The Ethical Imperative of Healthy Paternalism in Advance Directive Discussions at the End of Life

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It is a scene that is played out in hospital wards and emergency departments every day in the United States: a patient with cancer that is refractory to treatment is admitted with declining health and an admitting physician, frequently an internist or resident physician in training, is assigned with documenting the patient’s advance directives in the medical record as part of the admission checklist. The conversation takes a variation of the following: “Mrs. Jones, if your heart stops or you cannot breathe, would you want us to resuscitate you?” Depending on the discussion the patient may have previously had with her oncologist, her response may vary. Frequently, when the question is posed in this manner by an unfamiliar physician amid the stress of a clinical decline, the fearful answer is “Please do everything for me” and the admitting physician documents that Mrs. Jones is “full code.”

A survey of internal medicine residents in the United States has confirmed that this practice is commonplace. Although nearly all resident physicians faced with a patient of this description would assess that cardiopulmonary resuscitation (CPR) would not be beneficial, less than half would be likely to share that opinion with the patient and only one-third would recommend withholding CPR. The survey data suggest that an important reason for this reticence is the widely held belief that to offer prognostic insight and aligned recommendations would infringe on the patient’s autonomy and his or her right to make decisions in such a situation. In practice settings, it is not infrequent to find medical teams disgruntled by the outcomes of such discussions and begin to discuss ways to “make the patient DNR [do not resuscitate].”

The Congruence of Medical Ethics and Healthy Paternalism in End-of-Life Discussions

The bedrock principles of medical ethics include autonomy, beneficence, nonmaleficence, and justice. Autonomy refers to the right of patients to decide what happens to them. This principle means that informed adult patients can refuse or accept treatments, drugs, and surgical procedures according to their wishes based on the recommendations of their physicians. We assert in this Viewpoint that to offer CPR as an option when shared information, evidence of clinical benefit, the absence of significant harm, and a justification for intensive resource use are lacking would infringe on the collective principles of medical ethics. There is abundant evidence pertaining to the outcomes of CPR in advanced refractory cancers that must be considered in these discussions. In one exemplary study, the median survival of patients who presented to an oncology clinic for consideration of a phase I trial and subsequently underwent emergency CPR was 24 hours.

Oncologists routinely evaluate the pros and cons of management options in individual patients in the light of available evidence and offer patients their best opinion on options while providing guidance. When evidence suggests that further efforts with systemic therapy would not be helpful, best practices dictate that physicians discuss the prognosis and reasonable medical options with the patient and engage in shared decision making. This process may include plans for participation in a clinical trial, if appropriate, or symptom-directed palliative care. Most would agree that the patients should not be asked what they would want to do in this regard without this information-sharing in a truthful and compassionate framework, to avoid the delivery of ill-advised futile, toxic, and costly therapy. This “healthy paternalism” model of guided decision making is largely preferred by patients and medical care professionals alike. The frequent exception to this common practice with regard to discussions about the outcomes of CPR is at odds with the larger practice conventions and out of line with ethical obligations.

Patients typically rely on physicians to initiate conversations about end-of-life directives, and most seriously ill hospitalized patients prefer to make end-of-life decisions with physician advice. Discussing prognosis may actually improve the patient’s ability to cope with illness without decreasing hopefulness or survival. Successful end-of-life communication between patients and physicians is associated with superior psychosocial outcomes, less intensive treatment, greater patient satisfaction, and higher likelihood of death at home. New Medicare policy now encourages and reimburses health care professionals for end-of-life discussions, which, in addition to these benefits, may also reduce end-of-life costs.

What is the optimum manner in which such information and counsel should be conveyed when discussing advance directives with a patient with cancer? Given the historical shortfall in formal training in this regard among most physicians, including oncologists, the SPIKES (Setting up, Perception, Invitation, Knowledge, Emotions and Empathy, Strategy) protocol offers a compassionate and practical framework that physicians may choose to adopt. In the right setting, the physician takes time to explore a patient’s understanding of the disease, personal goals and expectations, and coping strategies within the context of his or her emotional landscape. The physician offers empathy and invites the patient’s need for information regarding the outcomes of the disease and possible interventions. Accurate information, which may be a revision of the patient’s...
prior understanding, is then provided in a compassionate framework. Linked to this information, the individualized goals of care and recommended pathways, which should include a recommendation for or against CPR efforts, are then clarified by the physician.

Implicit in this framework and pertinent to the focus on advance directives is that the physician who is discussing the outcomes of advanced cardiac life support with an individual patient feels qualified to estimate whether the efforts of CPR will be beneficial or not, so as to share the best information and offer the aligned recommendation. Physicians may choose to advocate for or against CPR depending on the merits of the specific clinical contexts and patient preferences. An admitting internist or medical resident may not be sufficiently informed with respect to the significant differences in prognosis between disparate cancers, their varied disease states, and comorbidities. Nevertheless, the survey data indicate that most residents (243 of 375 [64.8%]) want to discuss advance directives themselves rather than defer to attending physicians or primary oncologists; of these, 227 residents (93.4%) felt these discussions were their responsibility and 160 (65.8%) felt they had adequate training and knowledge to do so. These data may reflect the established structure of the discussions in which the physicians’ expertise on judging outcomes of CPR was rendered moot by the dominant culture of withholding of information and guidance. Consistent with the reluctance of physicians to share honest prognostication in a timely fashion with patients, among 2489 patients with metastatic cancer, only 508 (20.4%) had advance directives documented in the medical record. In a study among hospitalists discussing code status, none estimated the benefit of CPR or provided a recommendation.

**Conclusions**

We believe that the time is right to assert the ethical imperatives of a healthy paternalism in discussions regarding advance directives with patients with cancer. Given the widely held perception that the principle of autonomy requires withholding prognostication and advice during discussions on advance directives, additional research and educational interventions among physicians in training and practice are required to address this issue, which has major implications for both quality of care and cost-effectiveness. In these vital conversations with patients, a studied neutrality regarding outcomes of CPR should not be an option. Oncologists must lead the way in this regard and document these discussions in the medical record for the benefit of all medical caregivers. The false dichotomy between healthy paternalism and patient autonomy should be abandoned on ethical premises and in the interest of patients and society.

**ARTICLE INFORMATION**


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**REFERENCES**


