

A checklist to meet ethical and legal obligations to critically ill patients at end of life

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Abstract

Despite improvements in communication, errors in end of life care continue to be made. For example, health care professionals may take direction from the wrong substitute decision-maker, or from family members when the patient is capable; permit families to propose treatment plans; conflate values and beliefs with prior expressed wishes or fail to inquire about prior expressed wishes. Sometimes health care professionals know what prior expressed wishes are but do not respect them, or do not believe they have enough time to have an end of life discussion or lack the confidence, willingness and skills to manage one.

As has been shown in initiatives to improve in surgical safety, using a checklist presents opportunities to potentially minimize common mistakes and errors when engaging in end of life care. A checklist can help focus on what needs to be communicated rather than how it needs to be communicated. We propose a checklist to support health care professionals meet their ethical and legal obligations to patients at end of life. The checklist should minimize common mistakes and in situations where irreconcilable conflict is unavoidable, will ensure both healthcare teams and family members are informed and prepared.

Illustrative Case

An 84 year old patient is transferred to the ICU with respiratory failure due to hospital acquired pneumonia. Sheila has severe functional impairment, two stage 4 sacral wounds, and difficulty swallowing with a high risk of aspiration. While discharge home is unlikely Sheila's family and her SDM remain hopeful and

believe in her ability to rally. When Sheila suffered a respiratory arrest, a "full code" was run as per family's wishes; however after resuscitation it was apparent that she sustained a severe anoxic brain injury. The family continued to insist that "everything be done". A tracheostomy was performed and after some time in the ICU she was transferred to the floor. At this time the family began to report that Sheila was communicating with them. They are hopeful she will be back to her old self soon. One night she is again discovered in cardiorespiratory arrest due to aspiration of enteral feedings administered through a nasogastric tube. After another code her physician asked her family – "do you want us to keep treating her?" and the family responds, "it is not for us to decide when she dies – it is up to God to decide – and we cannot lose our grandmother right now – she means too much to us."

Introduction

Error in medicine has been defined as "failed processes that are clearly linked to adverse outcomes." [1] "Adverse outcomes" might be anything from longer recovery times to unnecessary suffering and death. However, the concept of medical error does not properly address mistakes that might arise while treating the 'dying patient'. Adverse outcomes at end of life require more thought because while traditionally in medicine death itself would be considered the worst of errors or adverse events it does not account for the fact that 100% of persons will die. Therefore, there may be better or worse ways to die (the philosophy of palliative care presupposes this fact) [2]. So error at end of life must consider adverse outcomes *other* than just death. When death is expected for a patient in the ICU or

elsewhere, there are several types of error that we do not always consider (Table 1).

TABLE 1.
Examples of 'error' at end of life:

Not acting on prior capable wishes
Not identifying legal substitute decision-maker(s)
Not explaining consequences of the treatment alternatives resulting in unrealistic expectations
Allowing a family members or SDM to 'direct' care resulting in treatment(s) that are not indicated

Repercussions of these errors include moral distress and moral residue for the family and treatment team [3-5]; prolonged stays in the ICU, and confusion, misunderstanding or conflict between team members or between health care professionals and family members [6,7]. These errors, when not identified, can also be the source of team-family conflict [3,8,9,10]. It has been suggested that end of life conflict should be addressed by creating policies and statements that guide healthcare professionals behaviour [3, 11-13] or defining notions of futility/inappropriateness [14,15]. While formally established professional opinions have provided information [16], such documents have done little to prevent end of life conflict [17]. Others have suggested that underlying all these errors is poor communication [7, 10, 18-20] and several mnemonics have been created to trigger important elements to raise in conversations (e.g. ASCEND, VALUE, etc) [21]. While these tools are useful in considering how one should communicate, they do not address what information is necessary to communicate in order to meet legal and ethical obligations to the patient. Further, if errors lead to conflict, they may actually be the source of communication problems rather than the other way around.

There is uncertainty regarding what constitutes an end of life conversation, (e.g., who should be involved, when it is appropriate, and what should be discussed) and also a lack of comprehensive documentation on end of life conversation [22]. For these reasons we propose a checklist that will support health care professionals to meet their basic ethical and legal obligations to patients at end of life, and documentation to support them. As has been shown in initiatives to improve in surgical safety [23], using a checklist presents opportunities to potentially minimize common mistakes and errors when engaging in end of life care. An effective checklist must be patient centered, process oriented and values driven.

Legal Framework

The checklist draws heavily from The *Health Care Consent Act* (HCCA) of Ontario because it is more detailed than the consent

laws from other jurisdictions (e.g. includes notions of withdrawal and withholding in its definitions) and also provides a novel process for resolving conflicts (i.e. Consent & Capacity Board) that has proven more efficient than traditional courts processes [24] that physicians find beneficial [25]. However, the broad ethical and legal principles are the same across Canada and this checklist could be used in any Canadian Province.

Checklist

In order to meet one's ethical and legal obligations and minimize errors when providing end of life care, we propose using this checklist (Table 2)

1. Ask the capable patient about his values and beliefs

Taking direction from a capable patient is required by the ethical and legal principles that underlie the principle of autonomy and The *Health Care Consent Act* [HCCA, 1996]. Sometimes, healthcare professionals turn to capable, caring informed families for direction on treatment decisions despite the presence of a capable patient. First, ask how your patient makes decisions in his/her family and/or how he/she would like decisions to be made. In some cases, a patient's or family's cultural values will reflect different models of decision making (e.g. elder family member makes all decisions or a group of family members or friends make decisions). Whatever the model of decision-making, it should be respected (within the law) and documented. Patients are presumed to be capable unless they no longer have an ability to understand the information required to make a decision or no longer have the ability to appreciate the consequences of making that decision [26]. It is only at this time that we can ethically and legally take direction from the substitute decision-maker. The HCCA also requires that the practitioner proposing the treatment be responsible for determining the capacity of the patient (http://www.e-laws.gov.on.ca/html/statutes/english/elaws-statutes_96h02_f.htm#s10s1). If the patient is deemed incapable, the practitioner must document finding of incapacity (and the reasons for it) and where appropriate explain the finding and its consequences to the incapable patient, advise of the right to challenge it and assist with that process if the patient indicates a desire to do so.

2. Ask the substitute decision maker about prior expressed wishes, and values and beliefs of the patient

In some end of life cases, the health care team will turn to the first identifiable family member to make decisions. However, it is the responsibility of health care professionals to identify the legally correct substitute decision-maker(s) to obtain consent. Culturally, there are many approaches to familial decision making. For example, some interpret kinship relations in a way that is not reflective of the HCCA interpretations of

kinship. In the HCCA, “brother” or “sister” means a genetically related or legally adopted individual. For others, “brother” or “sister” may be someone who has significant meaning in the patient’s life but is not legally related. In situations where there are multiple substitute decision makers, (siblings) a reasonable effort must be made to reach all of them. The HCCA sets out the hierarchy of substitute decision-makers and requires that they be *willing, available* and *capable* with respect to the treatment decision for which consent is sought. (http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_96h02_f.htm#s20s1). Substitute decision makers need to be informed of their obligations in decision making (http://www.e-laws.gov.on.ca/html-/statutes/english/elaws_statutes_96h02-f.htm#s20s2): they must consent or refuse consent first in accordance with prior expressed applicable and capable wishes, and if none exists, then based on best interests, as the legislation defines that phrase. Required considerations of “best interests” are carefully detailed in Section 21 to include the patient’s values and beliefs as well as clinical situation (e.g. is the patient likely to benefit from the proposed treatment?). Substitute

decision-makers *cannot* legally consent or refuse consent based on what they prefer for the patient, although in practice, this often occurs [24].

Ask substitute decision-makers about the patient’s prior expressed wishes and about the patient’s values and beliefs. One way to do this is to have SDMs recall a story about the patient [27]. These values and beliefs should inform how ‘benefit’ is construed [13].

Substitute decision-makers cannot propose treatments although it is quite common that they do. Nothing in the law requires a health practitioner to accede to proposals made by substitute decision-makers (or patients in some cases) for treatments that in the opinion of the practitioner are not indicated or offer no medical benefit. It is important to clearly communicate what is being *proposed* and in some cases to put limits on the duration of a proposed treatment(s). Discussions about all the above should be documented.

TABLE 2.
Checklist for meeting ethical and legal obligations at EOL

| | |
|--|---|
| <input type="checkbox"/> Ask the capable patient about wishes and beliefs | a. “What is your understanding of your condition?” b. “What worries you about your situation?” c. “How do you make decisions in your family?” d. “What is important to you right now when making decisions?” |
|Document. If the patient is not capable, document this before proceeding to 2. | |
| <input type="checkbox"/> Identify the legally correct SDM | a. See hierarchy of decision makers (HCCA, Sec. 20) b. Document decision maker(s) |
| <input type="checkbox"/> Ask the substitute decision-maker (SDM) | a. “Is there a living will?” b. “Do you know your role?” (e.g. to act on prior expressed wishes or best interests) c. “Do you know what the patient would have wanted in this situation and what was important to them ? (beliefs or share stories) |
| ...Document what you learned. | |
| <input type="checkbox"/> If there is no prior applicable wish, inform SDM about “best interests” | a. “If there are no prior expresses wishes we then have to consider what is in the best interests of the patient – that means “we can propose treatments that will change or improve the condition of the patient for the better, while taking into account their goals, values, and beliefs.” |
| <input type="checkbox"/> Propose <i>indicated</i> treatment plan | a. Say “We are going to do what will benefit your loved one and we will continue the treatments that are indicated and in her best interests.” OR b. “Your [patient] is really sick, we will provide treatment that improves or changes [his/her] condition for the better, so that leaves us with the following options... palliative care, comfort care ...” c. “When a treatment is no longer indicated, we will let you know that we are no longer providing it.” |
| <input type="checkbox"/> If NO consent is obtained... | a. Say “It is a challenge when we cannot reach agreement however; we have resources that can help us called the Consent & Capacity Board. They are a neutral third party that will come into the hospital and listen to both sides of the story. They will then decide what is in the best interests of the patient.” Patient will likely have a lawyer, as may we. You are entitled to have one also. Refer to www.ccboard.on.ca b. Document you have explained the role of CCB . Give the family time ask questions |

3. Form and Propose a Treatment Plan to the patient / substitute decision-maker

Treatment plans are defined in the HCCA as being proposed by one or more practitioners to resolve a condition or number of conditions. A “Plan of Treatment” may also include the withholding or withdrawal of a treatment. Health care professionals meet their ethical and legal obligations when they propose a treatment plan that is medically indicated and that reflects the patient’s previously expressed capable wishes applicable to the circumstances and / or the patient’s values and beliefs. There is no ethical or legal obligation to propose a treatment plan that is not medically indicated. However, it may be unclear if a life sustaining treatment is indicated or not.

There is a difference between providing non indicated treatment because the family demands it and a disagreement between what physicians agree on what is indicated. Either way, it is not appropriate to take direction from SDM’s on what is indicated. Deciding what is indicated is a matter of professional integrity.

The physician must exercise his/her judgement in determining what is indicated. The legal interpretation of the ‘standard of care’ may be useful in this regard. In *Crits v. Sylvester* [28] the court described the standard of care as “the degree of care and skill which could reasonably be expected of a normal, prudent practitioner of the same experience and standing.” How practitioners decide what is indicated can be done through collaborative approaches (e.g. Board Rounds, Team Rounds), that have been found useful in similar circumstances. In Ontario, the College of Physicians and Surgeons also provides guidance in its policy on end of life treatments. In particular, it describes the circumstances where end of life treatment should not be offered (“[When] there is almost certainly no chance that the person will benefit from CPR and other life support, either because the underlying illness or disease makes recovery or improvement virtually unprecedented, or because the person will be unable to experience any permanent benefit.” [13]. Whatever agreement or disagreement is found among team members should be documented. If no agreement can be reached regarding the determination that a treatment is not indicated (and therefore should not be proposed), then a treatment plan that is determined to be in the best interests of the patient (that may include withholding or withdrawal) should be proposed to the SDM for consent. Treatment plans may have to change when the patient’s condition changes. This information should be shared with SDMs when initiating treatment if it is reasonable, or when the patient’s condition requires it. This sharing of potential outcomes is especially important for substitute decision-makers who may have unrealistic expectations about treatment plans and who may not

appreciate the limits of treatment. Discussions should be documented.

Treatment plans and changes to them require consent, unless these treatments are no longer indicated. To meet the legal obligations of informed consent, the decision must be informed, voluntary, and provided by the legal substitute decision-maker. In situations at end of life, proposing treatment plans in the positive instead of focusing on what is not indicated is more effective [25] For example, if further aggressive treatment would not benefit the patient then palliative care should be proposed. If you believe that the substitute decision-maker is not providing consent in line with prior expressed wishes or best interests, then an application can be made to the CCB. The CCB process as a means of resolving end of life conflict have been described in detail elsewhere [3, 25, 29]

No CPR / Escalation

No CPR order and “no escalation” pose unique challenges in that they are often discussed in advance and include treatment that the team is not intending to perform. The patient’s condition is not static and the challenge for the team is deciding whether CPR is indicated in this context and that a patient’s condition cannot improve to a point where treatment may be indicated. According to the checklist if agreement can be reached on this point that treatment is not indicated then it is not a matter of consent and therefore does not need to be proposed. If the team is not sure whether CPR is indicated they can propose an appropriate plan of treatment and seek consent.

TABLE 6.
Benefits of Checklist

| |
|---|
| Minimizes common errors at end of life |
| Ensures patient centred decision-making by respecting wishes and values |
| Respects professional integrity and clinical judgment |
| Ensures team meets ethical and legal obligations to patients |
| Clarifies what constitutes an end of life conversation |

Conclusions

While excellent communication is desirable for any end of life conversation, healthcare professionals must first be able to meet their basic ethical and legal obligations to critically ill patients. A checklist for managing these obligations in end of life scenarios offers several benefits (see Table 3). The checklist we propose could minimize common mistakes and errors when engaging in end of life care by being patient centred, process oriented and values driven. The checklist will ensure the team takes direction from the correct substitute decision maker; the substitute

decision-maker consents in accordance with the legislative standards; that decision-making is patient centred by establishing prior expressed wishes, beliefs and values of the patient; and that there is respect for the professional integrity of physicians proposing treatment plans. Finally the checklist can reduce uncertainty regarding what constitutes an end of life conversation and provide clear steps to manage conversations at end of life

Illustrative Case Analysis

While the team was confident the patient was not capable it was not documented in the clinical notes. The team using the checklist documents this finding by dictating a note that the patient does not have the ability to understand the situation and appreciate the consequences of making a decision. Sheila is also too critically ill to be able to understand the “rights advice” and challenge the finding of incapacity. The team discovers through conversation the son is recognized as the legal substitute decision-maker and not the husband and that this family decision-making model is documented. After asking the family what their understanding of the situation is they discover the family expects that the patient will be fine in a few weeks because hospital visit “do her good.” And a birth is expected and everyone knew she wants to see the grandchild. There was no explicit advance directive or living will but the team did find out from her husband that she said when the dementia got really advanced “please no heroics” and “let me die.” The team also found out that the patient was a proud, highly valued member of her community who love to cook for others and never wanted to be a burden on anyone. The team took some time to explain the role of the SDM and it turns out that the family had no idea they had to make decisions according to prior expressed wishes or best interests. They said it was a great relief to learn that they did not have to carry the burden of the decision of life and death of their mother and wife. Based upon the information about prior wishes and values of the patient and clinical prognosis the team proposed a treatment plan based on palliative care to emphasis symptom control. They take some time to propose and go over the plan with the family, who are very concerned. A cousin who is also a Senator from California that carries a lot of influence wanted to be teleconferenced in to participate. The son authorized this sharing of his mother’s personal health information with the cousin. During the meeting the cousin demanded “everything” be done - he had not seen his aunt for a number of years and said she just “could not die now” The team explained respectfully that while sharing the information about the patient was ok the cousin did not have a formal decision-making role in the proposed treatment plan. The team gave some time for the family to think about the decision and explained that there was a conflict resolution resource we could both access called the Consent & Capacity Board if we could not reach agreement or

if the family could not decide whether palliative care respected the patient’s wishes, values and beliefs. A day later, the patient’s son consented to palliative care.

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