Physician Perspectives on Legal Processes for Resolving End-of-Life Disputes

Paula Chidwick and Robert Sibbald

Abstract
In order to understand how to effectively approach end-of-life disputes, this study surveyed physicians’ attitudes towards one process for resolving end-of-life disputes, namely, the Consent and Capacity Board of Ontario. In this case, the process involved examining interpretation of best interests between substitute decision-makers and medical teams.

Physicians who made “Form G” applications to the Consent and Capacity Board of Ontario that resulted in a decision posted on the open-access database, Canadian Legal Information Institute (CanLii), were identified and surveyed. This purposive sample led to 13 invitations to participate and 12 interviews (92% response rate). Interviews were conducted using a prescribed interview guide.

No barriers to the Consent and Capacity Board process were reported. Applications were made when physicians reached an impasse with the family and further treatment was perceived to be “unethical.” The most significant challenge reported was the delay when appeals were launched. Appeals extended the process for an indefinite period of time making it so lengthy it negated any perceived benefits of the process. Benefits included that a neutral third party, namely the Consent and Capacity Board, was able to assess best interests. Also, when decisions were timely, further harm to the patient was minimized.

Physicians reported this particular approach, namely the Consent and Capacity Board has a mechanism that is worthwhile, patient centred, process oriented, orderly and efficient for resolving end-of-life disputes and, in particular, determining best interests. However, unless the appeal process can be adjusted to respond to the ICU context there is a risk of not serving the best interest of patients. Physicians would recommend framing end-of-life treatment plans in the positive instead of negative, for example, propose palliative care and no escalation of treatment as opposed to withdrawal.

Background
In hospital, when patients near the end of life, they are often unable to direct their own care. In these situations family members are usually consulted regarding any previously expressed wishes, advance directives, or to determine best interests. Rules to guide how decisions are made for incapable patients are usually legislated but vary from jurisdiction to jurisdiction. However, despite the locale, end-of-life decision-making is often difficult for families and clinicians and can involve conflict (Azoulay et al. 2009; Day 2007). Cases that result in conflict often involve an unresponsive patient with a poor prognosis (Sibbald and Chidwick 2010; Slutsky and Hudson 2009).

The management of end-of-life conflict varies from jurisdiction to jurisdiction. For example, in the state of Texas, a hospital
ethics committee can review such cases and make decisions about the “futility” of particular treatments that may result in a decision to withdraw life-sustaining treatment. These decisions cannot be appealed; however, a state court may be petitioned for the purpose of delaying the withholding or withdrawal of a life sustaining treatment while another healthcare provider is sought to care for the patient (State of Texas 1999). The Children’s Hospital in Boston has similarly developed a policy that allows ethics committees to make final decisions regarding withdrawal of life-sustaining treatment (Truog 2009). When these decisions are made families have the right to seek a court order to intervene. In the UK, the courts may be involved to address end-of-life cases (Oates 2000), though the British Medical Association’s own Guidance for Decision Making on Withholding or Withdrawing Life-Prolonging Medical Treatment advises that in situations where life prolonging treatment is not a benefit to the patient, review by courts should not be routinely sought (BMA 1999). Legal scholars in the United Kingdom advise that “passive actions” such as do not resuscitate (DNR) orders do not require the court’s authority (Oates 2000). In Manitoba, the College of Physicians and Surgeons produced a policy statement that gives physicians unilateral authority to make end-of-life decisions when there is conflict (Zivot 2010). The courts can intervene in these decisions as well (Golubchuk v. Salvation Army Grace General Hospital et al. 2008). Finally, in pediatric cases, several jurisdictions allow for intervention of a child’s aid-type service. This may result in a final decision taken by children’s aid or a hearing before a family court judge. Both the unilateral decision-making supported by the Manitoba Guidelines and the hospital ethics committee approaches of Texas and Boston have come under criticism (Harvey 2010; Truog 2009). Outside of Texas, then, the most common approach to dealing with conflict is for the team or ethics committee to make a decision and for families to apply to the courts for injunctions. Once before the courts, however, several legal questions can arise, for example: Is consent required for acts of omission (e.g., withholding) or just acts of commission (e.g., withdrawal)? Can the court force a healthcare professional to act in a manner contrary to his professional opinion (Rotaru v. Vancouver General Hospital Intensive Care Unit 2008)? Are hospitals liable for treatment decisions taken by its staff? And what is in the best interests of the patient? Further, the traditional court process works on a time frame measured in months and sometimes years, which has in some cases resulted in patients succumbing to their illness, despite all interventions, before a ruling can be reached on what was in the best interests of the patient (Child and Family Services of Central Manitoba v. Lavallee et al. 1997; Golubchuk v. Salvation Army Grace General Hospital et al. 2008; In Re. Claire C. Conroy 1985), and in other cases has resulted in outcomes where the ruling was too late to have any impact on the patients outcome (e.g., Karen Ann Quinlan [In Re. Quinlan 1985]).

In Ontario, the Health Care Consent Act (Health Care Consent Act 1996) stipulates that the substitute decision-maker (SDM) is required to base decisions on prior capable expressed wishes of the patient, and if these wishes do not apply to their current condition, are impossible to comply with or are not known, then the SDM shall act in the incapable person’s “best interests.” If a physician feels that a SDM is not acting in accordance with the patient’s best interests, they can make an application to the Consent and Capacity Board (CCB), an independent tribunal who will hear the case and make a binding decision on this specific question in a matter of days (Handelman and Parke 2008). The Consent and Capacity Board was created to address questions of application of the principles of consent and capacity as governed by the Health Care Consent Act in Ontario.

In pediatric cases, several jurisdictions allow for intervention of a children’s aid-type service. This may result in a final decision taken by children’s aid or a hearing before a family court judge. The prevalence of end-of-life conflict between patients and healthcare providers is difficult to quantify, particularly as some conflict may be necessary. We have no doubt that the vast majority of end-of-life conversations are well managed and require no formal conflict resolution processes. But given the frequency with which physicians indicate that they are providing medically “futile care” (Palda et al. 2005; Sibbald et al. 2007), and given the lack of any description of physicians’ perspectives on the various approaches to resolving end-of-life conflict when traditional approaches (e.g., mediation, communication strategies, hospital policies and/or exploring patient transfer) have been exhausted, we believe examining the approach from Ontario and its Consent and Capacity Board, can offer valuable lessons that might be extended to other approaches to end-of-life disputes.

Methods
Participants were identified by using an open-access database, the Canadian Legal Information Institute (www.canlii.org), where names and institutions are filed on the decisions from CCB hearings. The criterion for inclusion was that anyone who initiated a Form G application and was named in a decision available on the CanLii website from October 1996 to 2009. From this search, 13 cases were identified. This purposive sample led to 13 invitations to participate and 12 interviews (92% response rate). Interviews were conducted using a prescribed interview guide (see Appendix). The purpose of the interview was not to
recount details of the specific cases but, rather, to understand why physicians chose to make an application to the CCB and what they thought of the effectiveness of the process.

Interviews were not audio recorded but detailed notes were taken by both researchers (P.C. and R.S.) during the interview and written up immediately afterwards. Notes were compared and amalgamated to create a single interview summary. The interview summary was shared with the interview participant for member checking to ensure accuracy. The interview summaries were then analyzed (independently at first, and then collaboratively) for convergent themes regarding physician perspective on accessing the CCB process for challenging interpretation of best interests at the end of life.

Results
No Barriers to Initiating the Process
Before making an application to the CCB physicians generally perceived no barriers to the process, although there were questions about what the process entailed and how much time it might take away from bedside obligations. In most cases, it was not their first application to the CCB and more than half had learned about the process from ethicists. Before going to a hearing, physicians surveyed first sought consensus with the family using all available resources to mediate and provide conflict resolution.

At the point of impasse with a family, there were varied opinions ranging from the CCB as a positive way for families to have their positions formally heard to the more reluctant position that the CCB was a “last resort” as it may further “alienate” the family. Several acknowledged that it was easier to “just keep you head down and sign off problems to the next doctor (on rotation)” than to make these kinds of applications to the CCB. The common theme among participants who did take their cases to the CCB was a sense of obligation captured in the following quotation: “From an ethical or professional point of view, it would have been wrong to take no action.”

Participants reported they would avoid the CCB if they anticipated the imminent death of the patient even if it was their perception that “the family was clearly not making decisions that the patient would want.” In other words, it was seen as inappropriate to additionally burden the family with a CCB application: “Making an application seemed prohibitive when considerations of what families would go through in this process were taken into account.”

Physicians Accessing the Process
Applications were made when physicians reached an impasse with the family. In other words, there were significant divergent views on what each party thought was the best interests of the patient. The family was not comfortable with what the treatment proposed and the team felt that ongoing participation would result in further harm to the patient, was “unethical,” not in the best interests of patient and not acting in accordance with legislated instructions as outlined in the Health Care Consent Act of Ontario (1996). Obligations to do no additional harm were strongly expressed. One physician stated, “The cruelty that we inflicted on the patient … it felt like torture; it felt very wrong. There was no benefit at all to the patient, and I was not in a bystander role. I was the one doing this to the patient.” In such cases, applications were triggered by physician distress (Table 1).

<table>
<thead>
<tr>
<th>TABLE 1. Reasons for making Consent and Capacity Board application</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impasse with family</td>
</tr>
<tr>
<td>Aggressive treatment was not in best interests</td>
</tr>
<tr>
<td>Aggressive treatment would result in further harm</td>
</tr>
<tr>
<td>Moral distress</td>
</tr>
<tr>
<td>Substitute decision-makers acting in own interests</td>
</tr>
</tbody>
</table>

Challenges
Participants reported four main challenges in the process of applying to the CCB (Table 2). First, team and family dynamics were challenging (e.g., families were angry, there were strong emotions and strained relationships between family members and between the family and team). It was difficult to have regular meetings once the process was activated, as typical decision-making at this point was suspended. Some family members refused to even meet without their lawyers present.

<table>
<thead>
<tr>
<th>TABLE 2. Challenges in the Consent and Capacity Board process</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strained team–family dynamics</td>
</tr>
<tr>
<td>Time commitment</td>
</tr>
<tr>
<td>Appeals process</td>
</tr>
<tr>
<td>Knowledge gaps</td>
</tr>
</tbody>
</table>

Second, there were practical challenges mostly regarding time commitment (e.g., the time it took to receive faxes, negotiate with hospital administration, meet and speak with lawyers, go to hearings, make phone calls), writing clinical summaries and not having legal support. “The hearing took so long to set up – six weeks is a lifetime in an ICU.”

Third, there were significant challenges when a hearing ended with a decision that could not be acted upon because of a decision to initiate an appeal. Over a third of the cases our
participants were involved in went to appeal. One physician stated, “When the hearing was over and we won it wasn’t over because there was an appeal. An appeal drags the process out for an indefinite period of time and it becomes so lengthy it defeats the benefits of the process.” And, “What is challenging is that even after a decision it is not the end. The family has right of appeal. It is not resolved. So has anything been resolved in accessing this process” The appeal process, it was reported prevented decisions made by the CCB in the patient’s “best interests” from reaching the patient. Some concluded that because the appeals process was often so long, perhaps the CCB (as it is set up now) was not the best process for determining best interests for ICU patients. Moreover, while the patient waits for the appeal a whole new set of best interests “in keeping the patient alive” are raised. In other words, the best interests of a patient may be different in the context of a legal case that requires physicians to maintain the status quo throughout the length of the legal battle.

“The CCB offered a powerful tool that could benefit the patient – it could assist in evaluating best interests.”

Some reported that the appeal process prevented decisions from being made for the patient and promoted decisions desired by the SDM. “It became a mechanism suited to the [SDM] interests rather than the patients. And because it took so long it became meaningless in terms of serving the best interests of the patient.” And, “There are winners and loser in this process—we kept winning but we also kept losing because we could not withdraw life support—essentially act in the best interests of the patient—even though we won every appeal we lost because we were never able to act on it for the patients interests—it was all about the [SDM] all the way.”

Finally, physicians reported challenges around perceived lack of knowledge. First by the CCB about the ICU context, patient and setting including the gravity of these types of case; by the public guardian and trustee appointed to represent the patient in this process about the ICU patient and nature of the setting; and by the physicians in terms of understanding the CCB process, steps, preparation of clinical summaries and so on.

Benefits
Benefits were reported in terms of a decision being made in the best interests of the patient, that is, “did no further harm to patient” (Table 3). The process revealed a clear decision-maker and there was a sense that the CCB was a neutral third party, which removed any perception of conflict of interest in the physician’s role. One physician remarked, “The CCB offered a powerful tool that could benefit the patient – it could assist in evaluating best interests.” The hearing gave an opportunity for the different clinical and family perspectives to be heard; to hear about opinions that may not have been well explained; it promoted discussion “where participants can meet in the middle and it helped to settle down hurt and grievance on both sides.”

<table>
<thead>
<tr>
<th>TABLE 3.</th>
<th>Benefit in the Consent and Capacity Board process</th>
</tr>
</thead>
<tbody>
<tr>
<td>An authoritative decision is made.</td>
<td></td>
</tr>
<tr>
<td>The Consent and Capacity Board is perceived as neutral third party.</td>
<td></td>
</tr>
<tr>
<td>It is a forum for diverse opinions to be heard.</td>
<td></td>
</tr>
<tr>
<td>It gives a voice to the patient.</td>
<td></td>
</tr>
</tbody>
</table>

Overall, the process resulted in fewer family arguments; it gave a “voice to the patient’s needs; advocating for their welfare so they can die peacefully and comfortably rather than slowly and with suffering.” Most did not see any direct benefits for the team. The process consumed a lot of “moral energy” especially when there were delays and appeals. In only one case did staff feel supported and that someone listened to their concerns that they were providing care they did not think was appropriate.

**Recommending the Process to Colleagues**

All but one physician would recommend this process to their colleagues, remarking “the alternative to not going to the CCB is worse than going.” They added that all other resources ought to be exhausted first; physicians should assess whether the SDM might appeal a CCB decision (because this could significantly delay the process, or result in a worse outcome); physicians should consult with colleagues, the CCB and the Canadian Medical Protective Association (CMPA) for advice; and most importantly, if going forward, they should frame the treatment plan in the positive instead of negative, for example, propose palliative care and no escalation of treatment as opposed to withdrawal. In general, the process was reported as worthwhile, it was orderly and efficient and that they would make the time to do it again.

**Discussion**

No significant barriers were perceived to accessing the CCB and it would be recommended by 12 of the 13 to use as an effective resource to resolve disputes about best interests at end of life. Physicians did not use this process when patients were imminently close to death, despite all available interventions, such that there was no perceived benefit from making an application.

The applications were universally made when an impasse was reached with the family and after all available resources were
exhausted to resolve the impasse. In addition all physicians viewed further treatment as harmful to the patient and as such “unethical” to continue.

Appeals represent the most significant challenge in meeting and acting on best interests via the CCB. Given the unique ICU environment and the importance of timely decisions (e.g., measured in hours not weeks), an appeals process that is as expedient as the initial hearing may be required. As is, the appeals process delays decisions (proposed treatment plans) from being acted upon and therefore prevents actions that would benefit patients. At the end of the day, the intensivists and their teams are the only ones with the technical knowledge to treat these patients and as such need timely direction from courts or tribunals in treating the patient appropriately. In the absence of an expeditious appeal process treating the patient becomes increasingly difficult because the goal of care is indeterminate. Neither the SDM’s interpretation of best interests nor the physician’s interpretation can guide treatment decisions, but rather care becomes guided by the need to keep the patient alive long enough to endure the appeal. In cases where best interests are deemed by the physician (sometimes upheld by the CCB) to include limiting further aggressive treatment or withdrawal of treatment, this creates significant moral distress. In such a case, it is perceived that the appeal results in more harm to the patient than if no application had been made to the CCB in the first place.

The most significant benefits were reported in terms of “decisions being made in the best interests of the patient, that is, did no further harm to patient” and promoting a better communication between participants. Finally, it gave “voice” the patient’s needs. Overall, it was reported that the process was effective and worthwhile, orderly and efficient, and participating physicians would take the time to do it again.

While an apparent limitation of this study is its small sample size (n = 13), this figure must be contextualized. Our study involves only those end-of-life cases where conflict escalated to the point of requiring an outside panel to assist in decision-making. At the time of this study, there were only 14 end-of-life cases that had resulted in CCB involvement. Given this, we feel our response rate of 93% (13 of 14) is reasonable. This research was approved by the William Osler Health System’s Research Ethics Board.

**Conclusion**

Some argue that end-of-life disputes are relatively uncommon and can be addressed by use of the shared decision-making models (Luce 2010). White et al. suggest physicians using this model should discuss the nature and likely outcome of a given illness, explore the ramifications of forthcoming decisions, determine patient values, confirm that patients or families understand the information provided them, discuss preferred roles in decision-making, and achieve consensus about treatment courses that are most consistent with patient values. (2007). While this is a model representative of good clinical practice, there will always be difficult cases where consensus is simply not achievable. Further, it has been argued that none of the internal dispute resolution mechanisms in Manitoba and Texas are sufficiently fair and legitimate. (Pope 2010), and pressure to find approaches to resolving disputes at end of life and regarding what constitutes best interests are increasing (Frezza et al. 1998; Gilmer et al. 2005). While communication skills remain the focus of work to resolve end-of-life disputes (Alexander et al. 2006; Lautrette et al. 2007; Lorin et al. 2006), the CCB offers a quasi-legal approach to substitute when these other approaches are not sufficient.

**While an appeals process is fundamental, it must be able to provide direction quickly to minimize further harm and maximize benefits to the patient.**

Physicians reported that the CCB is a worthwhile, patient-centred, orderly, process-oriented and efficient approach for resolving end-of-life conflict and, in particular, determining best interest. They also reported that they would do it again if the appropriate case arose. However, an appeal of the decisions at the end-of-life can significantly minimize the benefits of determining best interest. While an appeals process is fundamental to fairness (Daniels and Sabin 2002), it must be able to provide direction quickly in order to minimize further harm and maximize benefits to the patient. This is one of the same criticisms of the traditional injunctive process for resolving end-of-life disputes. Finally, physicians found it useful to framing end-of-life treatment plans in the positive instead of negative (e.g., propose palliative care and no escalation of treatment as opposed to withdrawal). This avoided the legal conundrum of what constitutes best interests are increasing (Frezza et al. 1998; Gilmer et al. 2005). While communication skills remain the focus of work to resolve end-of-life disputes and regarding what constitutes best interests are increasing (Frezza et al. 1998; Gilmer et al. 2005). While communication skills remain the focus of work to resolve end-of-life disputes and regarding what constitutes best interests are increasing (Frezza et al. 1998; Gilmer et al. 2005). While communication skills remain the focus of work to resolve end-of-life disputes.

**References**


*Health Care Consent Act.* S.O. 1996. c. 2, Sch. A.

In Re Claire C. Conroy 486 Atlantic Reporter 2d. 1209 (New Jersey Supreme Court 1985).

In Re. Quinlan 79 American Law Reports 3d. 205 (New Jersey Supreme Court 1985).


About the Authors

Paula Chidwick, PhD, is director clinical & corporate ethics/ ethicist at the William Osler Health System, in Brampton, Ontario.

Robert Sibbald, MSc, is a clinical ethicist with the London Health Sciences Centre, in London, Ontario.

Appendix: Interview Questions

1. Before making an application to the Consent and Capacity Board were there any perceived barriers to the process?
   a. Was this your first application?
   b. How did you learn about the process?

2. What made you decide to go forward with the application?
   a. What challenges did you find in the process?
   b. What was the hardest part of the process?

3. What were the benefits of this process?
   a. For you and your colleagues?
   b. For the patient?
   c. What worked well?

4. What would you recommend to colleagues who are unsure of whether or not the process would be appropriate for them?

Note: Since the completion of this paper there have been nine more cases.