioners generally would have thought intervention warranted.”⁵⁹ Twaddle J further ruled that “the word

“treatment” when used in s. 25(3) is used only in a positive sense. There is no need for consent from anyone for a doctor to refrain from intervening.”⁶⁰

However, since *Lavallee*, it has been increasingly recognized that all treatments and treatment plans include acts of omission as well as acts of commission. For instance, in *Golubchuk v. Salvation Army Grace General Hospital*,⁶¹ which involved an individual who was kept alive by a ventilator and feeding tube, the patient’s family wanted to maintain the life-sustaining activities, while the hospital wanted to remove the ventilator and feeding tube in order to not prolong his perceived suffering and allow Mr. Golubchuk to die. Part of the analysis hinged on whether physical contact was required to remove the life-sustaining apparatus, which would constitute assault without consent. The court explained that trying to distinguish between “treatment” as an act of omission or commission is unhelpful and fails to reflect medical realities that nearly all treatment consist of both acts of omission and commission. Further, in the event of disagreement between the health care provider and patient or SDM, Justice Schulman outlined the rights of patients and SDMs to access a conflict resolution process by stating:

the right that should be afforded to patients who disagree with their doctors to be provided with a written outline of the procedures available to them and an opportunity to have the disagreement addressed with the help of a knowledgeable, trained and objective mediator, who would, in appropriate cases, be chosen from outside the hospital environment.⁶²

In contrast, in *Sawatzky vs. Riverview Health Centre*,⁶³ in caring for a patient with Parkinson’s disease and multiple co-morbidities, physicians placed a DNR order on the patient’s chart without informing the family. When the family applied for an injunction to block the order, Beard J. determined that the injunction was appropriate. She also considered the role of the Public Trustee, who took no role in the proceedings based on their interpretation of *Lavallee*, and characterized this as “the complete abdication of her [the Public Trustee’s] responsibility to Mr. Sawatzky, for whom she is responsible.”⁶⁴ Beard J. went on to state as follows:

Surely the role of the Public Trustee as committee and her duty to her wards extends past consenting to active treatment and encompasses participating in decisions leading to death even if, at the end of the consultation process, the doctor can act contrary to the wishes of the ward as they are expressed by the Public Trustee. She is still to express the ward’s wishes to the doctor. In many cases, if she refused to do so, there will be no vehicle for those wishes to be expressed. Surely, those who are not competent to speak on their own behalf deserve at least this level of

representation in the decision to end their lives. I cannot believe that the Court of Appeal ever intended their decision to be used by the Public Trustee in this manner.⁶⁵

This analysis of *Sawatzky* was subsequently applied by the Alberta Queen's Bench in *L.I.C. (Re)*, which concluded that:

Based on the case law to date, the courts have stated that a decision not to provide treatment is exclusively within the purview of the doctor and is not a decision to be made by the courts. Thus, it appears that the courts would not interfere with a medical decision not to provide treatment.⁶⁶

After the conflicting rulings in these cases, in 2002, the Manitoba Law Reform Commission (MLRC) decided to broach these issues of MSOC and unilateral orders to withhold treatments at the end of life in order to explore if further guidance for patients, SDMs, physicians, lawyers and others could be achieved.⁶⁷ In its review of the *Lavallee* case, the MLRC pointed out the narrow set of facts and framework on which it was decided and thus questioned its generalizability. The MLRC found no recognized positive right to life-sustaining treatments in its research and recommended that physicians retain authority to withdraw or withhold life sustaining treatment without consent based on considerations of the MSOC and the ability of such treatments to continue to provide medical benefits. The MLRC concluded,

it is fair to conclude as a general proposition that the physician has the ultimate power to withhold or withdraw life sustaining treatment without the consent of the patient. In exercising that power, there are onerous ethical and legal obligations of consultation, information and discussion the objective of which is to lead to a consensus decision, but where an impasse is reached the physician may withhold or withdraw life sustaining medical treatment. This may appear to be reflective of the discredited authoritarian, paternalistic medical practices of the past but there is reason for caution before entertaining a right to life sustaining medical treatment.⁶⁸

However, the report nicely outlined the "intuitive attraction of the notion of personal autonomy and support for a patient's right not only to refuse life sustaining treatment but also to *demand* life sustaining measures."⁶⁹ The report also explored the perception that consent is required in all situations of proposed withholding and withdrawal of life sustaining treatments, and the opposite view that consent should not be required when such treatment would not offer any medical benefit.

The MLRC called for a uniform and consistent approach to decision-making regarding withholding and withdrawing life-sustaining treatments across the province and across institutions. Its recommendations focused on communication and ensuring this process to decide on withholding and withdrawal was consistent, transparent and equitable.⁷⁰ The MLRC however did issue recommendations regarding conflict resolution practices that reflected the process previously outlined in *Golubchuk*, stating:

Where a consensus cannot be reached between the physician and the patient or substitute decision maker about withholding or withdrawing life sustaining medical treatment resort should be had to other available informal dispute resolution procedures. Institutional facilitators and mediators such as ethicists, pastoral care workers and other qualified persons can assist in finding a consensus between the physician and the patient/substitute decision maker. In some circumstances, independent external mediators may be helpful. Every reasonable effort should be used to secure agreement in as informal and sensitive a process as possible.⁷¹

The MLRC ultimately stated that when “all preceding measures have failed to produce an agreement the physician may, after an appropriate notice period, withhold or withdraw life sustaining medical treatment where such treatment would be medically inappropriate or professionally unethical.”⁷² As the MLRC explained further:

A corollary of the foregoing is that we do not favour a right to indefinite life sustaining medical treatment. The appeal of autonomous decision making and personal control of all end of life medical decision making is initially attractive. An unfettered right to life sustaining treatment, however, may result in unreasonable demands being made for indefinite inappropriate medical treatment. We cannot judge how significant a risk this is and we cannot quantify the burden on the health care system but there are additional and independent reasons for caution. First, the recognition of such a right may be inconsistent with the fundamental professional and ethical obligations of physicians not to provide medically inappropriate treatment. Second, it opens the door to a more general right to other forms of inappropriate medical treatment prior to the end of life situation. Third, human and economic health care resources are strained and some professional control over the use of medical technology to sustain life indefinitely is appropriate.⁷³

The MLRC reviewed a proposed draft policy of the College of Physicians and Surgeons of Manitoba (CPSM) in its report and proposed changes according to its own findings. The CPSM subsequently issued a “Statement on Withholding and Withdrawal of Life-

Sustaining Treatment” in 2008.⁷⁴ It states that physicians can unilaterally withhold or withdraw treatment if “the minimum goal of life-sustaining treatment is not realistically achievable or that it is realistically achievable but there are likely to be significant negative effects on the patient including, but not limited to, pain and suffering.”⁷⁵

Since this policy statement, the CPSM passed “By-Law 11, Standards of Practice of Medicine,”⁷⁶ which revokes all previous policies of the College. However, in its new “Code of Ethics of The College of Physicians and Surgeons of Manitoba” (approved December 2015), the CPSM states as an overarching and guiding principle in relation to life-sustaining treatments that physicians are to “ascertain wherever possible and recognize the patient’s wishes about the initiation, continuation or cessation of life-sustaining treatment.”⁷⁷ At the same time, By-law 11 maintains the earlier definition of the “minimum goal of life-sustaining treatment” as:

clinically defined as the maintenance of or recovery to a level of cerebral function that enables the patient to:

- achieve awareness of self;
- achieve awareness of environment; and
- experience his/her own existence.

For pediatric patients, the potential for neurological development must be factored into the assessment.⁷⁸

According to the Standards of Practice, if this minimum goal is not achievable and consent to withhold or withdraw is not obtained by the patient or SDM, a second opinion is required. If the second opinion supports the determination that the minimum goal cannot be reached, unilateral withdrawal of life-sustaining treatments can proceed with written notification to the patient and SDM that includes the physicians’ findings, those of the second opinion, and the time and date upon which withdrawal will proceed.⁷⁹

Manitoba is currently the only province in Canada to include such a definition of a “minimum goal” of life sustaining treatment and a process to unilaterally withhold treatments in its standards of practice. The Standards of Practice have not been challenged in court subsequent to the Supreme Court’s ruling in *Rasouli*. It is unclear if a court challenge arising in Manitoba regarding the unilateral decision to withdraw life-sustaining treatments would result in a very different ruling.

Elsewhere, pre-*Rasouli* cases across Canada highlight the tension between the MSOC, best interests, and consent. While these cases highlight the importance of considering

these issues, they do not resolve the tension in any definitive manner. In the Alberta case of *Sweiss v. Alberta Health Services*, Mr. Sweiss, the patient whose serious health conditions resulted in 98 previous hospital admissions and who suffered from significant cardiac disease, had sustained a cardiac arrest and severe neurological injury.⁸⁰ His physicians recommended withdrawal of life support and a DNR order. The family of the patient felt that this impugned their father's Islamic faith, and sought an injunction to discontinue the DNR order of the doctor and to prevent any doctor from removing the mechanical ventilation machine.⁸¹ Ouellette J ruled that life-sustaining treatment does not need to be provided if it is not in a patient's best interests and that patient wishes do not trump all other considerations. Ouellette J stated:

In light of the above, it is my opinion that simply because a medical procedure can be done does not mean that it should be done. I agree with the general premise that courts and patients should not require that doctors provide a course of treatment which is not in their best interest. I also believe that the patient's wishes and directions regarding his or her treatment are a factor which must be considered by the Court. It makes little difference whether these wishes and directions are grounded in religion or otherwise. Rather, what is key is that the patient's wishes, values, and beliefs are considered by the Court in making a determination in this context. However, it is also my view that a patient's wishes and beliefs should never be said to trump all other factors, principles, or opinions where a determination as to what is in the patient's best interest is being made. There may be situations where the patient's wishes or directions run contrary to his or her best interest or where they are inconsistent with what is just and equitable in the circumstances. For example, a direction not to provide a child or adult a necessary blood transfusion to avoid death.

In summary, I am of the view that the proper test to be applied is what is in the best interest of the patient. In determining the best interest of the patient there are several factors and considerations which should be taken into account. Although not exhaustive, they include:

- (i) the patient's actual condition;
- (ii) the medical treatment that is recommended;
- (iii) the wishes and directions of the patient; and
- (iv) what is just and equitable in the circumstances.

All of these factors and considerations must be weighed and balanced and no one factor should be considered determinative.⁸²

The ruling provided no specification on how any conflicts between perceived "best interests" and the MSOC could be resolved. In other words, the ruling does not clarify if

the MSOC “trumps” or outweighs considerations of “best interests.” The factors that are fundamental to determine if a treatment falls within the MSOC are engaged once again as part of the “best interests” test to determine which amongst various treatment options may be the best choice for the patient. But if the wishes and beliefs of the patient “run contrary” to the MSOC, the ruling provides no further guidance on how to resolve the conflict. Nor was further information on how to determine “what is just and equitable” provided.

In *L.I.C. (Re)*, a dependent patient with a long-standing brain injury under the guardianship of the Public Guardian suffered a cardiac arrest and was in a vegetative state.⁸³ Her physicians recommended that life support be withdrawn and a No CPR order be placed on her chart.⁸⁴ The family did not dispute this treatment plan⁸⁵ and the Public Guardian sought direction from the Court who relied on *Airedale NHS Trust v Bland*, which stated:

the question is not whether it is in the best interests of the patient that he should die. The question is whether it is in the best interests of the patient that his life should be prolonged by the continuance of this form of medical treatment or care.⁸⁶

LIC went on to conclude:

Based on case law cited above, it appears that the decision of whether or not to withhold or withdraw life sustaining medical care is inherently a medical decision, within the sole purview of a patient’s treating doctors.⁸⁷

In *IHV (Re)*, an incapable patient with end stage cancer and renal failure was recommended for palliative care and the withdrawal of other treatments.⁸⁸ One of her daughters refused to consent while the other agreed to the physician’s proposed treatment plan. The Court appointed a guardian and held “that it would be inappropriate for the courts to mandate by injunction medical treatment that may be contrary to the unanimous view of health care practitioners, as they are the ones with the expertise, experience, and the compassion.”⁸⁹

And in 2010, *May v. Alberta Health Services* reviewed the role of consent for a child who suffered severe neonatal encephalopathy at birth and required life support.⁹⁰ The physicians wanted to withdraw life support. The parents, acting as SDMs, refused to provide consent and sought an injunction to obtain independent medical opinions. The child died before the court could rule. However, the court subsequently issued an

advisory decision on the issue of the injunction. There the court held that an injunction sought in context of end-of-life or urgent life-threatening conditions should be tested in the “best interests of the patient.”⁹¹ Among these “best interests” factors are the role and value of additional medical opinions.⁹² Again, the court declined to discuss how these considerations should be weighed.

In British Columbia, the leading case on this issue is that of *Rotaru v. Vancouver General Hospital Intensive Care Unit*.⁹³ In this case the patient had developed an ischemic colitis that was not treatable.⁹⁴ She had recurrent episodes of shock and bleeding requiring admission to the intensive care unit and developed multisystem organ failure include renal failure. The nephrology team refused to offer dialysis as they felt it would fall outside the MSOC. All physicians involved recommended withdrawal of life-sustaining treatment since the patient had an irreversible, untreatable illness and was dying. The daughter refused to consent to this plan. At issue was whether a court could “order a doctor to treat a patient in a manner contrary to the judgment of the doctor.”⁹⁵ The court ruled that hope for a better outcome and a SDMs’ love for a patient is not grounds for a court to order treatment outside the MSOC. Burnyeat J stated:

There is no doubt in my mind that the Petitioner hopes that something can be done to reverse what the medical advisors believe is the inevitable result of the condition of her mother. The love for her mother was clearly evidenced by the submissions made by the Petitioner. However, that is not enough to ground an order to a medical advisor to treat Ms. Priboi in a manner which is contrary to his or her clinical judgment even if such an order could be made by this Court.⁹⁶

The ruling in *Rotaru* dealt with whether the court could order treatment once it had already been ceased and did not however deal with the same issues as seen in Manitoba and Alberta – that is to say at issue was not whether the court could prohibit physicians “from withdrawing forms of treatment or life support systems.” This distinguishes it from the decisions in *Golubchuk*, *Swastzky* and *Sweiss*. The Court did however also order that the patient’s medical records be made available to the daughter so that a second option could be sought in a further attempt to resolve the conflict.

I. United Kingdom

The challenge of balancing consent with the MSOC at the end-of-life is recognized worldwide. An exhaustive review of British law in this area is outside the scope of this paper, but some key aspects are worthy of note. Courts in the United Kingdom, which

many Canadian courts reference in their rulings, seem to consistently take the approach that the legal framework allowing for the withdrawal of life-sustaining treatment is based on the assumption that improved quality of death is preferable to prolonged life with increased suffering. This approach can be seen in the obiter of many cases.⁹⁷

The British courts have placed significant weight on the importance of the MSOC in determining how to resolve conflicts about the patient's best interests at the end of life. While consent is important, the MSOC has been perceived as the cornerstone of treatment that protects the patient from the real harms caused by aggressive treatments at the end of life. The courts' rulings reflect that in these conflict situations, death is inevitable and medical treatments are appropriately aimed at alleviating pain and suffering rather than adding to them. The medical opinion to cease treatment even without family or SDM consent flows from a value system placing a premium on the physician's responsibility to minimize suffering. This perspective was perhaps best articulated in the seminal House of Lords' case *Airedale N.H.S. Trust v Bland*.⁹⁸ The *Airedale* ruling noted that "the question is not whether it is in the best interests of the patient that he should die. The question is whether it is in the best interests of the patient that his life should be prolonged by the continuance of this form of medical treatment or care."⁹⁹

In addition to the case law are two important pieces of legislation: the *Mental Capacity Act 2005* (in England and Wales), along with its "Code of Practice;" and the *Adults with Incapacity (Scotland) Act 2000*, along with its "Code of Practice."¹⁰⁰ These pieces of legislation set out the determinants of a person's capacity; determine who can make decisions in the event of a person's incapacity, and how these decisions should be made; describe how a person may make provisions for future treatments should incapacity ensue. The statutes also include provisions to protect incapable patients in need of "serious medical treatment."

In the United Kingdom the authority to make decisions on behalf of an incapable patient rests with the physician and not the family.¹⁰¹ This is an important distinction from the legal framework in Canada, which makes the UK model more challenging to apply here. However, in certain circumstances, physicians must make an application to a specialized court, the Court of Protection, to determine whether treatment will be withheld or withdrawn. The Court of Protection relies in part on "Practice Direction 9E – Applications Relating to Serious Medical Treatment," which specifies that an application must be made when an incapable patient requires a "serious medical treatment," meaning:

treatment which involves providing, withdrawing or withholding treatment in circumstances where:

- (a) in a case where a single treatment is being proposed, there is a fine balance between its benefits to P and the burdens and risks it is likely to entail for him;
- (b) in a case where there is a choice of treatments, a decision as to which one to use is finely balanced; or
- (c) the treatment, procedure or investigation proposed would be likely to involve serious consequences for [patient].¹⁰²

These circumstances include the withholding or withdrawing of artificial nutrition and hydration from a patient in a permanent vegetative state (PVS) or a minimally conscious state (MCS), and for any situation involving an ethical dilemma in an untested area. It is important to note however that artificial nutrition and hydration can be withdrawn or withheld if consent is obtained from a capable patient or if a patient is incapable and continuing artificial nutrition and hydration would not be in his or her best interests, but the patient is not in a PVS or MCS.¹⁰³ It is only those patients in a PVS or MCS for whom an application to the Court of Protection must be sought in these circumstances.

Lawyers appearing before the Court of Protection are requested to seek an order that “the patient lacks capacity to consent to the continued life-sustaining treatment measures; and that, it would be in the patient’s best interests to withdraw the life-sustaining treatment.”¹⁰⁴ Hearings by the Court of Protection are generally private, which doesn’t facilitate understanding or promote the education of health care teams regarding best practices in decision-making, though there are provisions to make either the hearing or the publication of its reasons public.¹⁰⁵ Furthermore, since the authority to make decisions on behalf of an incapable patient rests with the physician and not the family in the UK, the Court of Protection has limited authoritative scope and it is difficult to see what advantages a similar Court could offer Ontarians when faced with disputes regarding the MSOC with respect to life sustaining treatments and CPR.

On the other hand, the General Medical Council (GMC), the British medical profession’s governing body, in its policy on “Treatment and Care towards the End of Life,”¹⁰⁶ emphasises a presumption in favour of prolonging life by requiring physicians to take “all reasonable steps to prolong a patient’s life” though stating “there is no absolute obligation to prolong life irrespective of the consequences for the patient, and irrespective of the patient’s views.”¹⁰⁷ It states that in the event of conflicts regarding the withholding or withdrawal of life support physicians should try to achieve

consensus, to provide a second opinion, hold a case conference or use mediation taking into account the legal framework for resolving disagreements. If conflict persists physicians are advised to seek legal advice in order to apply to the appropriate statutory body or court. When case law is considered the GMC advises that the courts will apply a “best interests” standard in England, Wales and Northern Ireland while courts in Scotland will adjudicate whether the treatment is “of benefit.”¹⁰⁸

The Intensive Care Society (the society of critical care medicine professionals in Britain) in its “Guidelines for Limitations of Treatment for Adults requiring Intensive Care”¹⁰⁹ states that life-sustaining treatments can be withheld or withdrawn if they “will not benefit the patient or the expected benefits are outweighed by the burdens of treatment”, and includes consideration of the wishes of the patient if possible and that attempts need to be made to determine what his or her wishes were. Moreover, “every withdrawal decision should be made upon its own merits and must not be made on the basis of either cost or medical convenience.”¹¹⁰ The guidelines do not however provide any guidance in the event of conflicts regarding withholding or withdrawal of life-sustaining treatments.

Case law has also provided further clarification of the term “best interests” which includes medical, emotional and all other factors relevant to the patient’s welfare but does not mean that treatment should be aimed at prolonging life no matter the consequences to the patient.¹¹¹ Different than seen in Canada, most of the cases that have arisen in the United Kingdom have dealt with issues around artificial nutrition and hydration and not withholding or withdrawal of life support. Furthermore in *Re J(A Minor)*¹¹² the court ruled that if a patient requests a treatment outside the MSOC the physician has no obligation to provide it however a second opinion should be sought. The responsibility remains with the physician to decide what treatments to offer, in other words, which treatments fall within the MSOC. If asked to adjudicate on withholding or withdrawing a treatment, the courts have considered if such a withholding or withdrawal accords with a responsible body of medical opinion however the court will make its own determination of whether such a proposal is within the patient’s best interests.¹¹³

In *Aintree University Hospitals NHS Foundation Trust v. James*¹¹⁴ the patient was admitted in 2012 with sepsis from an infected stoma originally created in 2001 after resection of a colon cancer. He developed multisystem organ failure, and sustained a cardiac arrest and anoxic brain injury. His physicians applied to the Court of Protection to withhold further life-sustaining treatments including CPR if he worsened. The Court

of Protection ruled against the physicians, however, the ruling was overturned on appeal which held the Court of Protection had used “too narrow a view of futility” and should have been “concerned instead with whether the treatment was worthwhile in the interests of the general wellbeing.”¹¹⁵ The patient died before the Supreme Court could rule; however, the appeal was heard due to the importance of the issues raised. The Supreme Court ruled physicians are permitted to withhold life-sustaining treatment when it is not in the patient’s best interest or is “overly burdensome.”¹¹⁶

There is scarce guidance on how to address issues of the MSOC in withholding and withdrawal of life sustaining treatments in other jurisdictions worldwide. This report explored legal frameworks in the United Kingdom which appear to give significant weight to the MSOC in determining the best interests of a patient in adjudicating conflicts regarding the withholding and withdrawal of life-sustaining treatments. Though not discussed here, the legal approach in other commonwealth countries such as New Zealand and Australia would generally appear to be similar to that of the United Kingdom.¹¹⁷

J. Summary and Conclusions

Canadian statute and case law to date have not clearly addressed all of the issues that arise in end-of-life care, in particular those surrounding issues of the MSOC and the withholding and withdrawal of life-sustaining treatments and CPR. The case law across Canada has somewhat clarified issues of the medical standards of practice, in particular the role of legal constructs of capacity; the need for consent; the need to consider the patient’s best interests (including that these include more than prolonging life itself); and the standards of substitute decision-making that need to be met. However as discussed above, it remains unclear whether the different statutory and policy considerations in different provinces would result in different court rulings if disputes about withholding and withdrawal of life-sustaining treatments require adjudication. This may result in inequity in the provision of treatment, which would be difficult to justify in law. In particular, the CPSM policy, which under certain circumstances permits the unilateral withdrawal of life-sustaining treatments, has not been subject to a legal challenge since the ruling of the Supreme Court in *Rasouli*. It is unclear if such a challenge could be withstood since the *Rasouli* ruling did hinge on a statutory interpretation of Ontario’s HCCA.

However, this significant discrepancy in approach to balancing the MSOC and patient wishes in resolving disagreements about withholding and withdrawal of life sustaining treatments arguably should prompt a consideration of:

- 1) the underlying reasons for such differences in policy approaches (for example, between Manitoba and Ontario);
- 2) the advantages and potential risks of using the MSOC to determine when such treatments should be withheld and withdrawn;
- 3) the means to more effectively, fairly and transparently resolve disagreements in a timely manner when SDMs want life-sustaining treatments to continue for incapable patients when such treatments fall outside the MSOC;
- 4) potential changes to statutes to clarify the legal underpinnings of treatment decisions and to render adjudications more just and transparent to all involved parties; and
- 5) the means through which statutes can and should effectively promote quality end of life care in these areas.

These issues remain inconsistently resolved in law, and variable approaches in addressing them in clinical practice only generate more confusion. Such variability and a lack of transparency raises significant concerns with respect to equal treatment of patients within the health care system that challenge notions of equality, equal benefit and protection in law.

II. MEDICO-ETHICAL CONCEPTS AND STAKEHOLDER PERSPECTIVES

In this section we build upon the legal review above and describe some key medical and ethical concepts relevant to decision-making for life-sustaining therapies. We begin with an explanation of the prevailing model of decision-making then explore the perceptions of CPR and decisions about CPR and life support in the medical community, legal community and the public. Since these perspectives vary in different parts of the world, we cite Canadian or Ontario literature whenever possible. Since the perspective of the legal community and SDMs has not been reported in the literature, we conducted a qualitative study to gain this perspective and report a summary of our findings.

Once again, the focus of this project was specifically on balancing the interests of patients, substitute decision-makers, family and health care providers in decision-

making over the withdrawal and withholding of life-sustaining treatment. Our review of the literature and our research were predominantly focused on this area.

A. Shared Decision-Making: the Prevailing Model within the Health Care Community for Treatment Decisions Nearing the End of Life

In the health sciences literature, the most commonly described model of decision-making for any medical decision is known as “shared decision-making”, where decisions are shared between the patient (or substitute decision-maker) and the health care team. Broadly speaking, this model involves using patient values (provided directly by the patient or through substitute decision-making) to select a treatment plan from a list of medically reasonable options (those treatments that fall within the MSOC), using a communication style and deliberation process that respects the patient’s preferences. When applied to a seriously ill patient, this model involves specific practices that are commonly grouped into 4 dimensions:

- Providing Medical Information
 - Discuss the nature of the decision
 - Describe treatment alternatives available within the MSOC
 - Discuss the pros and cons of these choices
 - Discuss uncertainty of benefits, risks and outcomes
 - Assess patient or SDM understanding
- Eliciting patient values and preferences
- Exploring the patient or SDM’s preferred role in decision-making
 - Discuss their knowledge of legal standards of substitute decision-making and the SDM’s and/or family members’ role and responsibilities in decision-making
 - Assess the need for input from others
- Deliberation and decision-making
 - Explore the context of the decision
 - Elicit the patient or SDM’s opinion about the treatment decision.¹¹⁸

The use of this shared decision-making model in the existing literature is associated with a high degree of patient and SDM satisfaction and, in most cases, when physicians, patients and SDMs discuss whether or not to provide life-sustaining treatment, all stakeholders are able to reach an agreement.¹¹⁹ Clinicians,¹²⁰ patients, and SDMs¹²¹ alike show a strong preference for consensus approaches to decision-making rather than unilateral decisions. Disagreements and intractable disputes are relatively rare.

Yet there are problems with the shared decision-making model. It is a challenging model to apply, and even in academic hospitals with a reputation for strong communication, only a small percentage of decisions include all of the elements described above.¹²²

The main problems with shared decision-making can be summarized as follows:

- 1) **Communication:** shared decision-making depends on good communication. The existing literature demonstrates that patients typically wish to avoid life-sustaining measures at the end of life,¹²³ but very few have discussed their wishes with their physician or an SDM,¹²⁴ even after they have been admitted to hospital with serious illness.¹²⁵ At the same time, clinicians often feel untrained to have these conversations,¹²⁶ and perceive that patients and SDMs are unwilling to discuss goals of care,¹²⁷ which leads to cursory conversations that are lacking in content and context or, often, no conversation at all prior to a crisis.
- 2) **Expectations for treatment:** shared decision-making depends on a good understanding of illness, prognosis, and the likelihood of benefitting from specific therapies. Most patients and SDMs have an unrealistically optimistic expectation of the benefit of life-sustaining measures¹²⁸ and lack the ability to understand the implications of a single decision on the subsequent cascade of decisions common among patients at the end of life. This may drive them to request treatments that could potentially be inconsistent with their values.¹²⁹
- 3) **Substitute decision-making:** shared decision-making depends on an SDM being able to represent the wishes, values and beliefs of an incapable patient. Research suggests that most SDMs cannot do this without considering their own relationship with the patient, and the value of life in general.¹³⁰
- 4) **Trust in health care providers:** shared decision-making depends on trust, and patients or SDMs with low levels of trust in doctors are also less willing to share responsibility with physicians and health care teams for determining the range of options in more value-sensitive decisions, such as whether or not to withdraw or withhold life-sustaining measures.¹³¹
- 5) **Time constraints:** shared decision-making requires time, and important treatment decisions often have to be made in urgent or emergent situations. When this happens, stakeholders often revert to a

“paternalistic” decision-making model in which the physician makes the decision him or herself.¹³²

When shared decision-making breaks down, there is a strong possibility that the patient will end up having no clear treatment plan, or having a plan that is inconsistent with their values. A recent study showed that only a minority of seriously ill hospitalized patients in Ontario have a documented treatment plan that is consistent with their values.¹³³

B. The MSOC for Life-Sustaining Measures at the Bedside in Ontario

The first section outlined how MSOC is defined in law and policy, and discussed some inconsistencies in the use of the term. As mentioned previously, outside of the courts, the MSOC is generally framed by professional societies for prospective or in-the-moment decisions; professional societies focus on a physician’s obligation to offer only treatments that they feel would “benefit” the patient.¹³⁴ This is a subtle distinction, placing the emphasis on determining whether something will be of benefit rather than whether or not another physician with similar training would offer it. But it can be challenging to define “benefit” since this may depend on the goal of medical care in any particular situation.¹³⁵

CPR is one treatment that can become the focus of a dispute between health care providers, patients and SDMs about benefit. For CPR, there are scenarios in which there is no reasonable prospect of successful resuscitation, such as unwitnessed cardiac arrests in a long-term care facility,¹³⁶ or patients with treatment-refractory metastatic cancer.¹³⁷ But there are also many situations where the medical literature has clearly shown the likelihood of survival is not zero, but still very low. In such situations, a reasonable person might feel that CPR is worthwhile because if CPR is withheld, the chances of surviving a cardiac arrest would be zero. But this consideration only considers survival and not what life after resuscitation would be like.

Survival alone as an endpoint overlooks the very real harms that CPR and life-sustaining measures can cause for some individuals at the end of life, which have been well documented. For instance, patients who survive CPR often require prolonged efforts at resuscitation, suffer severe anoxic brain injury, and only “live” to die in the near future. Those who survive long enough to be placed on life-sustaining measures often experience significant pain, anxiety, and shortness of breath.¹³⁸ Survivors often have a very poor quality of life and functional impairment after critical illness.¹³⁹ Patients who

receive more aggressive care report a lower quality of life prior to death,¹⁴⁰ and bereaved family members of patients who die in intensive care settings report higher rates of depression.¹⁴¹ Health care providers who provide non-beneficial aggressive care at the end of life report higher rates of post-traumatic stress disorder and burnout.¹⁴² Finally, advance care plans that specify limitations on aggressive end-of-life care are associated with lower health care costs at the end of life even though patient outcomes are not changed.¹⁴³

In other words, a reasonable person could feel that CPR is not justified in some cases because it would lead to a very high likelihood of suffering for the patient, family members and health care workers alike, and at great cost to the health care system. Withholding CPR, on the other hand, would lead to a much higher likelihood of a peaceful and comfortable death.

Of course, this places a great deal of importance on how one defines “benefit.” Published studies of “non-beneficial treatment” generally include one or more of the following definitions:

- ***Ineffective treatment***
 - *“Quantitatively futile”*: There is no chance that the treatment will achieve the desired effect of resuscitation (e.g. CPR in a decapitated patient).
 - *“Qualitatively futile”*: The treatment may restore circulation and vital signs but there is no chance that this patient will recover to leave the ICU environment (i.e. the patient is permanently unable to recover to the point of independent function).
 - *Inconsistent with patient-defined goals*: The treatment may restore vital signs and the patient may be able to leave the ICU environment, but the best possible outcome is still below the minimum functional level that the patient would find acceptable.

- ***Not Cost-Effective***: Life-sustaining therapy is often costly, and when the likelihood of benefit is extremely low, these therapies may not appear cost effective. Of course, anything that is not effective is by definition also not cost effective, but the two concepts should not be conflated and any discussion of cost-effectiveness involves a broader discussion of effective use of health care resources and rationing, which is beyond the scope of this paper.

- ***Effective, but the burdens of treatment grossly outweigh the benefits***: Life sustaining therapy is often associated with a significant burden in terms of symptoms and functional decline. Some may not feel that these burdens are justifiable in the face of a small potential benefit (e.g. a

patient with a short prognosis due to an undercurrent terminal illness). This is not equivalent to ineffective care, however, and the balance of benefits and burdens is best determined by the patient him or herself.¹⁴⁴

Canadian clinicians generally share similar definitions of “non-beneficial treatment”. One qualitative study revealed that ICU-based physicians, nurses and respiratory therapists generally defined non-beneficial treatment to be “the use of considerable resources without a reasonable hope that the patient would recover to a state of relative independence or be interactive with his or her environment.”¹⁴⁵ A subsequent survey found that the most commonly accepted definitions of non-beneficial treatment were: “advanced curative or life-prolonging treatments that would almost certainly result in a quality of life that the patient has previously stated that he or she would not want” and “advanced curative or life-prolonging treatments that are not consistent with the goals of care (as indicated by the patient).”¹⁴⁶ Ontario physicians are often able to define “benefit” in specific cases, but when defining the MSOC, they will commonly make reference to patient values and consent.

These observations show the degree to which medical standards can relate to patient values or goals of care. This may be a good thing when it helps to arrive at agreement on a plan of treatment, but it can also be a bad thing when those values are unknown, unrealistic or incorrectly conveyed (as described above). Indeed, a large proportion of ICU clinicians report routinely providing life-sustaining therapies that they feel are non-beneficial.¹⁴⁷ In other words, a broadly-defined MSOC relies on patient values to a considerable degree, but patient values cannot always be smoothly incorporated into the MSOC.

C. The Therapeutic Imperative and the Idea of CPR as a “default” option

Some people believe that CPR is a default option, one that must be provided unless there is an agreement to withhold it. But this “default” approach is problematic at the bedside for many reasons, one of which can be illustrated in a realistic vignette:

Three Ontario physicians are called urgently to the emergency room – an oncologist, a surgeon and an intensivist. They are asked to see a patient with widely metastatic cancer, a malignant bowel obstruction and renal failure, clearly in his final hours of life. The patient is delirious and not capable of making medical decisions. The SDM is at the bedside pleading with the doctors to “do everything” to prolong his life, insisting that the patient receive chemotherapy, surgery and life support. All three physicians recognize that the patient is imminently dying and refuse to provide these therapies, offering palliative medications instead. The SDM

does not agree to this recommendation, and when the patient dies, the SDM registers a complaint with the CPSO. Only the intensivist would be disciplined in these circumstances, because CPSO policy treats CPR differently than chemotherapy and surgery.

In order to understand this apparent double standard for CPR (compared with other therapies), we must appreciate the history of resuscitation. CPR was first developed as a means of resuscitating patients who suffered a cardiac arrest apparently as a result of a primary cardiac arrhythmia. Much excitement surrounded CPR as it permitted outcomes that were unachievable in the past. In subsequent years, the use of CPR expanded to include virtually any situation in which a patient's cardiac output was undetectable.¹⁴⁸ In modern times, regardless of location, medical practitioners who encounter a pulseless individual would be typically expected to initiate CPR with the hope of resuscitating the patient. This is consistent with the traditional medical culture of "saving lives" and "erring on the side of life" whenever possible.

At the same time, physicians often wish to avoid CPR in patients nearing the end of life, reasoning that it can cause suffering for no apparent medical benefit. Accordingly, many professional societies have adopted policies that advise against the provision of CPR and life-sustaining therapies that health care providers consider to be non-beneficial. Some of these were reviewed in the previous section on law and policy regarding the withdrawal and withholding of treatment. Other policies are addressed below.

For instance, the CMA "Statement on Life-saving and -sustaining interventions" (updated 2013) specifies how:

There is no obligation to offer a person medically futile or non-beneficial interventions. Medically futile and non-beneficial treatments are controversial concepts when applied to life-saving and life-sustaining interventions. For the purposes of this document, "medically futile" and "non-beneficial" are understood as follows: in some situations a physician can determine that an intervention is medically futile or non-beneficial because it offers no reasonable hope of recovery or improvement or because the person is permanently unable to experience any benefit; in other cases the utility and benefit of an intervention can only be determined with reference to the person's subjective judgment about his or her overall well-being.¹⁴⁹

The British Medical Association's policy on "Decisions relating to cardiopulmonary resuscitation" (updated October 2014) indicates that:

In other cases, the decision not to attempt CPR is a straightforward clinical decision, if the clinical team has good reason to believe that a person is dying as an inevitable result of advanced, irreversible disease or a catastrophic event and that CPR will not re-start the heart and breathing for a sustained period. If there is no realistic prospect of a successful outcome, CPR should not be offered or attempted.¹⁵⁰

The Australian Medical Association "Position Statement on End of Life Care and Advance Care Planning" (updated 2014) specifies that:

Doctors should understand the limits of medicine in prolonging life and recognise when efforts to prolong life may not benefit the patient. In end of life care, medically futile treatment can be considered to be treatment that gives no, or an extremely small, chance of meaningful prolongation of survival and, at best, can only briefly delay the inevitable death of the patient....doctors are generally not obliged to provide treatments that are considered medically futile.¹⁵¹

While these organizations underscore the importance of respecting patient wishes and values, they state that a demand for CPR from a patient or SDM that is considered to be non-beneficial from the health care providers' perspective should be treated the same way as a demand for chemotherapy or surgery that health care providers believe would not result in benefit to the patient. Such requests should prompt an exploration of patient values, and a clarification of misunderstandings about the limitations of treatments.

From a medico-legal perspective in Ontario, CPR is a treatment. The HCCA does not specify that any treatments should be provided by "default," but a treatment can be provided without consent in situations where a patient "is apparently experiencing severe suffering or is at risk, if the treatment is not administered promptly, of sustaining serious bodily harm" under the "emergency treatment" section (s. 25). Presumably, emergency treatment would only apply to therapies that are expected to alleviate suffering or prevent serious bodily harm, and certainly not if the therapy itself would cause suffering for no realistic chance of benefit. In addition, a health practitioner cannot invoke s. 25 if there are reasonable grounds to believe that the patient expressed a capable wish that he or she did not want the treatment in question.¹⁵² Thus, an order to withhold CPR (effectively pre-empting the use of the emergency

treatment provision of the HCCA to perform CPR) could be justified on the grounds of either non-benefit or patient wishes.

The idea of CPR as a “default” treatment for cardiac arrest may be considered analogous to the idea of surgery and chemotherapy as “default” options for cancer. If a patient presents with cancer, they would usually be offered surgery and chemotherapy. But it would not be the MSOC to offer surgery or chemotherapy in all situations without considering the clinical circumstances and patient’s unique needs, or to continue such therapies even if they are only harming the patient until the patient agrees to stop.

Following the *Rasouli* decision (described in the previous section), some have argued that CPR is actually part of a “plan of treatment.” Again, under Ontario’s HCCA, a “plan of treatment”:

(a) is developed by one or more health practitioners,

(b) deals with one or more of the health problems that a person has and may, in addition, deal with one or more of the health problems that the person is likely to have in the future given the person’s current health condition, and

(c) provides for the administration to the person of various treatments or courses of treatment and may, in addition, provide for the withholding or withdrawal of treatment in light of the person’s current health condition.¹⁵³

If CPR were considered to be part of a plan of treatment that would exist by “default” or as the result of a conversation that occurred previously (e.g. on admission), then CPR would have to be provided in the event of a cardiac arrest (unless CPR would not provide oxygenated blood to the brain), and this plan of treatment could not be changed without consent.¹⁵⁴

However, there are some practical issues with this interpretation. First, most resuscitation conversations are brief and rarely achieve the standards of informed consent indicated in the HCCA, resulting in a very poor understanding of CPR and its risks, benefits and alternatives.¹⁵⁵ Second, resuscitation and life-sustaining treatments are commonly offered by physicians who do not themselves provide such treatments and may have an imperfect or mistaken understanding of their abilities to help and harm. In clinical practice, physicians are not always bound to follow treatment plans offered by another physician, or plans offered previously by the same physician under different circumstances. Even if the patient initially provided informed consent for CPR,

the second physician might have more expertise and experience with CPR and life-sustaining treatments, or the clinical situation may have changed. A primary care physician could refer a patient to a surgeon or oncologist with the plan to treat a newly-diagnosed cancer with chemotherapy or surgery, but the surgeon and the oncologist are not bound to provide those therapies if they feel that the therapies are inappropriate, even if the primary care physician obtained informed consent for that plan of treatment. Resuscitation is also conceptually different from many other treatment plans in that no specific therapies are provided immediately after consent is obtained for the plan of treatment. Resuscitation is provided after an event that is difficult to predict with precision (e.g., a cardiac arrest), and so by necessity the plan of treatment requires consent given in advance. An analogous situation would be organ transplantation. Patients with end-stage organ disease who are eligible for organ transplantation will be offered the option of being placed on an organ transplant waiting list. This is essentially a plan of treatment that triggers a specific therapy in the event that the patient comes to the top of the list and an organ becomes available. But if the patient deteriorates, or information becomes available that would make the transplant team feel that the patient was no longer eligible for a transplant, the patient will be removed from the transplant waiting list. This decision can be difficult and upsetting for patients and family members, but the decision is ultimately a medical one and consent is neither sought nor required.

Thus, there are a number of practical and ethical challenges to considering CPR a “default” treatment that requires consent to be withheld. This requirement would be a unique double standard in medical practice, one that is not applied to analogous decisions to withhold cancer therapies, or remove a patient from an organ transplant waiting list, among other examples.

D. How do Patients view Decisions about CPR?

From the public perspective, CPR is sometimes viewed as a “miracle” treatment, with the ability to restore patients to life. Although the expected success rate of CPR is very low for patients with advanced medical illness (<10%), the public perceives the success rate to be quite high.¹⁵⁶ The sources of this unrealistic optimism appear to be CPR awareness programs, personal medical training, and television.¹⁵⁷ Television appears to be a particularly strong influence on perception, since the average estimate of CPR success (~70%) is almost exactly the same as the success rate seen on popular television programs.¹⁵⁸ Patients who perceive higher rates of successful CPR are more likely to request it for themselves,¹⁵⁹ even if patients are not good at determining their own

likelihood of success. Patients often do not appreciate the harms of CPR and subsequent life-sustaining therapy, which include a high prevalence of pain, shortness of breath and anxiety.¹⁶⁰ When patients are informed about the actual process and low success rate of CPR, they will usually opt not to receive it.¹⁶¹ Yet one study found that a substantial proportion of ICU survivors would want such treatments even if there was no chance that they would prolong life,¹⁶² and another found that many patients request CPR even though their goals are to prioritize comfort care.¹⁶³

Many patients also do not learn specifics about CPR from their health care providers. Even seriously ill hospitalized Canadians often cannot recall having had a discussion about resuscitation and life support with their physician, and very few can describe CPR in specific terms.¹⁶⁴ Those who can recall having had a discussion about CPR would often describe it differently depending on whether they requested CPR or a No-CPR order.¹⁶⁵ Those who request CPR describe the procedure as a “restoration of life”, or they have no clear idea what is involved. Those who request a “No CPR” order view CPR as violent, traumatic and painful, with complications and only a brief, futile prolongation of life. Conversely, when asked about the meaning and consequence of a “No CPR” order, those who request CPR feel that this would result in substandard care, in some cases tantamount to euthanasia or assisted suicide. Patients who request a “No CPR” order feel that the medical team would provide comfort care and allow a natural process to take place.¹⁶⁶ Clearly, all patients understand CPR and CPR orders in fairly stark terms, focusing on specific concerns or hopes that may not necessarily reflect a typical experience.

When making decisions about CPR orders, patients often consider personal factors related to their quality of life, both current and anticipated.¹⁶⁷ Those who opt for CPR are typically experiencing and expecting a good quality of life, whereas those who opt for a “No CPR” order are often unsatisfied with their current or anticipated quality of life in the event of CPR. But patients also cite factors that are apparently unrelated to medical considerations, such as relational factors. Many speak of a desire to remain with family members, or to avoid being an emotional and physical burden on others. They also cite philosophical factors, such as a desire to complete life goals or to avoid delaying the inevitable.¹⁶⁸

E. How do Substitute Decision-Makers view decisions about CPR and Life-Sustaining Measures?

Since there was limited literature specifically representing the perspective of SDMs on this issue, we conducted qualitative research to better understand this important viewpoint. We sent out an invitation to a group of SDMs to participate in focus group sessions to discuss some of their experiences around substitute decision-making, and their views on different means of resolving disputes about withholding and withdrawing life-sustaining measures. A description of the research methodology and the qualitative coding scheme are available in the Appendix. We will summarize here some of the key themes identified in our research.

When discussing challenges in disputes about CPR and life-sustaining measures, SDMs identified challenges relating to understanding their role as an SDM, dealing with the emotional stress of having a critically ill loved one, and difficult interactions with physicians.

SDMs reported having limited discussion of their role as a decision-maker, usually in the context of the patient preparing a power of attorney document when the patient was updating his or her will. Of course, the SDM is often not present at the time that legal documents are prepared for other people, and they only come to appreciate the specifics of their role when the patient becomes ill. Some SDMs ultimately found the role very burdensome, and spoke of the need to inform prospective SDMs about the role prior to it being assigned to them. One commented that "...it's not something that anybody wants." SDMs felt that a better explanation of the SDM role would be helpful.

SDMs emphasized the emotional strain of having a critically-ill relative, and the perceived need to balance the wishes of the patient with the needs of other family members, while also considering the personal relationship between the SDM and the patient. Although SDMs could sometimes recall the patient having given them instructions or wishes (to avoid life-sustaining measures, for example), other relational issues meant that it was a "struggle to do the right thing."

SDMs routinely identified poor communication as a major challenge that they faced in their role. They identified deficiencies in both quantity and quality of communication with physicians. SDMs felt that honest and timely communication was important for developing trust, and that SDMs would feel much more comfortable following the suggestions of people who they trusted.

Many SDMs had only a vague understanding of the idea of a MSOC. Some understood it as a form of legal protection for physicians, and others understood it as a form of protection for patients, to prevent physicians from applying their own values to a decision. There was a general feeling that the uncertainty of prognosis made it difficult to have certainty around a medical decision or standard of care.

When SDMs were presented with different ways of explaining a decision- essentially a request to give consent to withdraw life-sustaining measures versus assent to a stated medical decision, there was a range of opinions from respondents. Some preferred the example where physicians gave options and asked the SDM to decide. Others preferred that the physician bear some of the burden of the difficult decision.

Similarly, there was a range of opinion about the ideal means of resolving disputes between physicians and SDMs, and whether CPR should be provided to patients if they develop a cardiac arrest while dispute resolution processes are ongoing. Some preferred a process of in-hospital conflict resolution, whereas others thought that it was better to seek adjudication within the legal system. Likewise, some felt that the medical team should “provide care to the maximum until the situation is resolved”, while others felt that the physicians should make the final decision.

Overall, our qualitative research was able to capture the various perspectives of SDMs. There were relatively few points of agreement among all participants- they agreed on the difficulty of fulfilling the role of SDM, and the poor quality and quantity of communication they received from physicians. SDMs had little to say about the MSOC and how it could play a role in decision-making around CPR and life-sustaining measures.

F. How do Physicians and Health Care Providers view Decisions about CPR and Life-Sustaining Measures?

Health care providers tend to view discussions of CPR and life support as part of a core concept of medical practice- “saving lives and warding off death.”¹⁶⁹ Although there is a broad realization of the limitations of medical care, there is still an underlying therapeutic imperative, and a notion that “death is like a failure.”¹⁷⁰ This may be one important reason why these conversations are avoided or postponed until very late in the disease course.¹⁷¹

When physicians do propose limitations on CPR or life-sustaining therapies, they perceive the conversation as a process of “making meaning” of the situation together with the patient or SDM.¹⁷² At times, this proceeds easily and consensus is quickly achieved. At other times, the progress is slower or it fails to arrive at consensus. In such cases, both qualitative¹⁷³ and quantitative¹⁷⁴ studies indicate that from the physicians’ perspective, decisions to provide CPR and life-sustaining measures that they believe to be non-beneficial are driven by the patient or SDM’s poor understanding of prognosis and the limitations of treatments. These drivers are made more powerful by the concerns about the medico-legal ramifications of a decision to withdraw or withhold CPR or life-sustaining therapies. As one participant in one study explained, “Right now a lot of the physicians perceive that the medical-legal environment is stacked against them.”¹⁷⁵

This perspective, whether true or not, is understandable in the face of the decision in *Rasouli*,¹⁷⁶ the HPARB ruling in *EGJW v. MGC*,¹⁷⁷ and the subsequent CPSO policy discussed in the previous section. Each of these is an example where consent from a patient or SDM is prioritized over the MSOC, which is to say what the health care provider believes to be the appropriate treatment.

It would not be uncommon for physicians to complain that in the current medico-legal environment, it is much easier in a situation of potential conflict to accede to a patient or SDM’s demand for aggressive care than to engage in prolonged negotiation, pursue conflict resolution, or apply for a hearing with the CCB.¹⁷⁸ There is also little personal incentive for physicians to advocate for a comfort-based approach in the face of disagreement from an SDM. The above-mentioned CPSO policy merely gives advice about the benefits of integrating palliative care into the treatment plan, while avoiding the stronger language (e.g. “must”) used to describe a physician’s obligation to provide CPR.

In other words, physicians perceive little risk if they decide to provide the most aggressive care available to them, but potentially significant risk if they propose a palliative-focused approach, even if the latter would meet what they believe to be the MSOC.

G. How do Members of the Legal Community View Decisions about CPR and Life-Sustaining Measures?

Since we could not find any literature representing the perspective of practicing lawyers on this issue, we conducted qualitative research to better understand this important viewpoint. A description of the research methodology and the qualitative coding scheme are available in the Appendix. We will summarize here some of the key themes identified in our research.

When discussing challenges in disputes about CPR and life-sustaining measures, lawyers identified challenges related to the family, health care system, legal system, and power dynamics between these actors. Other lawyers highlighted the challenges associated with letting families decide what to do. Families were emotional, they argued: they were emotionally affected by and invested in the situation, decision-making, and conflict, which was important to consider throughout the process.

There were three health system-related challenges that legal professionals emphasized. First, physicians' communication was limited both in the sense of whether the physician communicated with SDMs or how end-of-life communication was conveyed. To unpack limited communication, they said physicians many times didn't prepare the families for the situation of advanced illness: they didn't explain the patient's condition early enough, and discussed patient wishes and values too late. When requesting end-of-life decisions, they often presented the decision options bluntly, as a yes or no question, without much explanation and empathy.

Second, lawyers found that doctors did not really understand the law: they often made mistakes about determining the appropriate SDM, they didn't request consent when it was necessary, or requested consent without fully informing the patient or SDM about the options and potential consequences. Some lawyers also found that physicians questioned capable wishes only when the physicians wanted to withhold or withdraw life-sustaining measures, and didn't present the legal process if disagreement occurred.

Third, legal professionals felt that health care resource constraints were a challenge. Lawyers sometimes sensed that hospital bed and financial constraints were influencing proposals to withdraw life sustaining therapies, which is inappropriate because such concerns should not be part of end-of-life decision-making under the law. Legal professionals also recognized the constrained medical resources in various parts of the province that curtailed their access to experts and second opinions in conflict resolution

and adjudication processes. Time was also mentioned as a limited resource- one that shaped and constrained physicians' and patients' availability in end-of-life decision-making and conflict resolution.

Legal professionals identified three legal system-related challenges. First, litigation is expensive and time-consuming. Although parties might appear without representation in front of the CCB, self-represented litigants face challenges and lawyers cost money, and legal aid supported SDMs only in a limited number of cases. While the CCB made decisions relatively quickly, the appeal process through the courts took a long time. A few lawyers expressed concerns about the medical expertise of the CCB, since the physician was usually a psychiatrist instead of an expert in the appropriate medical field, such as an intensivist. Lawyers expressed concern about colleagues who had clients sign power of attorney documents without explaining to them and their named SDMs the roles and responsibilities of substitute decision-making and the nature of decisions covered in the form.

From the lawyers' perspective, both the health-care and the legal systems were characterized by uneven power relationships. In the health care system, physicians' knowledge and expertise put them in a position of power vis-a-vis their patients and SDM. Physicians could misuse their power, and lawyers felt that doctors sometimes "bully" or "coerce" substitute decision-makers in EOL decision-making and conflict. Doctors' expertise commanded them power in front of the CCB, recreating the doctor-SDM imbalance of power in the legal arena. The legal system also has its own issues with the balance of power, as it is most accessible to those who could afford legal assistance. While patients and SDMs often have to pay for their lawyers, the Canadian Medical Protective Association (CMPA) provides lawyers for physicians, giving a financial advantage and enhancing the physicians' position of power. Conversely some lawyers pointed out that their role was to represent their client and to strive to achieve the client's goal of keeping the patient alive for as long as possible (rather than to determine the patient's best interest). The lawyers commented that the slow pace of proceedings could work strategically in the SDM's favour in achieving the client's objectives.

Many lawyers criticized how physicians interpreted the *Rasouli* case, and the way in which it created inertia among physicians as they let families dictate care in end-of-life cases, even if they felt it was inappropriate. Disheartened by the legal process, physicians often did not challenge "wrong" SDM decisions, creating a problematic intersection of health and law.

We asked legal professionals about the role of the MSOC in cases of dispute, but most explained that the MSOC had not been used as an argument in their experience. They mostly understood the term from cases involving negligence. Most of them thought that MSOC could be used as a useful argument in these cases, but there were a couple of important considerations to keep in mind. First, the MSOC could help explain what medicine can potentially achieve and the limits of medical science. Second, the MSOC could be interpreted in multiple ways, especially at end-of-life. Lawyers argued that medical standards were often inconsistent, both locally and internationally. They also dissected the language of the definition of MSOC, and questioned such terms as “reasonable” and “disproportionate risk of harms and side effects,” which they felt suggested a subjective perspective.

For lawyers, there was a rift between the MSOC and the law. The MSOC defined the medical consideration and the law considered capable wishes, values, and best interests, shaped by culture, religion, and personal relations. Given the necessity of informed consent under the law, some felt that discussions could at times include alternatives that fall beyond the MSOC.

Yet we found that there was disagreement within the legal community about the idea of not offering treatment outside the MSOC. Some lawyers agreed that physicians didn’t have to offer treatments that they viewed inappropriate, or falling outside of the MSOC. Others thought physicians had to offer everything. There was also disagreement about how they viewed the protection of patients under the MSOC. Some thought that the MSOC protected patients and patients’ rights, especially if they were provided adequate information about options. Others, however, thought that the MSOC provided treatment options for patients and the law provided protection for them.

Most recognized the tension between respecting the MSOC and honouring an SDM’s request for a specific treatment, as SDMs do not have medical training and might not know the patient wishes. We also found disagreement among lawyers about decision-making, or rather, whom they consider to be the decision-maker. There were legal professionals who thought that physicians could make decisions about certain matters, while others thought that decision-making was solely the SDMs’ responsibility if the patient was incapable. In some cases, SDMs may agree with the idea of withdrawing life-sustaining treatment but are unwilling to say so explicitly. To address this concern, physicians will sometimes offer an “assent” model of decision-making, in which the physician proposes that he/she will bear the burden of the decision-making (with the agreement of the SDM). When presented with an example of “assent”, the lawyers all

felt assent did not meet legal standards even if some perceived it as a form of empathetic communication.

We also asked legal professionals to suggest mechanisms for improving decision-making and dispute resolution, and they identified family-related, health care- and legal-system related improvements. Some of the lawyers acknowledged that families were relational and thus made decisions relationally. In other words, they implicitly challenged the individualist conception of substitute decision-making, and recognized that SDMs were relational beings, and their decisions were influenced by their relationship to the patient and other family members, just as patients' wishes were influenced by their relationship to their family members. Accordingly, many lawyers called for educating about substitute decision-making when physicians and other providers ask SDMs to make decisions or when lawyers prepare power of attorney documents. They thus encouraged health care providers and lawyers to spell out the roles and responsibilities of SDMs to help the latter perform their duties.

Legal professionals had three health care system-related suggestions. First, they encouraged physicians to communicate better with SDMs, admitting their own uncertainty in certain medical situations, preparing families by communicating patients' conditions at an early stage, explaining treatment options, being empathetic towards the family, presenting the legal process of conflict resolution if they disagree and conveying their support even in situations of dispute. Legal professionals emphasized that it was important to have conversations about resuscitation framed appropriately and conducted at family meetings by experienced staff physicians. Second, they highlighted the importance of educating physicians about lawful decision-making and consent, as part of their core educational curriculum. Third, they encouraged the integration of the MSOC with the law, with physicians bringing the medical considerations, and SDMs contributing the wishes, values, and best interests of the patients. In this way, the MSOC and the patient's best interests could be woven together.

Lawyers also had suggestions to improve the legal system by instituting pre-hearing mediation. Many of them believed that some of the end-of-life cases could be avoided or settled by more communication and mediation among the parties in conflict.

Overall, our research was able to capture the perspective of key members of the legal community. The participants identified many challenges, and they were not always able to identify solutions for every challenge. Notably, the solutions they did make, including

communication, education, and mediation, are strategies intended to avoid or settle conflicts within the existing structures for adjudicating disputes that are in use today. While the lawyers called for better integration of the MSOC within the process of legal adjudication, they held onto the priority of the existing legal structures and the significance of consent under the law. While the lawyers acknowledged the role of relational personhood on decision-making, they did not make suggestions for how to overcome this issue while respecting the need for consent. The lawyers also did not mention any suggestions for addressing the perceived imbalance of power in the legal process, and the unequal access to justice and representation.

H. Summary and Conclusion

In this section, we described some of the key medical and ethical concepts relevant to decision-making regarding life-sustaining therapies. We reviewed the prevailing model of decision-making (known as “shared decision-making”), then explored the perceptions of CPR and decisions about CPR and life support in the medical community, legal community and the public.

We proposed that shared decision-making is an ideal model that seeks to blend medical facts with patient values, using a process aimed at achieving consensus. When this model works, it works very well. But this model relies on a number of key factors that are often missing in practice, including good communication, realistic expectations for the effectiveness of treatments, accurate substitute decision-making, trust, and time.

The MSOC is an important concept in decision-making, but as in the previous section, health care providers often struggle to define and communicate a precise definition of “benefit”. All stakeholders agree that the MSOC is rooted in patient values, but they do not necessarily agree on what this means for resolving disagreements in practice.

Recent policy developments have seemed to create a special status for CPR and life-sustaining measures in Ontario. But decisions to withhold or withdraw CPR and life-sustaining therapies are very complex and nuanced as well. No stakeholder group approaches these decisions through a logical analysis of medical facts and values, and every group has focused on different aspects of the decision. For example, patients and SDMs focus heavily on relational elements, and the effect of CPR and death on family members rather than the patient him or herself. Physicians focus on the benefit or non-benefit of the therapies, but they struggle to define or communicate these concepts; in

practice, physicians often accede to demands for CPR and life-sustaining measures in order to avoid professional and legal sanction. Legal professionals focus on the precise wording of the law, in particular the identification of the correct SDM and the need for consent for medical decisions. Notably, no stakeholder group appears satisfied with the current system for resolving disputes, but there is also no apparent consensus about a solution.

III. MECHANISMS FOR DECISION-MAKING AND CONFLICT RESOLUTION

In this section, we build on the previous two sections by describing and critiquing the existing mechanisms for decision-making and conflict resolution in Ontario, and mechanisms that exist in other jurisdictions. In particular, we will focus on how these mechanisms attempt to balance the desire to respect the MSOC (or at least the limitations of medical therapies) with the desire to obtain consent (or at least agreement among all stakeholders).

A. How do we currently balance the standard of care with the importance of consent?

In Section 2, we outlined a model for shared decision-making, but also detailed some of the challenges involved in shared decision-making, and some of the perspectives of patients, substitute decision-makers and health care providers on CPR and orders to withhold CPR and life-support. Patients, substitute decision-makers and health care providers are usually able to reach an agreement about the plan of treatment, but this is not always the case.

The CPSO outlines a dispute resolution process for disagreements about life-sustaining therapies in section 8.1 of their “Planning for and Providing Quality End-of-Life Care” policy. It mandates the following approach:

- Communicate clearly, patiently, and in a timely manner information regarding:
 - The patient’s diagnosis and/or prognosis;
 - Treatment options and assessments of those options;

- Availability of supportive services (e.g. social work, spiritual care, etc.); and
- Availability of palliative care resources.
- Identify misinformation and/or misunderstandings that might be causing the conflict and take reasonable steps to ensure that these are corrected and that questions are answered;
- Offer referral to another professional with expertise in the relevant area and facilitate obtaining a second opinion, as appropriate;
- Offer consultation with an ethicist or ethics committee, as appropriate and available;
- Where appropriate, seek legal advice regarding mediation, adjudication or arbitration processes that are available; and
- Take reasonable steps to transfer the care of the patient to another facility or health care provider as a last resort and only when all appropriate and available methods of resolving conflict have been exhausted.¹⁷⁹

Finally, Section 8.2 indicates that in specific situations where a physician and SDM disagree about an interpretation of a wish or the applicability of a wish to a specific treatment decision, the physician is advised to apply to the CCB for a determination.¹⁸⁰

Although this approach would be reasonable in many situations, there are a number of potential concerns with it. Most importantly, it focuses on the goal of achieving agreement; unless the CCB is consulted (and the decision is not appealed), consensus is the only means by which the resolution process can end. Agreement is desirable from a human perspective, but it does not necessarily mean that all stakeholders are meeting their ethical and legal obligations. Either stakeholder may agree to an inappropriate plan of treatment and compromise on important medical or ethical principles simply to avoid conflict, or out of a belief that they did not have the option of disagreeing. Indeed, this is likely a very common event, since both surveys¹⁸¹ and observational studies¹⁸² indicate that physicians frequently provide care that they feel is non-beneficial, and conflict avoidance is commonly cited as a reason for this.¹⁸³ Perceptions among lawyers of an uneven balance of power lead them to suggest that SDMs may also acquiesce to plans of treatment simply because they did not believe that they had other options.

The CCB is also not appropriate for most disputes about life-sustaining measures. The CCB is an administrative tribunal, created under the *Mental Health Act* and given an expanded legal mandate under the HCCA to, among other functions, review the legal

standard of substitute decision-making. The CCB was created to provide a more accessible and expeditious dispute resolution mechanism than the courts, and with strict timelines for commencing proceedings. Due to its creation under the MHA, its membership includes lawyers, psychiatrists and members of the public; its composition wasn't changed nor was its expertise expanded under the HCCA. There is currently no critical care or end-of-life care expertise on the Board.

The CCB's mandate is stipulated by statute (under the HCCA) to include limited powers to adjudicate the specific applications discussed below. It has no role in cases where the patient is capable, or where there is a clear prior applicable capable wish that is supported by the SDM (even if the requested treatment falls outside the MSOC). Nor does it have a statutory mandate to evaluate if treatment falls outside the MSOC. If a capable patient clearly requests CPR or life-sustaining measures (either personally or via prior expressed wishes) that fall outside the MSOC, the CCB could not be consulted. In such a case, without further clarity from statute or the courts, the patient might need to be initiated or maintained on life-sustaining measures indefinitely, regardless of the best interests of the patient and the health care providers' perceptions about the lack of medical benefit.¹⁸⁴

In cases of dispute about life-sustaining therapy, the CCB can have one of four possible roles:

- Application to become a representative of a person who is incapable with respect to treatment in order to give or refuse consent (Form C)
- Provide directions about a prior wish in various situations in order to consider whether the wish is applicable to the present circumstances (Form D)
- Consider a request from an SDM to depart from prior capable wishes (Form E; usually not involving a dispute with the medical team)
- Review SDM's compliance with rules of substitute decision-making (Form G)

In most cases, it is a Form G hearing where disagreements about life-sustaining therapies are brought to the attention of the CCB. Between 2009 and 2013, 23 such hearings were held;¹⁸⁵ sixteen ruled in favour of the medical team's proposal (i.e. withholding or withdrawal of treatments) while 7 ruled against the proposal (i.e. ordering that such treatment be initiated or continued). In the wake of the *Rasouli* decision from the Supreme Court of Canada (which suggested that the CCB could

adjudicate such cases), many expected that CCB consultation would become more common. On the contrary, only 3 Form G hearings were held in 2014 and 2015, a substantial decline.¹⁸⁶

The literature demonstrates that Ontario physicians prefer to avoid the CCB and the courts as a means of resolving disputes about life-sustaining therapy. In fact, a national survey of intensive care providers revealed that 87% of Ontario respondents felt that “our current means of resolving non-beneficial treatment are inadequate”, which was significantly higher than the result from the rest of Canada.¹⁸⁷ While the CCB was devised to be a timely process, in clinical practice the panel rarely schedules sufficient time to hear the evidence in end-of-life cases and hearings need to be adjourned until the same panel members can be reconvened. In the authors’ experience, this once resulted in a delay of a month before the next hearing could be convened. A study of the medical teams who participated in CCB hearings found that although there was some value in going through the process, the benefits were tempered by the time involved and the lengthy appeals process (to the courts).¹⁸⁸ This is very important for decisions about life-sustaining treatments and CPR, where the decision is often urgent and would need to be made long before the CCB could be convened. A conflict resolution strategy should be fair, transparent and feasible, and not create expectations of timeliness that cannot be met.

This leads to another important limitation of the open-ended dispute resolution process outlined by the CPSO. If the process can only end with consensus or with legal adjudication, and the patient could deteriorate at any time, a decision often needs to be taken while the process is underway. And since there is no room to compromise between CPR and “No CPR”, that decision will have to support one side’s position and not the other’s. The CPSO’s policy indicates that the decision to write a No CPR order “...cannot be made unilaterally by the physician”, and if a cardiac arrest occurs while the dispute resolution process is underway, the policy requires physicians to provide CPR unless the physiological goals cannot be achieved. In other words, the focus of the policy is on achieving agreement, but if that agreement is not achieved, it prohibits unilateral decision-making by the physician in favour of unilateral decision-making by the patient or SDM. No clear rationale is provided to explain why one form of unilateral decision-making would be more desirable than the other.

More concerning is the provision in the following paragraph, which instructs physicians to “...act in good faith and use their professional judgment to determine how long to continue providing CPR.”¹⁸⁹ This is a highly problematic instruction to a physician who

has already used his or her good faith and professional judgment to determine that CPR would be wholly inappropriate for any amount of time. Deciding when to start using judgment is itself an act of judgment. It also begs the question of why a physician can use their judgment to withdraw CPR, but not to withhold it. Cardiac arrests are also dynamic scenarios- patients frequently recover their cardiac output for a brief period, only to lose it again. Should each subsequent loss of vital signs be treated as a new cardiac arrest? And of course, this provision could lead to a scenario in which a physician would comply with a patient or SDM’s request for a written “full code” order, knowing that he or she would almost immediately discontinue CPR in the event of cardiac arrest due to an irreversible illness. This would appear disingenuous to any observer, and undermine trust in the health care system.¹⁹⁰

B. What are Alternative Models of Dispute Resolution?

There is generally a strong preference to resolve disputes by arriving at consensus through negotiation or mediation, and approaches to mediating conflict in the ICU have been published.¹⁹¹ Agreement is a desirable outcome, but when agreement cannot be achieved, we have to consider approaches such as arbitration or litigation. These may appear attractive in that they can result in a clear decision, but both parties run the risk of disappointment since they lose control of the outcome.

A recent national survey of intensive care providers sought to determine their agreement with different potential solutions to resolving disputes about therapy that is perceived by health care providers to be non-beneficial.¹⁹² We received the following responses:

Potential Solution	% Agreement
Better advance care planning	92
Improved communication training	88
Communication “outreach teams”	74
Legally-supported guidelines for admission or treatment	74
Public awareness campaigns about the limitations of ICU therapy	70
Committees to resolve cases with binding decisions	61

Although every option was endorsed by a majority of respondents, a few observations are noteworthy. First, respondents appear to prefer mechanisms that rely on consensus methods, such as better communication training and advance care planning. The non-consensus approaches were less popular. Notably, we found very similar results in a qualitative study of senior intensive care providers in Ontario.¹⁹³ This underscores the

strong preference of health care providers to also achieve consensus when possible, and suggests that they would prefer adjudication approaches be only a second-line option. Yet if consensus is the goal, conflicts may not be resolved as consensus may not be achievable.

Few would argue that decisions of this nature should be made unilaterally by one physician.¹⁹⁴ The considerations are complex and not purely medical, and the public would lose trust in the medical system if the process of arriving at those decisions is not transparent and subject to appeal. The CPSM mandates a process that includes a second opinion, and gives the family an opportunity to mount a legal challenge to any withholding or withdrawal of life-support yet it also permits unilateral decision-making on part of physicians if certain conditions are met in well-defined circumstances.¹⁹⁵

Some jurisdictions have opted for an open, binding arbitration process. The *Texas Advance Directives Act* specifies that disputes about withdrawal of life support should be referred to a panel of ethicists, which would issue binding decisions that cannot be appealed in the courts.¹⁹⁶ This approach has met with a mixed response from members of the medical and bioethics community.¹⁹⁷ Some have lauded the Act for the timeliness and transparency of the decisions. Others have concerns about the fact that it does not allow for judicial oversight and appeal, or that the panel has no physician members to provide expertise and skill in evaluating the MSOC considerations and challenging the claims regarding the MSOC specific to the patient's situation.¹⁹⁸ Another approach is that of the Court of Protection in the United Kingdom. The function (and limitations) of this approach were reviewed in the legal section above.

One review suggested the option of a judicial "shadow" to guide extrajudicial solutions.¹⁹⁹ This would involve the courts providing written opinions on some exemplar cases that would indicate to all parties how such cases would be handled by the courts, so that the same decisions might be implemented by the CCB or another hypothetical adjudicative body. This would permit judicial guidance without the delays and expense involved in an actual referral to the courts. However, as was shown in the first section of this paper, legal decisions usually hinge on specific details of each case, and so it may be challenging to decide which exemplar case to apply in a specific conflict. The shadow guidance would need to include many examples of different cases that could become subjects of a court case, and be very nuanced to avoid misunderstandings or generalizations.

Some have called for an adaptive response to decision-making, to match the preference of the substitute decision-maker.²⁰⁰ But this approach does not necessarily address concerns about violating the MSOC; some substitute decision-makers would want to have decisional authority over even technical medical decisions, such as the type of antibiotic used to treat an infection.²⁰¹

C. How can we discuss this Issue Constructively among Stakeholders?

Discussions of these complicated issues in the public forum can easily escalate into emotional and bitter discussions about the value of life in general, and concerns about how our society treats the vulnerable and the elderly. For this reason, many stakeholders choose to avoid these issues, as they are politically very controversial. This carries the risk that the resulting policies and legislative solutions may not benefit from the multiple inputs that are necessary to construct an appropriate framework. Unfortunately, our review of the literature and our qualitative research were not able to identify a useful approach for addressing this issue.

D. Summary and Conclusion

In this section, we built on the previous 2 sections by describing and critiquing the existing mechanisms for decision-making and conflict resolution in Ontario, and mechanisms that exist in other jurisdictions.

Our current mechanism for resolving disputes is focused primarily on achieving “agreement” rather than ensuring that the decision respects the MSOC (or at least some medical standard) or than ensuring it reflects patient values. Agreement is desirable, but it does not necessarily mean that all stakeholders are meeting their ethical and legal obligations. Ontario’s CCB has been suggested as an adjudicative method for dispute resolution, but the legal mandate of the Board is very limited in these situations; it could not be used to resolve many disputes, and in practice it is almost never used for this purpose.

Concern has also been expressed about the time required to engage in dispute resolution mechanisms. Since these disputes typically occur for patients who are deteriorating, the patient often dies or requires life-sustaining measures before the process is concluded. In Ontario, physicians are now required to provide CPR and most life-sustaining therapies if required while dispute resolution processes are underway. This means that the question underlying the dispute- whether or not to provide CPR or

life-sustaining measures- may be decided by the rules of the dispute-resolution process itself rather than any consideration of the respective roles of the MSOC and consent.

There is a strong preference among all stakeholders to use consensus approaches to conflict resolution when possible, and unilateral or adjudicative processes are less popular. Nevertheless, Manitoba and Texas have adopted non-judicial mechanisms for resolving disputes and withholding or withdrawing life support in situations where agreement or consent has not been achieved. Such mechanisms may offer more timely forms of dispute resolution. Others have suggested different models of providing judicial input into these decisions.

IV. ISSUES AND SUGGESTIONS

In this final section, we compile some of the key points and concerns from sections 1-3, and suggest policy approaches to address these concerns when possible. As a general comment, we feel that it is unlikely that we will ever develop a “perfect” model for decision-making and conflict resolution, or even one that everyone will find acceptable. This issue involves multiple complex factual, emotional, cultural and philosophical considerations, and disputes are common even in parts of the world that are much more culturally homogeneous than Ontario.

The law has provided some clarity for approaching these decisions, but large gaps and “gray areas” remain. Case law is helpful at times but heavily dependent on specific statutes and the facts of each case, which limits broad interpretation. Our current model of shared decision-making can work well, but it is unrealistic at times because it relies on key factors that are often missing in practice. Stakeholders frequently fail to approach these decisions through a rational analysis of facts and values. Patients and SDMs often fail to appreciate the severity of illness and the limited effectiveness of medical therapies in advanced illness; SDMs are poor at representing patient values; physicians often fail to communicate effectively, and fail to define a clear MSOC.

However, even if we cannot achieve a perfect solution, all stakeholders have an obligation and an interest in improving our current system. Incremental improvements in multiple aspects of our process of decision-making and dispute-resolution could lead to a dramatic improvement in outcomes for all stakeholders. This would be more realistic than seeking to adopt radical changes.

Once again, the focus of this project was specifically on balancing the interests of patients, substitute decision-makers, family and health care providers in decision-making over the withdrawal and withholding of life-sustaining treatment. Our suggestions are focused on this area specifically. The authors have tried to avoid generic or ubiquitous recommendations (e.g. “promote advance care planning” or “better communication”) that are found in other reports addressing broad limitations in end-of-life care.

Issue #1: Patients and SDMs often have a poor understanding of issues relevant to decision-making around CPR and life-support. This is due to:

- Poor communication by health care providers about the patient’s illness and prognosis
- Unrealistic patient and SDM expectations of prognosis and treatment effect
- Poor preparation of SDMs to fulfill their role

Suggestion: Emphasize the importance of communication regarding life-sustaining treatments and CPR as a professional obligation for practicing physicians, and a core component of training for future physicians.

Suggestion: Normalize and mandate the systematic use of advance care planning efforts that are tailored to the specific situation of the patient,²⁰² including a frank discussion of illness and prognosis, and the likely effectiveness of treatments including CPR and life-sustaining measures (and how this changes with advancing illness). Existing experts (including Intensive Care Unit health care providers) should be employed to discuss this issue with patients and SDMs in situations where communication has broken down or prognosis is unclear. We should not consider patients or SDMs to have given consent to a plan of treatment until these events have occurred.

Suggestion: Advance care planning discussions should always involve at least three individuals- the patient, the SDM, and a health care provider well trained to prepare the SDMs for their role by ensuring they are informed of legal standards, the roles and responsibilities of substitute decision-making, and some typical future decisions that they might have to make.

Issue #2: The Medical Standard of Care is poorly defined in general and rarely explained in practice.

- The MSOC is defined inconsistently among health care providers, particularly in regards to the potential “benefit” of a treatment in individual cases. There is a lack of clarity in general regarding the purpose of medicine and how this

interacts with the medical standard of practice (the “medical standard of practice” is distinguishable from the MSOC and both are explained later in this report).

- Even when treatments are felt to lie outside the MSOC, health care providers are not clear about whether they need to be discussed and offered to patients and SDMs.
- The MSOC has not been clearly raised as an issue in situations of conflicts with SDMs and both SDMs and lawyers are unclear regarding its role in decision-making and in conflict situations

Suggestion: A multi-stakeholder process (involving medical, ethical and cultural considerations) should be convened to establish a MSOC for life-sustaining measures, including CPR. This process should also develop explicit standards of practice for when and how the MSOC should be explained and specific treatments should be offered or discussed with patients or SDMs.

Suggestion: Enhanced education at the undergraduate, postgraduate and continuing educational level regarding the MSOC, and its relationship with standards of consent and decision-making.

Issue #3: Ontario’s current mechanisms for conflict resolution are ill-suited to resolving most disputes about CPR and life-sustaining treatment. This is because current mechanisms:

- Focus on achieving “agreement” among all parties rather than ensuring that the treatment plan reflects both patient values and medical realities regarding prognosis and treatment effectiveness.
- Make reference to the Consent and Capacity Board (CCB), which does not have the mandate or expertise to resolve many disputes about CPR and life-sustaining therapies (e.g. where the patient is competent, there is a clear prior capable wish, or there is a dispute about the MSOC for end of life treatment options).
- Can include lengthy appeals and a delay in access to justice, meaning that patients will often deteriorate and (according to current policy) receive CPR or life-support before the issue is resolved. Once life-support is initiated, it cannot be discontinued without consent. This also discourages the use of “trials” of therapy in situations where the potential effectiveness of life-sustaining measures is unclear. A decision to engage in formal conflict resolution, due to the length of this process, is effectively a decision to provide CPR and life-support- the same outcome as if the health care team had simply acceded to the patient or SDM’s request for life-support in the first instance.

Suggestion: In the event of conflict regarding the MSOC in end of life situations, clarify the *HCCA* to require greater timeliness and expertise in end of life care within the CCB or within any new conflict resolution mechanism that may be created to establish a conflict resolution mechanism that is transparent, responsive, expert, and considers both patient values and medical facts in arriving at timely, binding decisions about the use or non-use of life-sustaining measures. To ensure timely legal oversight, we may consider a hybrid approach to decision-making, including local adjudication boards (e.g. a modified CCB tribunal or even the regulatory college) guided by an explicit MSOC and/or a “shadow” judicial guidance (e.g. where an authoritative judicial body will give sample written rulings on a series of exemplar cases to guide local adjudication boards on real cases). The CCB could otherwise continue to speak to issues of capacity, consent and substitute decision-making, but include critical care expertise for such cases. Any processes should have a “fast track” access to courts with a clear timeframe for decisions to allow rapid resolution of any appeals.

Suggestion: Explicitly define the standard of practice to include the use of “trials” of life-sustaining therapy for situations of genuine uncertainty about prognosis or expectations of treatment. If the trial is not effective, and further life-sustaining therapy would be outside the MSOC, health care providers should be permitted to withdraw life-sustaining therapy (see Issue #4 below).

Issue #4: There is a lack of clarity about which treatments or treatment plans require patient or SDM consent.

- The Ontario *Health Care Consent Act* is not explicit about the treatments and treatment plans that do not require consent, which leads to inconsistent or overly literal interpretations about situations in which consent is required to withhold or withdraw CPR or life-sustaining measures.
- The current College of Physicians and Surgeons of Ontario policy functionally establishes CPR as a “default” treatment that must be provided unless the patient or SDM gives consent to have it withheld, even if CPR would be considered outside the MSOC. This is a unique double standard in medicine, which can lead to problematic situations at the bedside.

Suggestion: Clarify the definitions in s. 2 (1) of the *Health Care Consent Act* to formally eliminate the requirement for consent to withhold or withdraw treatments outside the MSOC, including CPR and life-sustaining treatments when appropriate. Furthermore, the medical criteria of “best interest” (s. 21 (2) (c)) should only be engaged when decisions are being made among treatment options that fall within the MSOC in the first place.

Suggestion: Discourage the resolution of disputes on the basis of interpretations of unclear statutory wording. Decisions and policy modifications should be based on foundational legal principles that serve the public best by promoting better decision-making for all stakeholders.

Appendix A – Qualitative Research Methods and Data

A. Qualitative Research Methods

Focus groups and semi-structured interviews were used to address the research questions among substitute decision-makers (SDM) and members of the legal community. Focus groups offered the advantage of exploring the participants' beliefs, views, and experiences, leveraging the social interaction among them to elicit shared experiences and cultural norms. Semi-structured interviews also explored participants' beliefs, views, and experiences, yielding more extensive and nuanced information about the individual. While focus groups were scheduled far in advance, interviews were more flexible adapting to research participants' schedule.

We relied on purposive sampling strategy to recruit focus group and interview participants between May and June 2016. TGH's Research Ethics Board approved the study, and all interview participants provided informed consent. We tapped into TGH's Patient Partner Program and Virtual Patient Focus Group to recruit a diverse pool of substitute decision-makers for the focus groups. We approached these groups because they have had experience with the health care system and had expressed an interest in being involved in providing their perspective on aspects of health care. Given the accelerated timeframe of this project, it was more efficient to approach the groups who have pre-indicated a willingness to participate, and simply acknowledge the potential bias that this would introduce than open the recruitment more publicly. We believe that any recruitment strategy would have introduced some potential bias.

Purposive sampling with criterion and snowball techniques were used for the recruitment of legal community members. We aimed to include chairs of the CCB, lawyers whose practice involves health law cases heard by the CCB or the Ontario Superior Court, and judges from the estate list.

Focus group sessions and interviews were conducted using an interview guide (available on request), audio-recorded and transcribed. NVivo Qualitative Software was used for data management and storage. We coded the transcripts inductively and iteratively following interpretive analysis, and recurring themes were identified.

B. Data and Results

We conducted two focus groups with a total of 8 substitute decision-makers (SDM; Appendix Table 1), following a semi-structured interview guide. Each focus group lasted 2 hours. We also conducted a semi-structured interview with an SDM who volunteered for the study but could not attend any of the focus group sessions. The interview followed the same semi-structured interview guide as the focus group, but only lasted an hour.

We conducted semi-structured interviews with 11 members of the legal community (Appendix Table 2). These were all conducted in person and lasted on average 57 minutes, ranging between 20 to 100 minutes.

The main themes from the legal interviews are provided in Appendix Table 3, and summarized in the main text. The main themes from the SDM interviews are provided in Appendix Table 4, and summarized in the main text.

Table 1. Substitute Decision Makers' Characteristics (n=9)

Characteristics	Value
Female	6
Age, mean	53 (range from 23 to 65)
Race/Ethnicity	
White*	7
Black	1
Asian	1
Arab	0
Latin American	0
Aboriginal	0
Religion	
Christian	3
Jewish	1
Muslim	0
Hindu	0
Buddhist	0
Sikh	0
Non-religious	2
Not reported	3
Substitute Decision Maker	9

Table 2. Legal Community Members' Characteristics (n=11)

Characteristics	Value
Female	5
Age, mean	52 (range from 36 to 64)
Race/Ethnicity	
White*	9
Black	1
Asian	0
Arab	0
Latin American	0
Aboriginal	0
Other	1
Religion	
Christian	3
Jewish	4
Muslim	0
Hindu	0
Buddhist	0
Sikh	0
Non-religious	3
Other	1
Professional Role ^x	
Patient Lawyer	9
CCB Member	2
CCB Chair	1
SSC Chair	0
Other	2

N.B. Some of these legal interview participants play or have played several professional roles, depending on the case, which they reflected on in the interviews.

Appendix Table 3

Name	
LEGAL	
1 CHALLENGES	
FAMILY	
Families are Emotional	<p>I say the people that are affected most by this are typically substitute decision makers and of course the incapable person... Families are always going to be very emotional at these times, there's no doubt about that. And that all has to factor into all of this.</p> <p>When we talk about who's got the most skin in the game, who's got the most in this, these people. It's the incapable person, the substitution decision makers.</p>
HEALTH SYSTEM	
Physicians' Limited Communication	<p>I think one of the reasons families and doctors get into this big disagreement is because there's no good communication. And I think that sometimes the doctors are really good at being doctors but they don't have a good bedside manner, they don't know how to communicate.</p> <p>Doctors haven't done a good enough job, either substantively or in some cases procedurally, of explaining why they are proposing what they're proposing.</p> <p>Sometimes we see the conflicts arise, because the patient and the substitute actually don't know their condition. They haven't been given the full information, and I'm going to say that the health practitioners think that they have communicated, but there's no communication taking place, so people don't know what their condition is. They don't know what the real options are. They're not always told all the options. They're basically told this or that.</p>
Physicians Misunderstanding the Law	<p>They're not making sure it's the correct substitute, if it's a substitute. They -- often the family members will -- or whoever bring the person in -- may not be the person with legal authority.</p> <p>Physicians, nurses, it doesn't matter who you are, they do not understand <i>Health Care Consent Act</i>; they do not understand consent...On questions of consent and capacity and how those are utilized in end-of-life issues, whether they're getting consent from the correct person, whether they're getting consent at all. In the health profession there's a huge problem about not getting consent.</p>

	<p>I run into the same problems with prior capable wishes because, and I haven't done a study on it, but my impression is that where the prior capable wish or the alleged or asserted prior capable wish is to withdraw or withhold treatment, extraordinary efforts are made to reason that it's applicable in circumstances. Whereas if the prior capable wish or purported prior capable wish is to give all treatments, extraordinary efforts in reasoning are made to say that well, it's not applicable in circumstances.</p>
<p>Health Care's Resource Constraints</p>	<p>Sometimes I've come across situations where I pick up, or I detect that the health care practitioner might be doing a bit of a cost benefit analysis. Trying to also kind of look through that piece, because that's not what I, as an adjudicator, should be considering.</p> <p>I'm not saying that the regional care is not excellent, but I'm just saying that it's a lot harder to ask for a second opinion in Gravenhurst or in Kenora or in Sue Saint Marie or North Bay or in some regional hospital than it is to ask for a second opinion if you've got a client at the Toronto Western Hospital. That's really about the fact that resources are different in different parts of the province.</p> <p>I mean obviously I know for the physician, the health care practitioners, time is limited, they're under a ton of pressure, all of these matters are time sensitive.</p>
<p>LEGAL SYSTEM</p>	
<p>Litigation is Expensive and Long</p>	<p>The cost of litigation is ridiculous. Unless you've got bags full of money that you want to just throw in principle at something, it doesn't pay, and most people aren't in that situation.</p> <p>You know, if it takes a week or two weeks to get to the Consent and Capacity Board, too bad. If it takes six months to get to the end of the appeal system, that's a legitimate complaint.</p>
<p>No Appropriate Physician Expert at CCB</p>	<p>So the CCB is supposed to be an expert tribunal but they're an expert in psychiatry. And they're still doctors and I'm sure they have some experience because they've done other cases, but they don't know anything about that area of medicine. So I think that's the problem.</p>
<p>Power of Attorney Document Not Explained to</p>	<p>I mean one of the problems is that –and hopefully this is changing, but lawyers used to do some like boilerplate power of attorneys for personal care that already had advanced directive in it... But often I think that wasn't really brought to public attention. Or people can</p>

<p>Families</p>	<p>change their minds later, but mostly I don't think it wasn't necessarily brought to people's attention, and the attorney signed it thinking that the power of attorney is basically just saying okay, my son is going to make decisions for me if I can't.</p>
<p>UNEVEN POWER</p>	<p>Obviously there's an access to justice issue, because most people can't afford to go out and hire a lawyer to go through the process.</p> <p>I think the CCB often is very medical-model pro doctor. I think there is a built in bias of some sort against families and patients. And it might not be a bias per se; I think maybe it's a power imbalance. Like the doctor shows up at the hearing and he or she is an expert. They can already give their opinion to families, but families, unless they have money, are not going to have their own expert. They are stuck with me.</p> <p>Physicians have a very special relationship that requires the utmost trust and good faith in dealing with their patients or the substitute decision makers because of the imbalance of power and knowledge.</p>
<p>REPRODUCTION OF THE SYSTEM</p>	
<p>Letting the Families Tell Physicians What to Do</p>	<p>But then we see physicians not ever wanting to go before the board. I had a person say to me, "We just concede to the substitutes rather than go to the board, even though we think it's totally wrong." And I'm shaking my head.</p> <p>The doctors who think you need consent for everything, and some physicians who think I have to do what the family says, misunderstand the Rasouli case, misunderstand the Health care Consent Act, and misunderstand their obligations to their patients.</p>
<p>Differences in Advocacy</p>	<p>if I'm retained by the substitute decision-maker, my goal is not to do what is – I'm not instructed to do what's in the patient's best interest. I'm instructed, "Don't let them kill grandpa."</p> <p>I'm not acting in your best interests. I'm acting according to your instructions. That's the lawyer's job. So when my substitute decision-maker client says to me, "Keep grandpa alive," they're not saying it's in dad's best interest to be kept alive. They're saying "keep him alive."</p>

	<p>They don't want me to argue with them. They want me to keep grandpa alive.</p> <p>So for example, if the substitute decision-maker retains me and says, "Keep my father alive," then here is my answer. "Okay. I've looked at the case. I think you're going to lose. It will cost you \$10,000 in legal fees to lose at the Consent and Capacity Board. It will cost you another 10 to \$15,000 to appeal that decision and lose at Superior Court, but that will buy 1 to 3 months. And then, it will cost you a further \$30,000 to lose at the Court of Appeal, and that will add another 2 to 6 months. How much do you want to spend on grandpa's life?"</p> <p>And I need to be that cold-hearted and that crass about it so that they understand what the prospects are, because people are coming to me with the belief that the health care system is trying to kill grandpa for no good reason, and I don't wish to mislead them. Because they will hear – they will frequently not hear what I say in any event, but my obligation in these cases, I think, is to be harsh to the extent necessary to convey the message that this is probably not a successful case. You're paying for delay. And from the doctor's perspective, of course, well, now we've got grandpa for six more months of torture, as we work our way through the appeal system, the courts need to figure out how to expedite that to re-enhance the physicians – and just, by the way, some of the lawyers who represent those physicians, because there are some lawyers who are highly critical of how long the process takes, and with some legitimate observation.</p>
<p>Strategies for Client advocacy</p>	<p>So strategically, even if your case doesn't have a lot of merit, even if you think you're going to lose your appeal there might be strategic in appealing it to the Board of Appeal, because it's going to take the time. It's probably going to take about six months to do all of that. And I don't know, I guess it could be done quicker if everyone's trying to really move it</p>

	<p>along. But it's going to take a few months. Strategically it may be of value to the family.</p> <p>And then at the Supreme Court, I mean you have to ask for permission, right? There's a no automatic right of appeals at the Supreme Court. It gets thousands of petitions every year and every year for the [different] cases. But just the process of asking for permission takes time.</p> <p>an appeal acts as a stay. So that adds more time, so if a family member wants to keep a relative alive and the board renders a decision against them, why don't they just file an appeal? And until that appeal is heard, the treatment cannot be withdrawn</p>
<p>2 MSOC</p>	
<p>MSOC Not Found In EOL Cases</p>	<p>In all the cases I have litigated or adjudicated, I don't think Standard of Care was ever argued by a physician.</p> <p>We use standard of care usually in law for negligence. But that's different I think from what you were talking about.</p>
<p>MSOC Can Be Interpreted in Multiple Ways</p>	<p>If you were looking at, especially when you're talking end of life, you're going to get opinions all over the map. And so the problem is that there really isn't agreement on a lot of things, and so what one clinician will tell you, another clinician will have an exact opposite opinion. So his is nice to say but I'm not sure that it has much meaning to it at the end of the day when you're talking about specific situations.</p> <p>I don't think there's a medical consensus, especially if you look at it globally. Like maybe if you look at Toronto, you get a lot of doctors but if you start looking across jurisdictions and different cultures...</p> <p>So, when you use words like "reasonably" and when you use words like "help" and when you use words like "disproportionate risk of harms and side effects," in whose estimation? Like from what perspective is that coming?</p>
<p>Rift Between MSOC</p>	<p>MSOC just gets you up to the point of whether to offer treatment. It</p>

<p>and the Law</p>	<p>doesn't go into what comes after, which might be consideration of prior capable wishes, consideration of values and wishes of the individual if they can be obtained,</p> <p>And I think part of the problem is that when it comes to end-of-life care medicine is not the only consideration...It's really a fraught issue. I guess I don't think it's purely a medical issue... So I think their cultural, religious, personal – even just a personal sense of where do you draw the line?</p> <p>Not only the standard of care but the law of course requires an informed consent, requires discussion of the alternatives. And therefore it's a very live question whether informed consent can be obtained when the alternatives are not discussed regardless of the fact the alternatives may not be consistent with the standard of care.</p>
<p>Disagreement about Not Offering Treatment</p>	<p>Health practitioners have the right not to offer something to meet this standard. And that's their professional role. They don't have to offer anything.</p> <p>It's simply within the purview of the physician, and I think in terms of what you offer I think that you should offer all the options that are available. If the doctor has an ethical conflict I think they still have an obligation to have someone find the option that they want.</p>
<p>Disagreement about Protection Under MSOC</p>	<p>Standard of care should protect patient rights, if the standard of care is adhered to effectively.</p> <p>It is protecting patient rights when it is really explaining to people the information that they are entitled to have. And this protects both the health practitioner and the patient and the substitute. This is the basis.</p> <p>I think the law offers protection for the rights of these patients. The standard of care offers treatment for these patients. I don't think the standard of care required of health care professionals is a means by which patients are protected. So, it's a good thing but not for that purpose.</p>
<p>Tension Between MSOC and Requesting Treatment</p>	<p>I think there is a tension in some cases. ... I think there's a tension when there is either ambiguity in terms of the SDM knowing what the patient would have wanted, and there's definitely a tension when the health care practitioners try to apply the standard of care and it conflicts with what the patient would have wanted. SDMs don't have - they're not adhering to the standard of care. They're just adhering to that health</p>

	care directive and they don't have the scientific knowledge you have that's based on medicine and clinical experience to really draw on.
3 CONSENT	
Disagreement around Decision-Making	<p>I don't have a problem with physicians saying that certain things are their decision and not the decision of a substitute decision-maker, as long as the SDM is not being bushwhacked, ambushed, and as long as if there is any significant disagreement, it gets adjudicated instead of the SDM being overrun.</p> <p>Physicians do not make decisions, they propose treatments. It's the law. Transferring the responsibility to the physician I think is wrong. I think ultimately it is the responsibility of the substitute decision maker.</p>
Consent is Needed, Assent is Not Legal	<p>I don't think assent is – you've got to get consent. That's what the law says.</p> <p>You need consent for treatment whether you're withholding or withdrawing.</p> <p>I'm not sure that it fits within a legal framework at all. And it feels like a bit of a cop-out to me of the physician's responsibility to get informed consent from the patient.</p>
4 IMPROVEMENTS	
FAMILY	
Acknowledging that Families Are Relational	<p>Not just the individual. I don't know if we're just made up of ourselves, but we are a combination of all of our experiences. You're not making a decision just for me. You're making a decision for all these people who are closest to me. I say philosophically, we consider what the wishes of the individual are, then I think we have to include the love they have for their family, and how they would want their family to feel as part of their wishes and part of who they are.</p> <p>The substitute is doing this because they're grieving, and they feel that mother liked you more, so I'm going to have to defend her. There's lots of that social stuff around this,</p>
Educating about Substitute Decision Making	<p>I think it would be nice if people were counseled to be more thoughtful about who their substitute decision makers are and were counseled to have more realistic understanding of what some of the decisions will be that have to be faced, and have had more discussion with their substitutes, their doctors about the kinds of situations that are going to arise.</p> <p>As a health practitioner you not only have to get consent but you have</p>

	<p>to advise the person this is how you make a decision, then it's all set out. And it's as simple as you can photocopy the sections from the Act and put it on and say here it is. You go competent wish. If there's no competent wish, you go to best interest test.</p>
HEALTH SYSTEM	
<p>Communicating Better with SDMs</p>	<p>Giving someone the knowledge is empowering. Letting them know that you don't have all the answers, that you could be wrong. And you would hope for them that you were wrong, but when it comes right down to it you don't believe you're wrong. But if they believe you are, then by all means, you won't feel offended as a physician if they were to apply to the board, to do everything to assist them. And I think sometimes that goes a long way with families.</p> <p>I say all this stuff is much earlier in telling people about their actual health and giving them the information about this so they really know their condition. Because when we're really at the end of life in those tough ones, that's a bad time to start that understanding. That's why I think it's got to start earlier.</p> <p>One needs to be careful in how that encouragement happens, because encouragement can fall into coercion quite quickly. For example, is it encouragement to tell a patient that if we continue to treat mom she will be in pain and agony and blood will start pouring out of her various orifices? Is that an attempt at a conversation or is that coercion? Is that making it worse, in order to achieve that result, and what's the appropriateness of that and how far should physicians go, I ask, in trying to convince a family that it's not appropriate to continue measures to prolong life</p>
<p>Educating Doctors About Decision-making and Consent</p>	<p>The physicians and nurses and whomever else is involved in this have to go back and have to know what the law is that relates to their practice. I mean there should be mandatory training.</p>
<p>Integrating MSOC With the Law</p>	<p>I think it's important to remember that physicians don't know anything about their patients beyond what their physical status is when it comes to seeing them. They don't know anything about who they are as a person. The family knows that, and that's why the Health care Consent Act balances that. Like when you're looking at what is the best interest, they balance it out with values and beliefs, which is something that the family will know more about usually, versus like some more medical explorations, which is what the doctor knows.</p> <p>As long as it integrates what a doctor should be proposing with what the rules are in the Health Care Consent Act, then that's a great start.</p>
LEGAL SYSTEM	

More Mediation	<p>I've been making submissions on changes to the Consent and Capacity Board processes, through the mental health legal community. I've asked them to consider more mediation options. I think that's always helpful because often some of them might be resolved by a conversation like this.</p> <p>When I am dealing with a family I try and get them back to the facility and the physicians and try and encourage a team meeting, so that there can be an open dialogue and a reflection of concern. Sometimes people are so bitter, so upset that that's not option, and you kind of have to size that up as you're moving along.</p>
----------------	---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

Appendix Table 4

Name	
SDM	
1 CHALLENGES AS SDM	
Limited Discussion of SDM	<p>My mom, a long time ago, when she updated her Will, her lawyer suggested that she also do the Power of Attorney and also the Power of Attorney for health, so there's a financial one and then the one for health. So I understand within that context, but not that I've recently had a conversation about it.</p> <p>For us I don't think there was any – my sister did have some papers done but doctors or health team I don't think that they participated or even mentioned anything like that.</p>
How the SDM Definition Should be Communicated (see vignettes)	<p>Probably option one I think from my perspective, because it lays it out a little bit better. So when I make these decisions about the treatment they're offering, they're saying specifically whether it is going to improve your wife or husband state. So I will keep it in my mind based on the treatment or what I'm seeing make that decision. That's one checklist, go to the next one and do it. As</p>

	<p>opposed to the second one that's kind of just a blurb but doesn't really get into the nitty-gritty.</p>
2 DECISION-MAKING	
Decision-Making is Relational	<p>My mother's in a dreadful state and she's there again in that role, and it's hard to balance it because it raises all kinds of things about your relationship with your siblings, your relationship with the person you're making decisions about and you don't recognize that at the time as you struggle to do the right thing.</p> <p>And I feel that sometimes you're not the only person who makes the decision, it's like a group decision. Not just one person would like to make that decision, but within consultation with the whole family or everybody who is part of this person's life will give some input. Some people might think this is better or some people think the other is better, it's hard to find balance to accommodate everybody's wishes. And in the end you want to respect the patient's final wishes and stuff..</p>
Patient Considerations in Decision-Making	<p>But I think what I found was dealing with seeing my mother in pain. It was disturbing to me to see that she was suffering. As a decision maker, I'm sure that impacted my thinking or ability to think, witnessing the uncomfortable, stressful situation for her made it more stressful for me and for my sister.</p> <p>I don't know how many times my mother has said, "If I go to sleep and die, I've had a great life, I am exhausted by trying to stay alive, I don't want to be here anymore", and then they get to the point that they can't articulate that but you know because it's been talked about before.</p>
Disagreement about Physicians' Decisional Authority	<p>I guess at the end of the day; I probably side with the doctor. I probably rely on the</p>

	<p>doctors by their conclusion or final advice.</p> <p>Because of white coat syndrome, I think very often there is a universal sense of, “I can’t because who they are and who I am”. We like to think we do, we like to think in more modern evolved times we would. I think 90% of the time I would just believe it. I would sit there and listen to what they said and, “Okay.”</p> <p>I’ve seen it from the medical side and how the doctors made decisions or how they didn’t inform us and how others did it differently. And ultimately, I don’t want the medical community making the decision for me to a certain point either. So I’m going to make the decision for me.</p>
<p>3 EMOTIONS</p>	
<p>Disagreement about Decisional Responsibility</p>	<p>We kind of came to that conclusion on our own but there was no major discussion from the doctor with us to explain all that. That would have been helpful because we felt terribly guilty. It’s a big responsibility for a family member to take on.</p> <p>It seems that a human being has a right to be informed of that if they are taking this incredible burden on. It’s like power of attorney is a burden, it’s not something that anybody wants.</p> <p>I consider it a privilege actually.</p>
<p>Families are Emotional</p>	<p>For me it was difficult to see someone dying that I care for and I wondered and asked – it was very emotional of course and painful.</p> <p>So then there’s all the guilt issues involved for the family member. Am I making the right choice?</p> <p>There’s always a hope that some miracle is going to happen, that this doesn’t need to be the end. This decision doesn’t need to</p>

	<p>facilitate someone dying. And yet it's the balance of that with the rationale watching someone you love in pain, knowing that there really is no hope for the kind of life, kind of quality of life that you know that person would want.</p>
<p>4 FAMILY-PROVIDER COMMUNICATION, RELATIONSHIP</p>	
<p>Physicians' Limited Communication</p>	<p>I felt kind of lost and in a way I was a primary I guess with certain things. So I never even got to talk to a doctor and that kind of alarmed me.</p> <p>And it's the shuffling in, it's the over verbiage that's medical and not human.</p> <p>There has to be compassion, I find that she was not shown compassion whatsoever or – and I felt that she was just left out because “Let's move to the next person, that's it, this is the end”.</p>
<p>Rationale for Physicians' Limited Communication</p>	<p>I think there is an armor that you wear just to that you cannot get destroyed by each and every case that you're pulled into.</p> <p>I know the doctors are very busy but still I felt it would have been nice if the doctor had talked to me even though I got in late.</p>
<p>Need for Better Communication</p>	<p>I think most everything comes down to one basic thing, it's communication and I think people at this point are hungering for really honest fair communications, look me in the eye you know tell me here are the options, this is what we can do and this is what can't do, how can we best help the family.</p> <p>So especially in a situation if somebody's dying or they get – there has to be sometimes compassion because compassion is very important and knowing that this person really cares.</p> <p>But I think also what is exactly the cause or condition of that person, is there anything really that can be done, and how can we</p>

	<p>make sure, trust the decision that what they've given us. Considering they did explain everything they've done and is there anything or there's nothing else, then if the trust has been established and I think that if they did explain everything and they took that moment to kind of discuss it with us then it would be easier to make a decision to withdraw.</p> <p>But when you get that honest communications and it's not going to be the result that you want, I mean I don't think people die with dignity unless you're on the golf course and you have a heart attack, then that's it. But you can die with some humanity you know and that comes from people treating you and your family like real people in this terrible situation, inevitable situation.</p>
<p>5 MSOC</p>	
<p>Vague Understanding of MSOC</p>	<p>That there's sort of a baseline or threshold about how we treat human beings. So we're not going to stick them on a gurney in the hallway, we're going to put them in a bed, we're going to feed, change or clean or keep the body nice or presentable, if they need oxygen they need oxygen, if they need this or need that. There are some basics, I can't list them all, but there are some sort of known basics if you're a doctor, and alleviating suffering is somehow in there.</p> <p>I don't know what it is to be honest. Unless I go and look it up.</p>
<p>Protection of Both Physicians and Patients Under MSOC</p>	<p>I think it protects physicians. I think it protects patients, but you've always got that same issue. You've got a question of whether or not something was the standard and whether the care met the standard. So there's always going to be that grey around interpreting, both the standard and the care,</p>

	<p>which complicates things.</p> <p>It's definitely drafted by a lawyer to make sure that they don't get sued.</p> <p>I would think that if a patient presents with certain clinical factors then the physician is duty bound by that standard of care to present this list of treatment options and so to that extent the physician isn't again in a position to have their own values influence or limit or narrow or for that matter expand what care services they're offering.</p>
<p>No one Knows What's Beneficial, Noone Knows When People will Die</p>	<p>And I know that nobody knows 100 percent in most cases what's going to be beneficial, what's exactly happening. For example, Paul had mentioned his mom had dementia. I read into Alzheimer's – nobody knows until after the person had passed away anyway what was really going on. So there's always an element of doubt there..</p> <p>There is no ability to be god in this relationship whether you believe in a god or not, there is no ability for anybody to know. For example, my mother was supposed to – we were told once she was going to die 8 years before she did. Nobody really knows. There's a standard where we know things are very close but 8 years is a long time. And I think misdiagnosis played a part. So we aren't divine beings with an absolute god like power.</p>
<p>Asking for Explanation</p>	<p>I don't think I have a problem with asking. I would expect the doctor to have a more fulsome discussion about – "I understand why you might want to do this but let me explain why I think this is very harmful."</p> <p>that's a possibility to ask, but at the same time, it's definitely the responsibility of the medical team to help that person understand why that will not necessarily be the decision to follow.</p>

6. DISAGREEMENT ABOUT ASSENT AND CONSENT COMMUNICATION (comments refer to 3 vignettes given to patients, describing approaches that ranged from asking for consent to giving assent for a medical decision)

And so number one I think contains the key messages, “We’ve done what we can, we don’t think we can do more, do you give us the consent”.

So I take that as I’m giving full authority to the doctor and it’s out of my hands...Okay, I’m not sure that I could – that would sit well with me. Again, the team approach and hopefully by then I would just give the consent.

“Oh we’re going to bear the burden together”, bite me. I know you have feelings, don’t get me wrong but – and I know when you go home tonight I know you will feel bad, don’t get me wrong either, but we’re not bearing this burden in the same way. So that sounds insincere to me. So that’s my thought about number three. So number two was kind of the same thing, there’s just fewer sentences.

And if you can’t make the decision, we will bear that burden and make the decision for you. So what you’re asking me in option three is telling you that. It’s communicating what the law is and they are going to take on the burden for you if you can’t take it.

In a situation where you’re very ill or a family member’s very ill, you’re going to be overwhelmed. Option one doesn’t to me, it almost led you into agreement. Option three while it bears more of a burden on the family I think, at least you have the choice of like passing this burden onto someone else or owning it - I would want my family member to get option three.

I definitely prefer option three. It also seemed to be more of a partnership. I kind of like the idea. I mean suffering is a big deal but I also – I like the idea that if somebody feels that more needs to be done that that can be done.

<p>7 CONFLICTS BETWEEN PROVIDERS AND SDMS (comments refer to 3 vignettes describing (1) no conflict resolution, (2) in-hospital conflict resolution, and (3) adjudication through the Consent and Capacity Board and the courts)</p>	
<p>Preference for In-Hospital Conflict Resolution Communication</p>	<p>Option 2 is, in my opinion, the better option because it tells the decision maker what all the options are so everything is on the table. So they're not – they express their disagreement, but they're saying, however, to help you, here's what we can do to come to a decision. So that is – how it's worded I think is very inclusive of all the things that need to be considered. Whereas option 1 is more confrontational and it's not supportive at all. It's almost like it's saying, look this is the right thing to do and we wash our hands of it.</p> <p>Well wait a minute, all these people in the process are from the hospital and you protect each other, so who's helping me in making this decision,</p> <p>I like that option two mentions the consent and capacity board though.</p>
<p>Preference for Legal System Adjudication Communication (see vignette)</p>	<p>Option 1 is just too clinical because it just explains it matter of fact and then puts the responsibility on the social worker to deal with the decision maker.</p> <p>I prefer option 3 because it sort of summarizes the act and why we have to move forward and why they have to go to the Consent and Capacity Board but it also then explains what will happen once a decision is made so that the decision maker also has an understanding of, okay so this may not work for me, this may not play in my favour. Option 2 is fine but I think it helps to have that extra sentence or two to explain what the aftermath will look like.</p>

	<p>The relationship in option 3 is so positive as they want to work together whereas option 1 is just, this is how it is, if you have any questions talk to the social worker. So it's not a very – it's not a clean approach, there's no partnership.</p>
<p>Disagreement about Life Support and CPR While Waiting for Legal Decision (see vignette)</p>	<p>So my personal opinion is under no circumstances do I want my loved ones to suffer any longer than they have to. And so that is one of the reasons why I would go for number two...I like the fact that at the end of the day, the doctors will have to make the final decision and they will not provide life support but will provide any other medical therapy that they feel is appropriate given her medical situation and values.</p> <p>I said one. No, what I'm saying is I think that if the family believes that there is value in the process of mediation, then I think the medical staff team should provide care to the maximum until the situation is resolved.</p>

ENDNOTES

¹ *Cuthbertson v. Rasouli*, 2013 SCC 53, [2013] 3 SCR 341 [*Rasouli*]. See also J Downar, RW Sibbald, and others, “Withholding and withdrawing treatment in Canada: implications of the Supreme Court of Canada's decision in the Rasouli case” (2014) 186:16 CMAJ E622 [Downar *Rasouli*].

² College of Physicians and Surgeons of Ontario, “Planning for and Providing Quality End-of-Life Care” (September 2002; revised September 2015) [CPSO policy 2015]. See also CPSO, “Planning for and Providing Quality End of Life – Post Approval Amendments” (Council Update, June 7, 2016). Online: <http://www.cpso.on.ca/Whatsnew/Council-Updates/May-30-31,-2016> (last accessed March 17, 2017), describing amendments to the CPSO, “Planning for and Providing Quality End-of-Life Care” (September 2002; revised May 2016) [CPSO policy 2016]. Online: <http://www.cpso.on.ca/CPSO/media/documents/Policies/Policy-Items/End-of-Life.pdf?ext=.pdf> (last accessed March 17, 2017).

³ *Fleming v. Reid* (1991), 4 OR (3d) 74, 82 D.L.R. (4) 298 (Ont. CA) p. 18-19 [*Fleming*].

⁴ *Health Care Consent Act, 1996*, S.O. 1996, c. 2, Sched. A (HCCA).

⁵ HCCA, note 4, s. 10 (no treatment without consent), s. 25 (emergency provisions).

⁶ *Crits v. Sylvester*, [1956] OR 132 at 143 (CA), aff'd [1956] SCR 991 [*Crits*].

⁷ See for example: Robert Sibbald and Paula Chidwick, “Best interests at end of life: A review of decisions made by the Consent and Capacity Board of Ontario” (2010) 25:1 J Crit Care 171 [Sibbald CCB review]; Chidwick and Sibbald, “Physician Perspectives on Legal Processes for Resolving End-of-Life Disputes” (2011) 14:2 Health care Q. 69 [Chidwick Perspectives]; Chidwick, Sibbald, and Hawryluck, “Best interests at end of life: an updated review of decisions made by the Consent and Capacity Board of Ontario” (2013) 28:1 J Crit Care 22 [Chidwick CCB]; Hawryluck, Sibbald, and Chidwick, “The Standard of Care and conflicts at the End of Life in critical care: Lessons from medical-legal crossroads and the role of a quasi-judicial tribunal in decision-making” (2013) 28:6 J Crit Care 1055 [Hawryluck Tribunal]; and Sibbald, Chidwick, and Hawryluck, “Standard of care and resource implications of the Cuthbertson v. Rasouli ruling” (2014) 186:5 CMAJ 327 [Sibbald Rasouli].

⁸ Hawryluck Tribunal, note 7; Sibbald *Rasouli*, note 7.

⁹ See for example: Canadian Medical Association, “CMA Statement on Life-Saving and-Sustaining Interventions” (CMA 2013). Online: <http://policybase.cma.ca/dbtw-wpd/Policypdf/PD14-01.pdf> (last accessed March 17, 2017); Resuscitation Council (UK), “Decisions relating to Cardiopulmonary Resuscitation (3rd edition)” [Resuscitation Council UK]. Online: <https://www.resus.org.uk/archive/archived-dnacpr-information/decisions-relating-to-cpr-2014/> (last accessed March 17, 2017); GT Bosslet, TM Pope, and others, “An Official ATS/AACN/ACCP/ESICM/SCCM Policy Statement: Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units” (2015) 191:11 Am J Respir Crit Care Me. 1318 [Bosslet].

¹⁰ CMA 2013, note 9; Resuscitation Council UK, note 9; Bosslet, note 9.

¹¹ HCCA, note 4.

¹² See also: B. Sneiderman, “Decision-Making at the End of Life” in Jocelyn Downie, Timothy Caulfield and Colleen Flood (eds.), *Canadian Health Law and Policy*, 2nd ed. (Toronto: Butterworths, 2002), 511, 513 [Sneiderman]; Joan M Gilmour, “Death, Dying and Decision-Making about End of Life Care” in Jocelyn Downie, Timothy Caulfield and Colleen Flood (eds.), *Canadian Health Law and Policy*, 4th ed. (Toronto: LexisNexis Canada, 2011), 399

[Gilmour].

¹³ Sneiderman, note 12.

¹⁴ Gilmour, note 12.

¹⁵ Sneiderman, note 12; Gilmour, note 12.

¹⁶ *Scardoni v. Hawryluck*, 2004 CanLII 34326 (ON SC) [*Scardoni*], as cited in *FF (Re)*, 2012 CanLII 38989 (ON CCB).

¹⁷ *Scardoni*, note 16, para 17.

¹⁸ *Children's Aid Society of Ottawa-Carleton v MC*, 2008 CanLII 49154 (ON SC) [*CAS v MC*].

¹⁹ *CAS v MC*, note 18, para 25.

²⁰ *Rasouli*, note 1, para 40.

²¹ *Rasouli*, note 1, para 43.

²² *Rasouli*, note 1, para 68.

²³ *Rasouli*, note 1, para 36, 37, 68.

²⁴ *Rasouli*, note 1, para 110.

²⁵ *Rasouli*, note 1, para 96.

²⁶ *Rasouli*, note 1, paras 45, 68.

²⁷ *EGJW v MGC*, 2014 CanLII 49888 (ON HPARB) [*EGJW*].

²⁸ Hawryluck, Oczkowski, and Handelman, "Must do CPR?": strategies to cope with the new College of Physicians and Surgeons of Ontario policy on end-of-life care" (2016) 63:8 Can J Anaesth 973 [*Hawryluck CPR*].

²⁹ *EGJW*, note 27, para 32.

³⁰ *EGJW*, note 27, para 33.

³¹ *EGJW*, note 27, para 32.

³² *EGJW*, note 27, paras 33, 34, and 35.

³³ *Hawryluck CPR*, note 28.

³⁴ CPSO policy 2015, note 2.

³⁵ CPSO policy 2015, note 2.

³⁶ CPSO policy 2016, note 2.

³⁷ CPSO policy 2016, note 2.

³⁸ CPSO policy 2015, note 2.

³⁹ CPSO policy 2015, note 2.

⁴⁰ *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996, c 181, s. 5 [HCCCFAA]; *Consent to Treatment and Health Care Directives Act*, RSPEI 1988, c C-17, s. 2 [CTHCDA]; *Hospitals Act*, RSNS 1989, c 208, ss. 54 [HA].

⁴¹ HCCCFAA, note 40, s. 12-12.2; CTHCDA, note 40, s. 16-17.

⁴² *Mental Health Services Act*, SS 1985-85-86, s. 25(1) [MHSA]; *Mental Health Act*, CCSM c M110, s. 29 [MAN MHA].

⁴³ *Adult Guardianship and Trusteeship Act*, SA 2008, c A-4.2, s. 101(2)-101(4) [AGTA].

⁴⁴ *Personal Directives Act*, RSA 2000, c P-6, s. 24(1) [AB PDA]; *Advance Health Care Directives Act*, SNL 1995, c A-4.1, s. 9(2) [AHCDA] and the *Personal Directives Act*, SNS 2008, c 8, s. 19 [NS PDA].

⁴⁵ *Fleming*, note 3.

⁴⁶ *Malette v. Shulman* (1990), 72 OR (2d) 417, 67 D.L.R. (4th) (Ont. CA) [*Malette*].

⁴⁷ HCCCFAA, note 40.

⁴⁸ CTHCDA, note 40.

⁴⁹ HCCCFAA, note 40, s.6; CTHCDA, note 40, s. 6.

⁵⁰ HCCA, note 4. Terminology in the B.C. statute is “health care” not “treatment.” Nova Scotia’s *Hospitals Act*, HA, note 40, employs the term “treatment” but does not provide a definition for the term. PEI legislation, CTHCDA, note 40, explicitly excludes “counselling... in the nature of advice, education or motivation” from the statute’s definition of “treatment.”

⁵¹ *Health Information Act*, RSA 2000, c H-5, s. 1 [HIA].

⁵² Hawryluck, Baker AJ, Faith A, Singh JM, “The future of decision-making in critical care after *Cuthbertson v. Rasouli*” (2014) 61:10 Can J Anaesth 951 [Hawryluck *Rasouli*].

⁵³ HCCCFAA, note 40, s. 9 (1.2).

⁵⁴ HCCCFAA, note 40, ss. 19(1), (3); AGTA, note 43, ss. 92(3 - 4); *The Health Care Directives and Substitute Health Care Decision Makers Act (Repealed)* [HCDSHCDMA] ss. 12, 16(3); AHCDA, note 44, s. 12(1); NS PDA, note 44, s. 15(4); HA, note 40, ss. 54A-B; CTHCDA, note 40, s. 13(1-2).

⁵⁵ HCCCFAA, note 40, ss. 12, 12.1, 12.2; CTHCDA, note 40, ss. 16-17; HCCA, note 4, s. 25(1), 25(9). Alberta’s AGTA, note 43, does allow a physician to provide emergency health care to an adult in certain situations and, per s. 24(1) of Alberta’s PDA, note 44, allows, in certain situations emergency “medical services” without consent to a person who has made a personal directive and is incapable. In Manitoba MHA, note 42, stipulates that emergency medical treatment may be given to a patient, without consent, if there is imminent and serious danger to the patient’s life or to a limb or vital organ and the patient, is not mentally competent in the physician’s opinion or is otherwise unable to give consent. In Nfld, the AHCDA, note 44, s. 9(2), defines conditions when a situation warranting emergency care exists and wherein consent is not required similar to the HCCA, note 4. In Nova Scotia, the PDA, note 44, s. 19, stipulates criteria to provide emergency health care that once again parallels the HCCA, note 4.

⁵⁶ *Child and Family Services of Central Manitoba v. Lavallee et al*, 1997 [1997] M.J. No. 568, 154 D.L.R. (4th) 409 (C.A.) [Lavallee].

⁵⁷ Lavallee, note 56, para 4.

⁵⁸ Lavallee, note 56, paras 5-6; *The Child and Family Services Act*, C.C.S.M., c. C80, s. 25(3) [MAN CFSA].

⁵⁹ Lavallee, note 56, para 14.

⁶⁰ Lavallee, note 56, para 13 ; MAN CFSA, note 58, s. 25(3).

⁶¹ *Golubchuk v. Salvation Army Grace General Hospital et al*. 2008 MBQB 49 [Golubchuk].

⁶² Golubchuk, note 61, para 29.

⁶³ *Sawatzky v. Riverview Health Centre Inc.*, [1999] 6 W.W.R. 298 (Man. Q.B.), para 59 [Sawatzky].

⁶⁴ This analysis of *Sawatzky* is found in *L.I.C. (Re)*, [2006] A.J. 190, 2006 ABQB 130 (QB) [LIC], para 27, citing *Sawatzky*, note 63, para 52.

⁶⁵ LIC, note 64, citing *Sawatzky*, note 63, para 59.

⁶⁶ LIC, note 64, para 36.

⁶⁷ Manitoba Law Reform Commission, “Withholding or Withdrawing Life Sustaining Medical Treatment – Report 109” (December 2003) [MLRC]. Online: http://www.manitobalawreform.ca/pubs/pdf/archives/109-full_report.pdf (last accessed March 20, 2017).

⁶⁸ MLRC, note 67, 4.

⁶⁹ MLRC, note 67, 5.

⁷⁰ MLRC, note 67, 11-13.

⁷¹ MLRC, note 67, 12.

⁷² MLRC, note 67, 12-13.

⁷³ MLRC, note 67, 13.

⁷⁴ College of Physicians and Surgeons of Manitoba, “Statement on Withholding and Withdrawal of Life-Sustaining Treatment” (2008).

⁷⁵ Jocelyn Downie and Karen McEwen, “The Manitoba College of Physicians and Surgeons Position Statement on Withholding and Withdrawal of Life Sustaining Treatments (2008): Three Problems and a Solution” (2009) 17 Health LJ 115, 116 [Downie CPSM].

⁷⁶ College of Physicians and Surgeons of Manitoba, “Withholding and Withdrawal of Life-Sustaining Treatment” as Schedule D to *By-law 11, Standards of Practice of Medicine* (effective December 14, 2015 with amendments to December 21, 2016) [CPSM Bylaw 11]. Online: <http://cpsm.mb.ca/cjj39alckF30a/wp-content/uploads/ByLaws/By-Law-11.pdf> (last accessed March 20, 2017).

⁷⁷ College of Physicians and Surgeons of Manitoba, “Code of Ethics of The College of Physicians and Surgeons of Manitoba” (December 2015), as Schedule G to *By-law 1, The Affairs of the College and the Code of Ethics* (effective December 1, 2008 with amendments to July 14, 2016). Online: <http://cpsm.mb.ca/cjj39alckF30a/wp-content/uploads/ByLaws/By-law-1.pdf> [Code of Ethics].

⁷⁸ CPSM ByLaw 11, note 76, 50.

⁷⁹ CPSM ByLaw 11, note 76, 55 and 56.

⁸⁰ *Sweiss v. Alberta Health Services*, 2009 ABQB 691 (CanLII), paras 1-6 [Sweiss].

⁸¹ *Sweiss*, note 80, para 9.

⁸² *Sweiss*, note 80, paras 63-65.

⁸³ *LIC*, note 64, paras 1-6.

⁸⁴ *LIC*, note 64, para 7, 9.

⁸⁵ *LIC*, note 64, para 8.

⁸⁶ *LIC*, note 64, para 33, citing *Airedale NHS Trust v Bland*, [1993] 1 All ER 821 (HL) 14 [Airedale], 893.

⁸⁷ *LIC*, note 64, para 36.

⁸⁸ *IHV (Re)*, 2008 ABQB 250 (CanLII), 449 AR 211 [IHV (Re)].

⁸⁹ *IHV (Re)*, note 88, para 27.

⁹⁰ *May v Alberta Health Services*, 2010 ABQB 213 (CanLII), 498 AR 167 [May].

⁹¹ *May*, note 90, para 22.

⁹² *May*, note 90, paras 24-27.

⁹³ *Rotaru v. Vancouver General Hospital Intensive Care Unit*, 2008 BCSC 318 (CanLII) [Rotaru].

⁹⁴ *Rotaru*, note 93, para 5.

⁹⁵ *Rotaru*, note 93, para 12.

⁹⁶ *Rotaru*, note 93, para 18.

⁹⁷ *R (a minor) (wardship: medical treatment)* [1991] 4 All ER 177, [1992] Fam II, and *Re J (a minor) (wardship: medical treatment)* [1990] 3 All ER 930, [1991] 1Fam 33.

⁹⁸ *Airedale*, note 86.

⁹⁹ *Airedale*, note 86, 16.

¹⁰⁰ United Kingdom, *The Mental Capacity Act 2005* (2005 Chapter 9), along with the UK Office of the Public Guardian, “Mental Capacity Act Code of Practice” (published July 22, 103, updated January 12, 2016). Online: <https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice> (last accessed march 21, 2017). See also United Kingdom, *Adults with*

Incapacity (Scotland) Act, 2000 (2000 ASP 4), along with the Scottish Government, “Adults with Incapacity (Scotland) Act 2000 - Codes of Practice” (various documents and dates of publication). Online: <http://www.gov.scot/Topics/Justice/law/awi/010408awiwebpubs/cop> (last accessed March 21, 2017).

¹⁰¹ GT Bosslet, M Baker, and TM Pope, “Reason-giving and medical futility: contrasting legal and social discourse in the United States with the United Kingdom and Ontario, Canada” (September 2016) 150 *Chest* 3 714.

¹⁰² Court of Protection Practice Rules, “Practice Direction 9E – Applications Relating to Serious Medical Treatment” (July 2015) 1 [CPR]. Online: <https://www.judiciary.gov.uk/wp-content/uploads/2015/06/copd-pd-9e-serious-medical-treatment.pdf>.

¹⁰³ See for example *Burke v. GMC* [2005] EWCA Civ 1003 [*Burke*]. Online: <http://www.bailii.org/ew/cases/EWCA/Civ/2005/1003.html> (last accessed March 21, 2017). See also *NHS Trust v Ms D* [2005] EWHC 2439 (fam). Online: <http://www.familylawweek.co.uk/site.aspx?i=ed1484> (last accessed March 21, 2017).

¹⁰⁴ CPR, note 102, para 18.

¹⁰⁵ CPR, note 102, para 16.

¹⁰⁶ United Kingdom General Medical Council, “Treatment and care towards the end of life: good practice in decision making” (May 2010) [GMC]. Online: http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp (last accessed March 21, 2017).

¹⁰⁷ GMC, note 106, Principles 10, 12.

¹⁰⁸ GMC, note 106, 30.

¹⁰⁹ Intensive Care Society, “Guidelines for limitations of treatment for adults requiring intensive care” (2003) 3 [Intensive Care Society]. Online: http://icmwk.com/wp-content/uploads/2014/02/limitation_of_treatment_2003-2.pdf (last accessed March 21, 2017).

¹¹⁰ Intensive Care Society, note 109, 3.

¹¹¹ *Wyatt & Anor v. Portsmouth Hospital NHS & Anor* [2005] EWCA Civ 1181; *Burke*, note 103; *NHS Trust v. Ms D*, note 103; *NHS Trust v MB* [2006] EWHC 507 (Fam); *An NHS Trust v S & Ors* [2003] EWHC 365 (Fam); *Glass v the United Kingdom* [2004] ECHR 103.

¹¹² *Re J (A Minor) (Child in Care: Medical Treatment)* [1992] 2 All ER 614.

¹¹³ See for example *Re A (Male Sterilization)* [2000] FCR 193; *Re S (Adult Sterilization)* [2000] 2FLR 398; *Health And Social Services Trust v PM & Anor* [2007] NIFam 13 (21 Dec 2007).

¹¹⁴ *Aintree University Hospitals NHS Foundation v. James*, (2013) EWCA Civ 65 [*James*].

¹¹⁵ *James*, note 114, para 38.

¹¹⁶ *Aintree University Hospitals NHS Foundation Trust (Respondent) v. James (Appellant)* [2013] UKSC 67, as discussed in The Supreme Court, “Press Summary” (October 30, 2013). Online: https://www.supremecourt.uk/decided-cases/docs/UKSC_2013_0134_PressSummary.pdf (last accessed March 21, 2017).

¹¹⁷ L Willmott, B White, and J Downie, “Withholding and Withdrawal of “futile” life-sustaining treatment: Unilateral medical decision-making in Australia and New Zealand” (2013) 20 *JLM* 907. Online: https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2806814 (last accessed March 21, 2017).

¹¹⁸ DB White, CH Braddock, and others, “Toward shared decision making at the end of life in intensive care units: opportunities for improvement” (2007) 167:5 *Arch Intern Med* 461 [White].

¹¹⁹ D Garros, RJ Rosychuk, PN Cox, “Circumstances surrounding end of life in a pediatric intensive care unit” (2003) 112:5 *Pediatrics* E371.

¹²⁰ J Downar, JJ You JJ, and SM Bagshaw, “Nonbeneficial Treatment Canada: Definitions, Causes, and Potential Solutions From the Perspective of Health care Practitioners” (2015) 43:2 Crit Care Med 270 [Downar Nonbeneficial].

¹²¹ DK Heyland, C Frank, D Groll, “Understanding cardiopulmonary resuscitation decision making: perspectives of seriously ill hospitalized patients and family members” (2006) 130:2 Chest 419 [Heyland Cardio]; SK Johnson, CA Bautista, SY Hong and others, “An empirical study of surrogates' preferred level of control over value-laden life support decisions in intensive care units” (2011) 183:7 Am J Respir Crit Care Med 915 [Johnson ICU].

¹²² White, note 118, 461, 467.

¹²³ DK Heyland, P Dodek, G Rocker and others, “What matters most in end-of-life care: perceptions of seriously ill patients and their family members” (2006) 174:5 CMAJ 627 [Heyland perceptions].

¹²⁴ DK Heyland, DE Allan, G Rocker and others, “Discussing prognosis with patients and their families near the end of life: impact on satisfaction with end-of-life care” (2009) 3:2 Open Med e101 [Heyland prognosis].

¹²⁵ DK Heyland, D Barwich, D Pichora and others, “Failure to Engage Hospitalized Elderly Patients and Their Families in Advance Care Planning” (2013) 1 JAMA Intern Med 10 [Heyland ACP].

¹²⁶ C Schroder, D Heyland, X Jiang and others, “Educating medical residents in end-of-life care: insights from a multicenter survey” (2009) 12:5 J Palliat Med 459 [Schroder].

¹²⁷ JJ You, J Downar, and others, “Barriers to Goals of Care Discussions With Seriously Ill Hospitalized Patients and Their Families” (2015) 175:4 JAMA Intern Med 549 [You].

¹²⁸ Heyland Cardio, note 121.

¹²⁹ JC Weeks, EF Cook, SJ O'Day and others, “Relationship between cancer patients' predictions of prognosis and their treatment preferences” (1998) 279:21 JAMA 1709 [Weeks]; DJ Murphy, D Burrows and others, “The influence of the probability of survival on patients' preferences regarding cardiopulmonary resuscitation”(1994) 330:8 N Engl J 545 [Murphy].

¹³⁰ J Elliott and I Olver, “Choosing between life and death: patient and family perceptions of the decision not to resuscitate the terminally ill cancer patient” (2008) 22:3 Bioethics 179 [Elliott].

¹³¹ Johnson ICU, note 121.

¹³² M Muller-Engelmann, H Keller, N Donner-Banzhoff and others, “Shared decision making in medicine: the influence of situational treatment factors” (2001) 82:2 Patient Educ Coun 240 [Muller-Engelmann].

¹³³ Heyland ACP, note 125.

¹³⁴ CMA 2013, note 9, 2; Resuscitation Council UK, note 9, 9; Bosslet, note 9.

¹³⁵ L Hawryluck, “The Critical Care Perspective – In Reply to “Last Rights: *Cuthbertson v. Rasouli* – What the Supreme Court Didn't Say about End-of-Life Treatment Decisions”” (2015) 36:2 Health Law Can 6.

¹³⁶ SC Zweig, “Cardiopulmonary resuscitation and do-not-resuscitate orders in the nursing home” (1997) 6:5 Archives of family medicine 424 [Zweig].

¹³⁷ SK Wallace, MS Ewer, KJ Price and others, “Outcome and cost implications of cardiopulmonary resuscitation in the medical intensive care unit of a comprehensive cancer center” (2002) 10:5 Support Care Cancer 425 [Wallace].

¹³⁸ DB White and JM Luce, “Palliative care in the intensive care unit: barriers, advances, and unmet needs” (2004) 20:3 Crit Care Clin 329 [White ICU].

¹³⁹ CE Cox, T Martinu, SJ Sathy and others, « Expectations and outcomes of prolonged mechanical ventilation” (2009) 37:11 Crit Care Med 2888 (quiz 2904) [Cox]; MS Herridge, CM Tansey, A Matte and others, “Functional disability 5 years after acute respiratory distress syndrome” (2011) 364:14 N Engl J 1293 [Herridge].

¹⁴⁰ AA Wright, B Zhang, A Ray and others, “Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment” (2008) 200:14 JAMA 1665 [Wright].

¹⁴¹ Wright, note 140.

¹⁴² ML Mealer, A Shelton, B Berg and others, “Increased prevalence of post-traumatic stress disorder symptoms in critical care nurses” (2007) 175:7 Am J Respir Crit Care Med 693 [Mealer].

¹⁴³ LH Nicholas, KM Langa, TJ Iwashyna and others, “Regional variation in the association between advance directives and end-of-life Medicare expenditures” (2011) 306:13 JAMA 1447 [Nicholas]; B Zhang, AA Wright and others, “Health care costs in the last week of life: associations with end-of-life conversations” (2009) 169:5 Arch Intern Med 480 [Zhang].

¹⁴⁴ TN Huynh, EC Kleerup, JF Wiley JF and others, “The Frequency and Cost of Treatment Perceived to Be Futile in Critical Care” (2013) 173:20 JAMA Intern Med 1887 [Huynh]; RD Piers, E Azoulay, B Ricou and others, “Perceptions of appropriateness of care among European and Israeli intensive care unit nurses and physicians” (2011) 306:24 JAMA 2694 [Piers].

¹⁴⁵ R Sibbald, J Downar, and L Hawryluck, “Perceptions of “futile care” among caregivers in intensive care units” (2007) 177:10 CMAJ 1201 [Sibbald futile care].

¹⁴⁶ Downar Nonbeneficial, note 120.

¹⁴⁷ Downar Nonbeneficial, note 120; JL Vincent, “Forgoing life support in western European intensive care units: the results of an ethical questionnaire” (1999) 27:8 Crit Care Med 1626 [Vincent].

¹⁴⁸ GJ Annas, “CPR: when the beat should stop” (1982) 12:5 Hastings Cent Rep 30 [Annas].

¹⁴⁹ CMA 2013, note 9.

¹⁵⁰ Resuscitation Council UK, note 9.

¹⁵¹ Australian Medical Association, “Position statement on end of life care and advance care planning” (2014). Online: https://ama.com.au/sites/default/files/documents/AMA_position_statement_on_end_of_life_care_and_advance_care_planning_2014.pdf (last accessed March 21, 2017).

¹⁵² HCCA, note 4, s. 26.

¹⁵³ HCCA, note 4, s. 2(1).

¹⁵⁴ CPSO Policy 2015, note 2, s. 5.2: “While the conflict resolution process is underway, physicians may not write a no-CPR order. If an event requiring CPR occurs, physicians must provide CPR unless the patient’s condition will prevent the intended physiologic goals of CPR (i.e., providing oxygenated blood flow to the heart and brain) from being achieved.”

¹⁵⁵ Heyland Cardio, note 121.

¹⁵⁶ Heyland Cardio, note 121.

¹⁵⁷ GK Jones, KL Brewer, HG Garrison, “Public expectations of survival following cardiopulmonary resuscitation” (2000) 7:1 Acad Emerg Med 2000 48 [Jones].

¹⁵⁸ SJ Diem, JD Lantos, JA Tulsy, “Cardiopulmonary resuscitation on television. Miracles and misinformation” (1996) 334:24 N Engl J Med 1578 [Diem].

¹⁵⁹ Weeks, note 129.

¹⁶⁰ White ICU, note 138.

¹⁶¹ Murphy, note 129.

¹⁶² M Danis, DL Patrick, LI Southerland and others, "Patients' and families' preferences for medical intensive care" (1988) 260:6 JAMA 797 [Danis].

¹⁶³ JH Rose, EE O'Toole, NV Dawson NV and others, "Perspectives, preferences, care practices, and outcomes among older and middle-aged patients with late-stage cancer" (2004) 22:24 J Clin Oncol 4907 [Rose].

¹⁶⁴ Heyland Cardio, note 121.

¹⁶⁵ J Downar, T Luk, RW Sibbald and others, "Why do patients agree to a "Do not resuscitate" or "Full code" order? Perspectives of medical inpatients" (2011) 26:6 Gen Intern Med 2011 582 [Downar DNR].

¹⁶⁶ Downar DNR, note 165.

¹⁶⁷ Downar DNR, note 165.

¹⁶⁸ Downar DNR, note 165.

¹⁶⁹ J Kryworuchko, PH Strachan, E Nouvet and others, "Factors influencing communication and decision-making about life-sustaining technology during serious illness: a qualitative study" (2016) 6:5 BMJ Open e010451 [Kryworuchko], 4.

¹⁷⁰ Kryworuchko, note 169.

¹⁷¹ Heyland ACP, note 125; Kryworuchko, note 169; JW Mack, A Cronin, N Taback and others, "End-of-Life Care Discussions Among Patients With Advanced Cancer A Cohort Study" (2012) 156:3 Ann Internal 204 [Mack].

¹⁷² Kryworuchko, note 169, 5.

¹⁷³ Sibbald futile care, note 145.

¹⁷⁴ Downar Nonbeneficial, note 120.

¹⁷⁵ Sibbald futile care, note 145, 1203.

¹⁷⁶ *Rasouli*, note 1.

¹⁷⁷ *EGJW*, note 27.

¹⁷⁸ J Downar, M Warner and R Sibbald, "Mandate to obtain consent for withholding nonbeneficial cardiopulmonary resuscitation is misguided" (2016) 188:4 CMAJ 245 [Downar Mandate].

¹⁷⁹ CPSO Policy 2016, note 2. The authors wish to underscore that this step, while commonly mentioned in many conflict-resolution processes, is almost universally unsuccessful. It would not be realistic to expect to find another willing provider to take over care from a physician who felt that it was non-beneficial and outside the MSOC. Most physicians view the request to transfer care solely as a means of obtaining an external second opinion.

¹⁸⁰ CPSO Policy 2016, note 2.

¹⁸¹ Downar Nonbeneficial, note 120; Vincent, note 147.

¹⁸² Huynh, note 144; Piers, note 144; Kryworuchko, note 169.

¹⁸³ Sibbald futile care, note 145, 1203.

¹⁸⁴ Downar *Rasouli*, note 1, e624.

¹⁸⁵ Health Consent Quality Collaborative, *CCB End-of-life Cases, Form G Cases* (updated to September 15, 2015) [HCQC]. Online: <http://consentqi.ca/law/overview-2/end-of-life-cases/> (last accessed March 21, 2017).

¹⁸⁶ HCQC, note 185.

¹⁸⁷ Downar Nonbeneficial, note 120.

¹⁸⁸ Chidwick Perspectives, note 7.

¹⁸⁹ CPSO Policy 2015, note 2, s. 5.2.

¹⁹⁰ Hawryluck CPR, note 28, 6.

¹⁹¹ K Knickle, N McNaughton, and J Downar, “Beyond winning: mediation, conflict resolution, and non-rational sources of conflict in the ICU” (2012) 16:3 Crit Care 308 [Knickle].

¹⁹² Downar Nonbeneficial, note 120.

¹⁹³ Sibbald futile care, note 145.

¹⁹⁴ TM Pope, “Medical futility statutes: no safe harbor to unilaterally refuse life-sustaining treatment” (2007) 71:1 Tenn L Rev 80 [Pope].

¹⁹⁵ CPSM ByLaw 11, note 76.

¹⁹⁶ Texas, *Advance Directives Act (Texas Health and Safety Code ch. 166)*, (1999) 76th Leg., ch. 450, Sec. 1.02 (eff. Sept. 1, 1999), s. 166.046(e) “Procedure if Not Effectuating a Directive or Treatment Decision.” Online: <http://www.statutes.legis.state.tx.us/Docs/HS/htm/HS.166.htm> (last accessed March 21, 2017).

¹⁹⁷ RL Fine and TW Mayo, “Resolution of futility by due process: early experience with the Texas Advance Directives Act” (2003) 138:9 Ann Intern Med 743 [Fine]; RD Truog, “Counterpoint: The Texas advance directives act is ethically flawed: medical futility disputes must be resolved by a fair process” (2009) 136:4 Chest 968; 971-963 [Truog]; DB White and TM Pope, “The courts, futility, and the ends of medicine” (2012) 307:2 JAMA 151 [White].

¹⁹⁸ Fine, note 197; Truog, note 197, White, note 197.

¹⁹⁹ White, note 197, 152.

²⁰⁰ JR Curtis and MR Tonelli, “Shared Decision-Making in the ICU Value, Challenges, and Limitations” (2011) 183:7 Am J Respir Crit Care Med 840 [Curtis].

²⁰¹ Johnson ICU, note 121.

²⁰² See for example Judith Wahl, Mary Jane Dykeman and Brendan Gray, “Health Care Consent and Advance Care Planning in Ontario” (Commissioned by the Law Commission of Ontario, January 2014). Online: <http://www.lco-cdo.org/wp-content/uploads/2014/01/capacity-guardianship-commissioned-paper-ace-ddo.pdf> (last accessed March 21, 2017).