7.1.6 Demands for Inappropriate Treatment

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Learning Objectives

1. To provide an understanding of the frequency, importance and reasons for demands for treatment
2. To examine the moral and legal obligations on physicians to provide requested treatment and inappropriate treatment
3. To determine how one should respond to a demand for treatment that a physician considers inappropriate, and yet endeavour to preserve the patient-physician relationship
4. To offer a framework to guide communication with family members who are demanding treatment

Case 1

A female patient with advanced Alzheimer's disease is bedridden and non-communicative. Two prior episodes of aspiration pneumonia have been successfully treated in the intensive care unit. One week after discharge to the medical ward, the woman's saturations are 87% on 100% oxygen. The X-ray shows infiltrates consistent with recurrent aspiration. The two children, one of whom has power of attorney, want their mother re-intubated and readmitted to the intensive care unit.

Case 2

A male patient who had previously chosen not to receive palliative chemotherapy for an advanced malignancy opted instead to receive homeopathic treatments at home. The man returns to hospital near death. The oncologist writes that the patient is now too sick to withstand chemotherapy. The admitting physician asks the spouse if cardiopulmonary resuscitation (CPR) is to be performed in the event that the patient suffers a cardiac arrest. The spouse states that there is a clear preference for it to be performed in order to allow the homeopathic treatments time to work.

Questions

1. What are the frequency, importance and reasons for requests, or demands, for treatment?
2. What moral and legal obligations exist for physicians when addressing demands for treatment?
3. How should you respond to demands for treatment that you consider inappropriate?
4. In the face of sustained disagreement, what resources can guide your communication with family members?

Discussion

Q1. What are the frequency, importance and reasons for requests, or demands, for treatment?

In 2003, in Toronto, demands for inappropriate treatment was the important ethical problem faced on a daily basis in the intensive care unit. A recent survey of medical ethicists in Toronto, Ontario, identified conflict over treatment decisions as the most significant problem in medical ethics. Treatment outside of the standard of care or contrary to the best interests of the patient is often felt to be inappropriate. Treatments that will only prolong the dying process of an unconscious or minimally conscious patient are frequently considered to be futile and inappropriate. Providing inappropriate care can distress healthcare workers especially if treatments are physically injurious to the patient.

Demands for treatment can arise for many reasons. A “diagnostic approach” is described elsewhere. Commonly, however, one or more of the following reasons underlie treatment demands:

- **Inaccurate or biased physician judgment:** While it is desirable for families and patients to trust their physicians, questioning medical decisions is not inappropriate. For example, physicians are at
risk of excluding a treatment option inappropriately on the basis of patient age or physicians' personal religious beliefs.

- **Apparently abrupt changes in the goals of care:** Patients or their family members may be poorly informed of the burdensome nature or relative ineffectiveness of treatments. A state of denial can contribute to this lack of awareness. Extreme levels of stress for family members at or around the end of life likely contribute to their using denial to cope. Similarly, abruptly changing the goals of care, from curative to palliative, may result in demands for treatment.

- **Efforts to obtain consent for treatment limitation:** The consent process demonstrates that the treatment under discussion is available. Sustained disagreements over treatment are often preceded by efforts to obtain permission to withhold or withdraw one or more contested treatments. Demands for treatment can never be said to arise spontaneously if they were preceded by efforts to obtain consent for treatment withdrawal.

- **Values-based disagreements:** Patients or their family can appreciate and understand the medical situation but still want treatments for religious or personal reasons. Using statistics to justify withdrawal of life-sustaining treatments is similarly problematic since some people will believe any chance of survival at all is worth pursuing. For others, personal or cultural beliefs about the sanctity of life may support a desire for continued treatment in the absence of apparent benefit. Such beliefs must be carefully considered and respectfully addressed.

**Q2. What moral and legal obligations exist for physicians when addressing demands for treatment?**

**Moral Obligations**

The “CMA Code of Ethics” of the Canadian Medical Association states: "Consider first the well-being of the patient." A report of the Institute of Medicine concludes that the obligation of the physician is that "of bringing to bear every possible resource to prolong active and healthy life and accepting death only when it is felt to be inevitable and then trying to mitigate its connection with suffering." (Confounding this recommendation is the reality that most people die after becoming inactive and unhealthy!)

**Legal Obligations**

The courts have been reluctant to directly address the requirement to provide contentious treatment but frequently find family members to be the most appropriate decision-makers for incompetent patients. While demands by a surrogate decision-maker for treatment alone are insufficient for treatment, physicians need to recognize the limitations on their clinical judgment and consult the literature to determine how best to proceed.

Practically, physicians should ask themselves: "Would the treatment being demanded be provided by a respectable minority of physicians or to other patients?" If the answer is clearly yes, then a strong obligation to provide the treatment exists. (However, clear scientific evidence that the treatment would not be effective in obtaining the desired goal would also demonstrate that the treatment is outside of the current standard of care.) When doubt exists, openly obtaining other medical, legal and ethical opinions can help ensure that one will meet legal and medical obligations to care.

**Q3. How should you respond to demands for treatment that you consider inappropriate?**

The "CMA Code of Ethics" requires one to "first consider the well-being of the patient." In end-of-life care situations, "and the patient's family" should be added. A recent study showed that having a relative die in the intensive care unit resulted in post-traumatic stress in 70% of respondents. Heated conflicts over treatment limitation will only intensify psychic trauma.

Before meeting to discuss demands for treatment, consider the prognosis, treatment options and likely outcomes. Consulting with the other experienced or involved physicians beforehand is prudent. Addressing demands for treatment requires time and a suitable space to meet. Other health care personnel, including pastoral care services, nursing and social work, are desirable. At the meeting, names, relationships and responsibilities should be established.

Attentive listening and allowing family members a full opportunity to talk is extremely important. At the end of the meeting, one should know how and why demands have arisen. One experienced
intensive care physician at my institution told me that, almost invariably, conflicts he has witnessed have arisen because no one took the time to listen. *The meeting should be long enough to ensure family members or patients have an opportunity to express themselves and appreciate what they have been told.*

**Negotiating Treatment Options**

Approaches to negotiation include *shared decision-making* or *making and communicating an allowable determination of non-efficacy*. It is important to consider the appropriate approach for a given clinical situation. Of course, no approach can guarantee that treatment demands will not arise. Communication examples are shown below in italics.

**Shared decision-making (example from Case 1 — an elderly patient with aspiration pneumonia and Alzheimer's disease)**

*I would like to talk with you about your mother, and hear what you feel about the care and where we might go from here. Did you ever talk with her about the kinds of treatment she would want in this situation?*

Shared decision-making is most appropriate when treatment is potentially effective and physicians are uncertain about the best or required course of action. From within this context, physicians bring technical expertise, clinical experience and a concern for the well-being of the patient to the bedside. Specific treatment recommendations are appropriate.

Patients or their proxy decision-makers bring values, beliefs, hopes, fears and needs, providing an expert opinion on the appropriateness of specific treatments and treatment goals for themselves or their loved ones.

In Case 1, a trial of ventilation has previously been successful. If the patient's proxy decision-makers provide evidence that the patient would have wanted such treatment, there exists an obligation to provide it. However, one could still advise against treatment, on the basis that the patient is dying as a result of Alzheimer's disease and therefore treatment is death-prolonging, rather than life-sustaining.

*I appreciate what you have explained. I would recommend that we not readmit your mother since she is dying slowly of Alzheimer's disease. I would propose we focus upon ensuring her comfort and doing conservative steps to keep her alive. How do you feel about this option? However, if you wish another trial of treatment in the intensive care unit, it will be done.*

Shared decision-making fits well with the current requirement to respect and honour autonomy. It accounts for individual and cultural variation and enhances choice. However, exploring preferences creates an obligation to provide the treatments in question. Refusing to provide treatment after establishing that it is clearly desired has the potential to generate conflict over who has decisional authority as well as the decision itself.

**Making a determination of non-efficacy (example from Case 2 — demands for CPR for a patient dying of metastatic cancer)**

*I can appreciate your position and how you want treatment. If there was some way that admission to an intensive care unit or CPR could allow your husband to survive, I would very willingly try to save his life. But at this point, his condition is so severe that there is nothing we can do to stop him from dying. I hope with you that the treatments from the homeopathic doctor are effective, but if they are not, the treatments we could use would not be effective. At this point, we can give him fluids and antibiotics and oxygen and time.*

Giving the "bad news" that medical treatment cannot save a patient is appropriate when true. In the second case, CPR could not work since the cause of death will be metastatic cancer, not cardiac arrest. Physicians may recognize that at some point in the illness trajectory, recovery is no longer an option and informed consent no longer of use. Essential steps to giving such bad news are described elsewhere and available on the Internet. It is useful to separate one's intentions from one's capabilities.

*There is nothing that can be done that has not already been done. Your husband is dying. I wish I could give you some other news.*
When making determinations of non-efficacy, physicians must ensure that they are acting within the standard of care and that their assessment is supported by scientific evidence and would be supported by their colleagues. Individualized assessments may be difficult but are a hallmark of medical practice. When uncertain as to the best course of action, a therapeutic trial can be offered.

No matter what we do, he is likely to die, but we could try a short period of life support in the intensive care unit if you wish.

Q4. In the face of sustained disagreement, what resources can guide your communication with family members?

Physicians should strive to normalize disagreements and take steps to keep them from escalating into conflict. Opening up disagreements to external scrutiny is essential, but this step requires a willingness to provide the life-sustaining treatments until a consensus decision is reached. (An expert opinion about treatment after the patient has died is of little use to the family members.) Ethics committees and other third parties may help to restore or maintain communication when there is a breakdown in relationships. Therapeutic trials may resolve some disagreements. Unconditionally agreeing to provide treatment will not improve the quality of the doctor-patient relationship.

We know that sometimes these disagreements arise. I also want to do what is best for your mother. Sometimes it can help to get other people involved. I am very uncomfortable with the decision to admit your mother again to the intensive care unit since it will not allow recovery and will only prolong the dying process. I will ask the ethics committee to give me some advice about how to continue. In the meantime, we will do what we can to support you and provide the treatment you request for your mother during this very stressful time.

Conclusion

Demands for life-sustaining treatment are the most important ethical problem facing physicians today. Physicians must strive to ensure that their recommendations and assessments are within the standard of care. In end-of-life care situations, they must ensure that compassionate care for patients and family members is provided. Persistent demands for treatment must be carefully explored. Disagreements based upon differences in values should be respected and opened up to external review. Keys to managing treatment demands include the following:

- Develop a clear assessment of prognosis and options and obtain second opinions and up-to-date information whenever necessary. Provide treatment options within the context of the patient's overall condition, acknowledging that death is not a negotiable outcome when necessary.
- Have a structured meeting with patients and/or their family members of suitable duration. Attentive listening and provision of emotional support can resolve disagreements and/or make it less likely that disagreements will escalate into conflict. Recognize and accommodate the very significant levels of stress that family members may experience in end-of-life care situations.
- Determine if you wish to use shared decision-making. If this is the case, consider delimiting some options at the outset. ("Clearly CPR could never be effective, but some options include. . . .") The expert assessment that a patient cannot be saved cannot be shared with family members. Once patients are recognized to be dying, give family members the bad news that no treatment will save the patient and provide emotional support to facilitate acceptance. After this shared view is established, negotiate decisions to withhold or withdraw death-prolonging treatments.
- Intractable disagreements are best viewed as arising from differing visions of what is the best for the patient. The importance of maintaining patient comfort and dignity to the best of one’s abilities can help establish common ground. No one wants family members to suffer unnecessarily. Throughout the negotiation process, take efforts to build and maintain a relationship with distraught family members.

References

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