

The Beneficial Role of a Judicial Process When "Everything" Is Too Much?

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Abstract:

This narrative is written with the intent to encourage physicians as well as other healthcare professionals to use judicial processes, such as those provided by the Ontario Consent and Capacity Board, to help resolve conflict with treatment decisions between care providers and decision-makers. Through the presentation of a fictional yet common case scenario, it is argued that after all attempts at mediation have been attempted that the timely use of a third party is in the patient's, the family's and the healthcare team's best interests.

Recently there has been media attention about two families who have involved the legal system to challenge end-of-life decisions recommended by the medical care providers. The first case involved a family in Alberta who contested the do not resuscitate (DNR) order made by an MD, and the second case involved a Winnipeg family contesting the decision of medical staff who want to withdraw life support from a person for whom ventilator support is deemed to be of no benefit. In this article, a fictional scenario familiar to healthcare professionals involved in end-of-life care decision-making is presented to illustrate the challenges of a difficult case, the process and benefits of involving a neutral party and some lessons learned. The overall argument presented in this article is that when all mediation attempts have failed, involving a neutral third party like Ontario's Consent and Capacity Board (CCB) is in the best interest of the staff, the family and, of foremost importance, the patient. (CCB is an independent body created by the provincial government of Ontario under the Health Care Consent Act. It conducts hearings under the Mental Health Act, the Health Care Consent Act, the Personal Health Information Protection Act and the Substitute Decision Makers Act. Board members are psychiatrists, lawyers and members of the

general public appointed by the lieutenant governor in council.)

CASE SCENARIO

An elderly patient was admitted to hospital with a progressive and terminal illness from which there was no hope of recovery. The patient was admitted to the intensive care unit as he was ventilator dependent due to poor respiratory function. This patient also required a percutaneous endoscopic gastrostomy tube for nutrition and hydration. Further complications arose, including diminished kidney function, internal bleeding, rashes and serious bed sores. The patient was in obvious, ongoing discomfort, which was exacerbated each time dressings on his bed sores had to be changed - and this was done frequently due to the contamination from diarrhea consequent upon tube feeding. Treatment options such as dialysis, angiography and surgery to identify where the bleeding was occurring and to respond to it were too risky, and there were no benefits in the short or long term to proceeding.

This scenario was further complicated by the patient's *incapacity* to participate in treatment decisions and the role of the family members who were the substitute decision-makers (SDMs). (*Capacity* means that a person is capable with respect to treatment, admission to a care facility or a personal service if the person is able to understand the information that is relevant to making a decision about treatment, admission to a care facility or personal assistance service and able to appreciate the reasonably foreseeable consequences of a decision or lack thereof. An *SDM* is a person who is authorized to give or refuse consent on behalf of a person is incapable with respect to treatment.) The SDMs were the patient's children, determined according to the hierarchy of SDMs set out in Section 20 of Ontario's Health Care Consent Act. It seemed to the patient's treatment team that the patient's children were not ready to accept their father's death and could not recognize that it was imminent.

Unfortunately, this patient never discussed his end-of-life wishes with his family, so they had no guidance from him. Nonetheless, the healthcare team was obliged to involve the SDMs in the treatment decision process as proxies for the patient.

Using a word that is familiar to most healthcare practitioners, the patient's SDMs demanded that the healthcare team do "everything" to keep the patient alive, including procedures that would be very risky and have no benefit to either the patient's prognosis or quality of life. The SDMs were also resistant to the patient receiving pain medication, believing this would cause or hasten the patient's death.

As in many of these cases, the healthcare team, including doctors, nurses, social workers, a bioethicist and management, spent many hours communicating with the family to update them on the patient's condition and treatment plans and to respond to their inquiries. There were also numerous phone conversations with the family at all hours of the day when they called to request updated information, ask for interventions to be done and challenge the care being provided.

This scenario reflects a common situation in many healthcare settings; such situations have the effect of taxing limited resources and creating moral distress for the staff who feel that there are more humane forms of care available. Certainly one of the first questions that should be asked is whether this patient should have been admitted to the intensive care unit (ICU) given his diagnosis and prognosis. While it could be argued that denying the admission of patients such as this to the ICU is appropriate, it creates an immediate situation of conflict and confrontation between families/SDMs who want everything done and the staff who feel that such treatment would be inappropriate. As well, the futility or inappropriateness of treatment is not a legal ground for withholding it - nor is it legal to discontinue a treatment because it is futile. This is because the Health Care

Consent Act requires treatment in accordance with consent obtained. Therefore, a health practitioner who disagrees with the SDMs' decisions is obliged to assist in finding a treatment team who agrees with the SDMs, to treat according to the consent given or to apply to CCB to challenge the SDMs' decisions. In Ontario, as in many other jurisdictions, there is a renewed look at the admission, discharge and triage criteria for critical care utilization that may give some guidance in these types of situations; but for now, these remain pending.

CONSENT AND CAPACITY AS A RESOURCE

When all attempts to mediate and negotiate treatment decisions fail, what options exist for the healthcare providers to resolve this type of conflict? There are methods to challenge substitute treatment decisions. In Ontario, the method is an application to CCB. CCB is a quasi-judicial body that assists healthcare team members and families to make difficult treatment decisions, especially when there is conflict about what should be done. When there is unresolved conflict between members of the treatment team and SDMs, one of the roles of CCB is to determine whether or not the SDMs are giving or refusing consent to treatment in accordance with the principles for doing so. Those principles are stated in s. 21 of the Health Care Consent Act. When "in-house" conflict resolution fails, CCB can mediate. If this mediation fails, CCB adjudicates - and its decision is binding upon the parties, subject only to appeal to the Ontario Court of Justice. If CCB agrees with the health practitioner, it directs the SDMs to give consent to treatment as proposed by the health practitioner; if they do not, the SDMs cease to be SDMs for the purpose of that decision.

CCB is therefore an important resource for health practitioners, not only to resolve conflict but also to assist them in obtaining lawful consent to treatment. In Ontario, for example, the Health Care Consent Act requires health

practitioners to obtain substitute consent not only from the right surrogates but also in accordance with the principles for giving or refusing consent. In other words, health practitioners' legal obligation to their incapable patients is to identify the right SDMs and get the right consent.

PREPARING FOR A HEARING: WHAT WAS DONE

Numerous family meetings were held with the healthcare team family and SDMs to update them on the patient's condition and to agree on the best treatment options for the patient. When resolution of the conflict between "doing everything" and providing comfort care could not be achieved, a family meeting with the attending doctor and the bioethicist took place to inform the SDMs that an application to CCB for a review of their treatment decisions was being initiated. The treatment team informed the family of the reason for the hearing, application process and time frames within which a hearing would take place. In Ontario, CCB is mandated to hold a hearing within seven days of the application, but quicker hearings are possible depending on urgency. As part of our process, CCB reviewed the sections of Ontario's Health Care Consent Act identifying decision-makers (s. 20) and the principles for giving or refusing consent (s. 21).

Before proceeding with the application for a hearing, a few key things had to be done as part of due process. First, the health care team established that the patient had been assessed as incapable with respect to the treatment being proposed. Secondly, they ensured that this finding was documented because the hearing would begin with a review of the finding of incapacity - if this were not confirmed, the patient would be "deemed" capable to make his own decisions. Thirdly, they made sure that a doctor would be available, be willing to sign the application and be present at the hearing. The health care team further ensured that hospital administration and risk management were aware that they were proceeding with

the application to CCB. Lastly, they encouraged the doctor to inform his medical insurer that they were embarking upon this process.

As part of the process, consideration was also given as to whether a "collaborative" rather than an "adversarial" application could be made to CCB. In Ontario, a collaborative CCB hearing can be requested using Form D, to seek direction when capable wishes are uncertain, or Form E, to depart from previously expressed capable wishes. Both of these forms initiate a collaborative, non-adversarial approach by the healthcare team and the SDMs for CCB's assistance. However, neither of these approaches was viable given the resolute position that the family took. Consequently, a Form G application, which is used for a more adversarial hearing, was requested as the healthcare team felt that the SDMs were not acting according to capable wishes applicable to the circumstances or in the best interest of the patient as set out in the Health Care Consent Act.

With these things done, the attending physician signed the Form G application, with a treatment plan appropriate to the patient's needs attached. In this case, the proposed treatment was comfort care/palliation, which would include pain management. When the form was completed, it was faxed to CCB. Almost immediately CCB staff began a pre-hearing process of contacting involved parties, both the hospital and SDMs. In some instances, a pre-hearing by a third party can mediate the differences. In this case, a pre-hearing was initiated but mediation was not possible. Within three days of filing, the application a hearing was scheduled to take place.

OUTCOME

The case came to its own conclusion when this elderly patient had a cardiac arrest a day before the hearing date. Cardiopulmonary resuscitation was initiated but unsuccessful, as was expected given the diagnosis,

prognosis and multiple co-morbidities. It is arguable that this patient could have died a more dignified and peaceful death than occurred.

LESSONS LEARNED

Over time both practitioners and CCB have learned several lessons from cases such as the one presented. These following lessons should be kept in mind when dealing with future such cases.

Impact on the Family

Initiating a hearing is always the last resort and should not be started until due diligence has taken place to resolve or mediate the conflict over treatment decisions. It is important in these situations to consider how the person became ill and why the person needs hospital care. When a person had been a thriving, active, healthy individual but is struck down by a sudden debilitating illness like a burst aneurysm that causes significant brain damage or even brain death, families will need time to grieve the loss of the person they knew. The shock of these situations requires us to be patient with the family as they come to terms with the change in their loved one from independence to dependence. We also need to expect that families will want to be assured that the diagnosis and prognosis are correct. This may mean that they will seek alternate opinions. They will also want to be assured that all that can be done has been done. Most often, families come on their own to the decision to withdraw treatment or treat palliatively.

In situations of a progressive illness, it is still a shock to family when their loved one becomes seriously ill and is on the threshold of death, even though the evolution of the disease is evident. Ideally, people with progressive illnesses should be routinely reassessed and treatment

options discussed as their condition evolves, thereby limiting surprises and hopefully leading to treatment decisions being made that are truly beneficial, including the treatment of any psycho-social or spiritual pain.

In cases where there is disagreement but the patient is not suffering acutely, we have more time to build treatment consensus with the healthcare team, family and SDMs. However, if the patient is suffering acutely, it is important to take immediate steps to alleviate the suffering. When all reasonable avenues of conflict resolution have been exhausted, it is appropriate and in the patient's best interest to use the third-party option of going to a CCB hearing.

It is equally important to lay out the procedure for resolving the conflict as early as possible so that family members do not feel "bushwhacked." Often when the treatment team recommends a decision with which SDMs disagree, the SDMs first hear it from the attending physician, then from other members of the team, the patient advocate, a social worker, possibly a chaplain and sometimes a member of the hospital's risk management team. Finally, someone mentions the legal process. It is no surprise that SDMs frequently feel that they are under attack when, from their perspective, all they are trying to accomplish is that "everything be done" for a loved one.

Health practitioners should also keep in mind that a collaborative application to CCB, as described above, might be an option and that CCB through a pre-hearing is prepared to mediate disputes between SDMs and health practitioners before commencing a formal hearing.

Impact on the Team

One of the significant outcomes of cases like the one presented is the negative impact on the team. In these situations, staff commonly experience moral distress as they want to do the right thing to alleviate suffering but

cannot. Cases such as this evoke strong emotional responses such as anger as well as antipathy toward the family and patient, making staffing more difficult. Another emotion that can impact the team is the feeling of unfairness to the quiet, compliant patients who are not getting as much time as the "difficult" patient and family. Sometimes going to CCB sooner may help staff feel that a resolution is being worked on and enable them to cope better. Taking into concern the reaction of staff to difficult cases demonstrates good organization ethics and helps prevent the serious consequences of moral distress such as decreased job satisfaction and employee loss.

Issue of Professional Licensure

A further lesson learned is that there was a belief that going to CCB could affect professional licensure. In fact, the College of Physicians and Surgeons encourages applications to CCB to resolve treatment disputes between its members and SDMs. This misunderstanding was a barrier that inhibited some staff from considering the use of this resource. Overcoming this barrier was achieved through education provided by CCB members who went to hospitals to talk about their role and answer questions about the law as it relates to treatment decisions. This was a beneficial experience for the care providers and helped us move forward.

Importance of Communication

One of the practical lessons learned was that having a brochure about decision-making and the law in lay terms is very helpful. A pamphlet enables both staff and family members alike to be familiar with who can make decisions and under what circumstances, how those decisions should be made and what to do if there is disagreement among decision-makers or if treatment decisions cannot be

agreed to between staff, SDMs and/or family.

Families are often in denial that nothing can be done to save the patient or restore his or her health. From their perspective, their loved one has been "written off." They see ongoing efforts to replace active treatment with palliative care as the hospital's need for the bed, as the treatment team's indifference to their loved one and/or as a financial decision. As different hospital staff attempt to reason with them, they see this as a barrage of callousness. Much of these perceptions could be avoided if a member of the treatment team explained, as soon as the issue arose, the steps that can (and will) be taken to resolve the dispute. It is equally important to explain that if a compromise cannot be reached, an independent quasi-judicial tribunal (such as CCB in Ontario) will make a legal, binding decision that can only be reversed on appeal through the courts.

As a matter of respect for the institution where one works and for good process, it is important to inform administration, including risk management, that an application is being considered. Administration may be able to help with resolving the conflict, they may be privy to information that should be considered before the application is filed and they need to be aware of the possibility of media coverage. Administration or risk management can also be a resource in obtaining legal advice and support.

ETHICAL LENS

The essential question of bioethics is, What should we do? The question of what we *should* do is first answered by the good that all care providers *want* to do. It is also answered by the values motivating the patient, the SDM and the healthcare providers. It is further answered by the medical facts including history, diagnosis, prognosis, symptoms and pain level. The law, which is referred to as the minimal ethic, also has a role to play in achieving the good and in

doing what we should. In this case scenario, the good is to relieve pain and suffering. From an ethics point of view, after exhausting all attempts to resolve the conflict over treatment decisions, using a legal remedy is not the minimal ethic but a significant ethic as it plays an important role in upholding the principle of beneficence.

RECOMMENDATIONS

Contingent on the specifics of each case, it is recommended that relevant healthcare professionals develop markers that give an indication that they have exhausted all reasonable in-house mediation attempts. When these markers have been met, then contact and application to CCB can be done in a timely way ensuring appropriate patient care is given. Another important recommendation is that the organizational values, such as respect for staff, be demonstrated through opportunities to help them with the moral distress they will inevitably feel as a result of working with difficult cases. Finally, the experience in Ontario shows that creating a similar system to CCB in other provinces would help healthcare practitioners and SDMs resolve issues respecting the needs of the incapable person in a prompt and expert way.

CONCLUSION

In an Ontario Court of Appeal case on appeal from CCB, the court had this observation about the role of the board:

[46] ... The disagreement between the S.D.M. and the health practitioner potentially creates tension and the Act recognizes this by providing for a neutral expert board to resolve the disagreement. Indeed, after hearing submissions from all parties, the Board is likely better placed than either the S.D.M. or the health practitioner to

decide what is in the incapable person's best interests. Thus, the Board should not be required to accord any deference to the S.D.M.'s decision. (M., A. v. Benes 1999) What is there to do when "everything" is too much? When the team has done all it can reasonably do to resolve conflict and SDMs are not giving or refusing consent to treatment in accordance with the principles for doing so, CCB in Ontario or its equivalent in other jurisdictions can be a resource to alleviate a patient's unnecessary suffering, the guilt families feel and the moral distress inevitably experienced by staff.

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