



# Best interests at end of life: an updated review of decisions made by the Consent and Capacity Board of Ontario<sup>☆</sup>

Paula Chidwick PhD<sup>\*</sup>, Robert Sibbald MSc, Laura Hawryluck MD, FRCPC<sup>1</sup>

*William Osler Health System, London Health Sciences Centre, Schulich School of Medicine and Dentistry, Western University, University Health Network, University of Toronto*

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## Abstract

**Purpose:** To increase our understanding of the notion of “best interests” in end of life disagreements through an updated review of decisions made by the Consent and Capacity Board of Ontario. There was a significant increase (235%) in decisions from this tribunal between 2009 and 2011. “Best interests” test is used when no prior expressed wishes are known to the surrogate decision-makers.

**Methods:** Purposively sampled written decisions of the Consent and Capacity Board of Ontario between 2003 and 2011 that focused on the “best interests” of patients at the end of life. Interpretive content analysis was performed independently by 3 reviewers, and themes were identified by consensus.

**Results:** We found substitute decision makers (SDMs) rely on an appeal to their own values or religion in their interpretation of best interests; physicians rely on clinical conditions; board emphasizes alignment with Health Care Consent Act. In the more recent cases, we found that SDMs report that patients value suffering; that SDMs have unrealistic hope for recovery and can communicate and get direction from the incapable patient; that SDMs need education on their role and responsibility as SDM; and that SDMs need time to provide consent, and that most proposed treatment plans that were sources of conflict included “palliative care.”

**Interpretation:** Several lessons are drawn for the benefit of health care teams engaged in disagreements at end of life with SDMs over the best interests of patients.

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## 1. Introduction

Disagreement between proxy or substitute decision-makers (SDMs) and physicians about how to care for

patients at the end of life continue to result in court cases across Canada [1-4] and internationally [5,6]. Where patients are unable to participate in decision making either directly or through advance care plans, a common approach to resolving these disagreements is to appeal to a patient’s “best interests” [7-10]. Generally, best interests take into account both patient’s considerations (ie, values and beliefs), and medical considerations (ie, which treatments are indicated and how likely they are to provide benefit, etc). Despite a common framework from which to address the patient’s clinical condition and values, disagreement on what constitutes best interests for individual patients persist.

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<sup>\*</sup> Corresponding author. Tel.: +1 905 494 2120x56630.

*E-mail address:* [Paula.chidwick@williamoslerhs.ca](mailto:Paula.chidwick@williamoslerhs.ca) (P. Chidwick).

<sup>1</sup> Dr Hawryluck has been involved in 2 of the CCB cases reviewed and has written an affidavit to the Supreme Court that discusses how a pending critical care case raises issues of national importance to all Canadians.

In Ontario, best interests are determined via the consent process as outlined in the Health Care Consent Act (HCCA) (See [Box 1](#)). The physician first considers what treatment(s) are indicated according to the standard of care, determines if there are any relevant prior expressed wishes or values of the patient, and then proposes a plan of treatment to the SDM to seek consent or refusal. It is then the role of the SDM to consent or refuse the proposed treatments [7]. This is different from, for example, in the UK, where physicians determine best interests and do not require a family's consent to act on this determination [8]. Ontario is also unique in that where a physician believes that an SDM's refusal to consent to a treatment plan is not in the best interests of the patient, then that physician can involve a neutral third party called the Consent and Capacity Board (CCB). The CCB can then decide whether the SDM properly followed the legislation, effectively determining what constitutes the legally interpreted best interests of the patient. The decisions of the CCB have proven valuable in developing the notion of best interests in practice, in particular, where disagreement is most troubling at end of life [11].

Past research on best interests as interpreted by physicians, family members, and the CCB show that SDMs often conflate

Box 1 Sec. 21(2) of the HCCA (1996).

In deciding what the incapable person's best interest are, the person who gives and 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 wellbeing.
    - ii. prevent the incapable person's condition or wellbeing 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 wellbeing is likely to improve, remain the same or deteriorate without 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.

a patient's values with explicit wishes, that religious values and positions have no bearing on a patient's best interests unless they can be specifically demonstrated to have been held by the patient, that SDMs are more likely to focus on their own values rather than the patient values, and that a patient's "condition" required assessment of more than life itself [12]. Since 2009, there has been a dramatic increase in the use of the CCB to resolve end of life disagreement (2 per year between 2003 and 2008 to 5 per year between 2009 and 2012). In addition, this increase has been accompanied by international attention on the CCB's effectiveness on resolving disagreement [13]. As such, we felt it was appropriate to review these new decisions in order to determine if there is anything new to learn regarding how best interests are interpreted by physicians, SDMs, and the law.

## 2. Methodology

We searched a public online, nonprofit database managed by the Federation of Law Societies of Canada [14] to search for relevant CCB decisions available from 1996. In total 1367 cases were collected. Out of these, purposive sampling was used to identify those concerned with the best interests of patients regarding treatment issues at the end of life. In total, we identified 26 decisions. An analysis of the first 12 of these cases was reported in 2009 [12]. The 14 new cases were similarly independently read and analyzed by three researchers (R.S., P.C., and LH), and then consensus was reached on themes and codes. First, cases were read to identify statements 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 been involved in CCB cases by assisting health care teams access and were previously familiar with the nature of arguments prepared for such hearings.

In total, 28(100%) decisions constitute a purposive, illustrative sample of end of life disputes to examine 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 the role of best interests.

## 3. Results

A summary of all CCB cases concerning end of life is listed in [Table 1](#). Of these cases, proposed treatment plans commonly suggested withdrawal of life sustaining treatments, the majority of decisions favored the opinions of the physician, and more than a quarter of all cases were appealed. The frequency of end of life cases brought to the CCB increased in 2009. Of note, 38% (n = 5) of cases between 2009 and 2012 were dismissed (finding the SDMs

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