Best interests at end of life: A review of decisions made by the Consent and Capacity Board of Ontario

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Keywords: End of life; Conflict; Best interests; Consent and Capacity Board; Decision making; Legal decisions.

Abstract
Purpose: When patients are unable to communicate their own wishes, surrogates are commonly used to aid in decision making. Although each jurisdiction has its own rules or legislation governing how surrogates are to make health care decisions, many rely on the notion of “best interests” when no prior expressed wishes are known.

Methods: We purposively sampled written decisions of the Ontario Consent and Capacity Board that focused on the best interests of patients at the end of life. Interpretive content analysis was performed independently by 2 reviewers, and themes that were identified by consensus as describing best interests were construed, as well as the characteristics of an end-of-life dispute that may be most appropriately handled by an application to the Consent and Capacity Board.

Results: We found that many substitute decision makers rely on an appeal to religion or God in their interpretation of best interests, whereas physicians focused narrowly on the clinical condition of the patient in their interpretations.

Conclusions: Several lessons are drawn for the benefit of health care teams engaged in end-of-life conflicts with substitute decision makers over the best interests of patients.

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1. Introduction

In the health care setting, informed consent is necessary to legally and ethically provide treatment to patients. When a patient is no longer capable of making decisions, a substitute decision maker (SDM), surrogate, or proxy is asked to step in to make decisions on behalf of the incapable person. Rules to guide how decisions are made for incapable patients vary. In Ontario, the Health Care Consent Act (HCCA) [1] stipulates that the SDM is required to base decisions on prior capable expressed wishes of the patient, and if these wishes no longer apply, are impossible to comply with, or are not known, then the law stipulates that the SDM shall act in the incapable person’s “best interests” (see Box 1). This is a common approach used in many jurisdictions in Canada and elsewhere [2-6].

Best interests are generally invoked when it is necessary to provide the means of decision making for persons who are not capable. Although not perfect, some argue that appealing
Box 1 Sec. 21(1) of the HCCA (1996)

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.

Box 2 Sec. 21(2) of the HCCA (1996)

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.

relating to consent to treatment and capacity to make treatment decisions (eg, appointing SDMs, determining incapacity, and determining compliance with prior expressed wishes) [17,18]. The board was formed and given its authority through the passing of the Ontario HCCA in 1996. One type of dispute that the board hears relates to disagreement about whether proposed treatment plans are in the best interests of patients. After conducting such a hearing, the board will adjudicate who is in fact acting in the best interests of the patient, that is, the health care team or the SDM, and, if requested, will provide its reasons in a written decision [19]. The board will hear cases of this nature only when the medical team feels it appropriate and files an application or when a dispute between SDMs prevents decisions from being made and they make an application to the board. In reviewing the written decisions of the CCB of cases relating to best interests at EoL, the authors sought not only to better understand what is meant by best interests but also to describe the characteristics of an EoL dispute that may be most appropriately handled by an application to the CCB. The review will also promote a better understanding of the role of best interests as it relates to EoL decision making.

to best interests is the preferred way to make decisions for patients who are no longer capable [7]. Moreover, best interests, Coggon argues [7], need to be considered as a construct rather than a concept that aid in good decision making to avoid the challenges of appropriately being applicable in varying and diverse situations. That is, a single concept could not properly be applied in every single unique case and be meaningful. As such, in areas that invoke best interests, such as the English Mental Capacity Act 2005 [8] or the Ontario HCCA, there are “questions and processes that are recommended for people in their decision-making” [7] (see Box 2).

At the end of life (EoL), best interests are important because so few critically ill patients have the capacity to participate in treatment decisions themselves or have left detailed instructions with their surrogates. A recent report cites capacity of critically ill patients in as few as 5% of cases, with only 20% of surrogates knowing exactly what they would have wanted [9]. Concerns about what constitutes best interests often arise when there is disagreement between what the health care team believe their obligations to the patients are and what the SDM is claiming to be best for the patient [10-14]. These disagreements are not surprising given the gap between health care provider and family perspectives regarding EoL care in general. For example, Jacobs et al [15] found that 61.3% of the public believe that a miracle can a save person in a persistent vegetative state, whereas only 20.2% of health care professionals believed the same. A total of 57.4% of the public felt that divine intervention can save a person when physicians think that treatment is futile, whereas only 19.5% of trauma professionals agreed [16]. At the heart of these disagreements are many moral questions, namely, should we actively withdraw or cease to escalate therapy, or continue to add new interventions, or “do everything?”

In Ontario, the Consent and Capacity Board (CCB) acts as a neutral third party that adjudicating on matters
2. Methodology

The authors searched a public online, nonprofit database managed by the Federation of Law Societies of Canada [20] to search for relevant CCB decisions available from 1996 (when the CCB was created) to 2008 using the keywords form G, form C, end-of-life, ventilator, withdrawal, and withhold. In total, 328 cases were collected. Out of these 328 cases, purposive sampling was used to identify those concerned with the best interests of patients regarding treatment issues at EoL. In total, we identified 12 decisions (see Table 1). With the exception of 1 case involving an infant, all patients were elderly persons (the youngest, 74 years, and the oldest, 92 years). All 12 cases considered the nature and meaning of best interests in relation to the patient. Of the 12 patients involved, 3 had advanced directives. In 8 of 12 cases, the CCB had agreed with the applicant proposing withdrawal or no further escalation in treatment, that the best interests of the patient were served by their treatment plan. In 1 case, the CCB did not render a decision.

Table 1  Summary of CCB decisions reviewed

<table>
<thead>
<tr>
<th>Case</th>
<th>Hearing date</th>
<th>Treatment (plan) in disagreement</th>
<th>At issue</th>
<th>Board decision</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. G. (Re)</td>
<td>February 2009</td>
<td>Wean from ventilator and DNR order</td>
<td>Best interests</td>
<td>A tracheotomy and feeding tube were not in the best interests of the patient.</td>
</tr>
<tr>
<td>2. B. (Re)</td>
<td>January 2009</td>
<td>Wean from ventilator and DNR order</td>
<td>Prior wishes AND best interests</td>
<td>Weaning from the ventilator and a DNR order were in the best interests of the patient.</td>
</tr>
<tr>
<td>3. M.B. (Re)</td>
<td>December 2007</td>
<td>Feeding (PEG) tube</td>
<td>Best interests</td>
<td>A feeding tube was not in the best interests of the patient. (This decision was the result of a form C hearing, and so technically, the board’s decision was to appoint an SDM whom they felt would make decisions in the best interests of the patient.)</td>
</tr>
<tr>
<td>4. E.J.G. (Re)</td>
<td>September 2007</td>
<td>Wean from ventilator and DNR order</td>
<td>Best interests</td>
<td>Weaning from the ventilator and a DNR order were in the best interests of the patient.</td>
</tr>
<tr>
<td>5. C.D. (Re)</td>
<td>July 2007</td>
<td>Withdraw nutrition/hydration</td>
<td>Best interests</td>
<td>Withdrawal of nutrition/hydration and a DNR order were in best interests of the patient.</td>
</tr>
<tr>
<td>6. G.A. (Re)</td>
<td>July 2007</td>
<td>DNR order</td>
<td>Prior wishes AND best interests</td>
<td>DNR order was consistent with patient’s prior expressed wishes and was also in their best interests.</td>
</tr>
<tr>
<td>7. K.M.S. (Re)</td>
<td>June 2007</td>
<td>Withdraw nutrition/hydration</td>
<td>Prior wishes AND best interests</td>
<td>Withdrawal of nutrition/hydration was consistent with patient’s prior expressed wishes and best interests.</td>
</tr>
<tr>
<td>8. E.B. (Re)</td>
<td>February 2007</td>
<td>No feeding tube</td>
<td>Best interests</td>
<td>A feeding tube was not in the best interests of the patient.</td>
</tr>
<tr>
<td>9. B. (Re)</td>
<td>March 2006</td>
<td>Wean from ventilator and DNR order</td>
<td>Prior wishes AND best interests</td>
<td>Weaning and DNR order were consistent with patient’s prior expressed wishes and were also in their best interests.</td>
</tr>
<tr>
<td>10. P. (Re)</td>
<td>June 2005</td>
<td>DNR order</td>
<td>Best interests</td>
<td>DNR order was in best interests of the patient.</td>
</tr>
<tr>
<td>11. I.A. (Re)</td>
<td>April 2004</td>
<td>Dialysis</td>
<td>Best interests</td>
<td>Dialysis was not in the best interests of the patient. (This decision was the result of a form C hearing, and so technically, the board’s decision was to appoint an SDM whom they felt would make decisions in the best interests of the patient.)</td>
</tr>
<tr>
<td>12. H.J. (Re)</td>
<td>October 2003</td>
<td>No ventilatory support, inotropic support, resuscitation, or readmission to ICU</td>
<td>Best interests</td>
<td>No ventilatory support, inotropic support, resuscitation, or readmission to ICU was in the best interests of the patient.</td>
</tr>
</tbody>
</table>

DNR indicates do not resuscitate; ICU, intensive care unit. PEG, percutaneous endoscopic gastrostomy.

* Treatment plans usually consisted of many interventions. Here, we outline only the contested aspects of each plan.

b Both these decisions resulted in an appeal that was eventually dismissed at the Superior Court (Grover v. Butler. ON SC; 2009; and Barbulov v. Circone. ON SC; 2009).

c This decision was appealed to the Superior Court and overturned (Scardoni v. Hawryluck. ON SC; 2004).
because certain matters of procedure had not been completed, specifically, an appropriate SDM had not been chosen. In another case, the decision was appealed to the Superior Court of Ontario, where it was reversed, but without prejudice to the attending physician to reapply to the board if circumstances changed.

These 12 decisions constitute a purposive, illustrative sample of EoL disputes suitable for exploring how best interests are framed by SDMs, physicians, and the CCB. Interpretive content analysis was used to describe (compare and contrast) and make inferences about the characteristics of the cases to better understand what cases may appropriately be brought forward to the CCB and the role of best interests in these cases. All 12 cases were independently read and analyzed by 2 researchers (R.S. and P.C.), and then consensus was reached on themes and codes. First, cases were read to identify chunks of data that related to a concept or idea, and then we divided the cases into 5 sections: medical status, treatment plan, SDM interpretation of best interests, applicants’ interpretation of best interests, and CCB interpretation of best interests. We then identified specific themes within each section.

The authors have both been involved in CCB cases by assisting health care teams access and navigate the process.

3. Results

3.1. Medical status

There were 8 common indicators of medical status of patients (Table 2). All were “incapable” to make their own health care decisions; patients had either compromised consciousness (minimally conscious to persistent vegetative state) or experienced symptoms of advanced dementia. Patients were described as having multiple comorbidities and “cascading” health problems. Many of the patients were described as “in the dying process.” All patients were also in the intensive care unit at the time of the application. Other common themes among patients included irreversibility of condition, inability to swallow, recurrent infections, and chronic bed sores. Most patients could be described by 5 or 6 of these descriptors.

<table>
<thead>
<tr>
<th>Table 2</th>
<th>Themes regarding the medical status of patients for whom best interests are unclear</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Incapable</td>
<td></td>
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<tr>
<td>2. Compromised consciousness</td>
<td></td>
</tr>
<tr>
<td>3. Symptoms of dementia</td>
<td></td>
</tr>
<tr>
<td>4. Cascading health problems</td>
<td></td>
</tr>
<tr>
<td>5. Irreversibility of condition</td>
<td></td>
</tr>
<tr>
<td>6. Inability to swallow</td>
<td></td>
</tr>
<tr>
<td>7. Recurrent infections</td>
<td></td>
</tr>
<tr>
<td>8. Chronic bed sores</td>
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</tr>
</tbody>
</table>

3.2. Treatment (plan) at issue

None of the cases focused on a singular treatment (eg, dialysis and ventilator) but rather a proposed treatment plan that included several actions. In 3 of 12 cases, the medical team was proposing active withdrawal of life support (ventilator) that would result in the death of the patient. The other 8 cases involved treatment plans that included an order not to escalate the level of care (eg, implementing a do-not-resuscitate order or forgoing a feeding tube or dialysis).

3.3. Substitute decision makers’ interpretations of best interests

As SDMs advocate for their interpretation of the patient’s best interests, 2 clear themes arose from the 12 cases (Table 3). First, the relevance of God, specifically, or religious values was frequently argued (8/12 cases). For example, some SDMs held the position that it was up to God to decide when someone should die, and thus, withdrawal was inappropriate (eg, “Christians do not hasten death” and “No one should play God”). Others argued that the patient’s religious values required that all possible interventions to be used in the prolonging of their life (eg, “Where there’s life, there’s hope”).

Second, SDMs emphasized their own values and not those of the patients when arguing for the best interests of the patient. For example, although SDMs may have been asked what the patient would have wanted, they often reported on what they wanted.

<table>
<thead>
<tr>
<th>Table 3</th>
<th>Themes arising from SDMs’ interpretation of best interests</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Relevance of God/religion</td>
<td></td>
</tr>
<tr>
<td>2. Emphasized own values over those of the patient</td>
<td></td>
</tr>
</tbody>
</table>

3.4. Applicant’s interpretation of best interests

The first theme among clinician arguments about the best interests of their patients is that they relied only on Sec. 21(2) c of the HCCA; that is, they were concerned only with the clinical facts of the case (Table 4). Physicians relied on detailed chart notes, second and third opinions, and clinical evidence to demonstrate that their patients had little to no chance at recovery. Frequently, physicians referred to the cascading nature of symptoms and secondary medical issues (eg, infection, skin breakdown, and sequential organ failure).

<table>
<thead>
<tr>
<th>Table 4</th>
<th>Themes arising from the applicant’s position regarding best interests</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Focus on clinical evidence.</td>
<td></td>
</tr>
<tr>
<td>2. Inability to benefit/likelihood to cause harm</td>
<td></td>
</tr>
<tr>
<td>3. Other treatments available</td>
<td></td>
</tr>
</tbody>
</table>
Some described medical indicators that were the “worst” they had ever seen, citing many specific measures.

3.5. Board’s reasons

In 9 of the 12 decisions, the board decided that no prior expressed capable wish that was applicable to the circumstance existed, and therefore, the best interests standard was appropriate for deciding (see Box 2). In the 3 remaining cases, the board’s decision was based on a prior expressed wish, but they also noted that their decision would be the same if they were incorrect in applying the prior expressed wishes of the patient. Four themes arose in the board’s reasons for their decisions (Table 5). First, patient values are distinctly different and cannot be interpreted as prior expressed wishes. For example, the motto “live, struggle, and do your best” was considered a statement of value but did not constitute a prior expressed wish.

Second, a patient’s condition was seen as more than life itself. “Merely being alive does not constitute best interests, especially when one considers cascading effects of treating symptoms and considering well being as including dignity, and constant invasions and humiliations were subject to and should be enough.” “Condition refers to the person’s overall health if that is relevant and not just a single diagnosis” [21].

Third, religious values were considered relevant only if they could be demonstrated to have been held by the patient. In other words, because a patient was Catholic did not alone suffice to demonstrate that he/she adhered to specific Catholic values.

Fourth, SDMs did not consider their obligations under the HCCA. In each of the form G decisions, the board agreed with the applicant that the SDM had not complied with the instruction in Sec. 21(2) of the HCCA. In particular, the board felt that in each of these cases, the SDM had not considered section (c) that refers to the clinical prognosis and whether the proposed treatment is likely to have a particular effect.

4. Discussion

Our findings highlight some important aspects of disagreements between health care providers and SDMs and the notion of best interests that are to guide the process when no capable prior applicable patient wishes are known.

<table>
<thead>
<tr>
<th>Table 5</th>
<th>Themes arising from the board’s reasons</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Distinction between values and wishes</td>
<td></td>
</tr>
<tr>
<td>2. “Condition” more than life itself</td>
<td></td>
</tr>
<tr>
<td>3. Religious values considered only if demonstrated to have been held by patient</td>
<td></td>
</tr>
<tr>
<td>4. SDM focused on patient values and not clinical prognosis as required by HCCA.</td>
<td></td>
</tr>
</tbody>
</table>

The health issues and medical issues experienced by patients in the cases that physicians brought to a CCB hearing were substantial and cascading*. Considering how these consequences might negatively impact the patient is an important part of informed consent.

The focus on religion and God was a common factor in SDMs’ conceptions of best interests. This may be related to SDMs’ lack of knowledge about their legal and ethical obligations. In addition, it may be related to the finding that a disproportionate percentage of the public in comparison with health care providers believe in the ability of miracles to save patients at the end of their life [15]. Another recent study found that patients who reported a high level of positive religious coping were about 3 times as likely to receive mechanical ventilation and life-prolonging care than were those who disclosed a low level of coping through faith [22].

From the perspective of the health care teams, best interests were often described in clinical terms with little consideration of the patient’s values. This is consistent with other findings [23]. The HCCA clearly indicates that patients’ prior values must be weighed against the clinical factors in considering best interests. Physicians and teams may currently not have sufficient access to patients’ values to be able to weigh these factors.

4.1. Challenging an SDM

Although not all jurisdictions provide a mechanism to address the situation where an SDM is not providing consent that is in the best interests of the patient, many have. In Ontario, when the team is considering challenging the SDM, the only necessary criteria are that the patient is incapable and there is disagreement about the appropriateness of the treatment plan put forward by the health care team. Here, we put forth our recommendations for health care teams who will seek the CCB as a mechanism for resolving an EoL disagreement.

1. First, excellent communication is key to addressing EoL cases where best interests may be in question [24-27]. It is important that SDMs have a clear understanding of their role as SDMs. Also, all conversations should be well documented in the patient’s record. It is often the case that SDMs believe that the decision before them is theirs to make according to their own values and beliefs, and as a result, SDMs are commonly burdened with the idea that they “will end up killing their ‘loved one’ if they refuse treatment.” This kind of misunderstanding about their role typically supports fears and guilt that may not be necessary.

2. It is important that there is a clear discussion with the SDM regarding prior expressed wishes of the patient.

* Physicians frequently referred to cascading health issues when proposed treatments were felt to result in adverse effects/outcomes that were worse than the medical issue that the treatment proposed to address.
For example, the physician could ask the SDM, “Did your mother ever discuss what she would want in a situation like this?” If any wishes are not applicable to the decision required, then the team can legally and ethically move to the best interests test in the HCCA.

3. The best interests standard includes elements of a patient’s prior values and also of the clinical condition he/she is currently in. The medical status of a patient appropriate for an EoL hearing typically includes an irreversible condition accompanied by cascading health problems. When faced with a patient in whom medical interventions will not improve or change the patient’s condition for the better, then the team may not be serving the patient’s best interests by considering further active, aggressive, or life-sustaining treatment. For some, these conditions represent what has been recognized in the literature as “futile” treatment [28]. Given this, best interests may be a consideration in how we think about what might be medically indicated. Based on this analysis, this may also include treatments that fall within the standard of care but may not be in the best interests of the patient. As such, although we can offer these treatments, perhaps we should not. One might argue that because options “can” be offered to them, SDMs are entitled to, at the very least, know what these are. But the issue is whether treatments that are not “indicated” ought ever to be presented as an option in the first place [29].

4. When the team and/or the physician has determined their understanding of best interests, they are ready to propose a treatment plan. Proposed treatment plans at EoL are often framed in terms of “withdrawal of life support” and/or “no escalation of treatment” (eg, forgoing a feeding tube or no dialysis). Teams may avoid the issue of whether consent is required for a treatment plan that includes withholding by framing treatment plans in the positive sense, for example, proposing palliative care and/or comfort care that would address symptoms and comfort, but this approach has not yet been tested in law. In some cases, disputes arise concerning best interests when SDMs request a treatment that may never have been offered or may lie outside the standard of care. However, patients and SDMs are not in position to propose treatment plans, rather they can only consent to a treatment plan proposed by their physician or team.

5. There are concepts in the HCCA that are poorly understood. For example, “values” and “wishes” were frequently conflated in the decisions reviewed. Wishes are to be followed with regard to treatment decisions only when applicable. Frequently, statements made by the patient are more clearly associated with an expression of values than being a specific and applicable wish. For example, in 2 decisions, it was found that the statements “my mother loved food and would not have wanted to die hungry” and “where there is life, there is hope” were both more representative of a value and not a prior expressed wish. Religious values can be properly considered only as one element of best interests, and even then, only if demonstrated to have been held by the patient. “Condition” and “well-being” are not defined in law but based on our analysis; condition refers to a person’s physical and mental state, and well-being refers to quality of life and includes the notion of “dignity.” Finally, “life” cannot be considered in and of itself to constitute best interests [11,30].

5. Conclusion

In conclusion, the review of these decisions can be informative to health care professionals in understanding the role of best interests at EoL. In Ontario, Canada, this analysis may also inform physicians when and what cases may be appropriate to bring forward to a CCB hearing. Engaging in a legal process such as that provided by the CCB can promote dialogue that is respectful and result in expeditiously serving the best interests of the patient. Although we are unaware of any jurisdictions with processes similar to that of the Ontario CCB, the same process of identifying best interests and ensuring that surrogates are acting in good faith can ensure a patient-centered approach to EoL care in any hospital.

Finally, the many unique and notable processes for resolving EoL disputes in different jurisdictions should now be evaluated against one another to ensure that similar standards are being used to determine the best interests of patients.

References

[21] M.B. (Re) COCCB.