Review: Compassionate Care for the Living and the Dying

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As an elder law attorney, I spent my career helping my clients prepare for incapacity and death. A part of that preparation entailed assisting them with the execution of living wills and/or other health care directives. My goal was to ensure that their wishes with regards to end-of-life care were known and respected. Because of my experiences comforting and counseling sick and dying clients I have spent my academic career researching and writing about the ethical and legal issues surrounding end-of-life decision-making.

Two phenomena make a discussion of this subject so important. First, due to the aging baby boomer population, the number of patients who face these types of decisions will continue to increase. Second, as a consequence of the existence of medical technology that enables physicians to artificially sustain life longer, more people will be forced to make end-of-life decisions. Legislatures and courts have taken steps to establish processes that make it easier for patients to provide information to their health care providers about their choices with regards to end-of-life care. Nonetheless, Professor Shepherd claims that laws exclusively designed to help patients express their end-of-life preferences may not be needed. According to Professor Shepherd, the better approach would be for health care providers to treat end-of-life choices similar to other types of medical decisions.

Professor Shepherd starts the article by discussing two instances. The first case involved a conflict between the contents of a living will and the opinion of the patient’s health care agent. Relying on the living will, the hospital asked the patient’s wife who was also his health care agent for permission to remove him from life support. After the wife objected, the hospital successfully obtained a court order to discontinue life support in accordance with the wishes the patient had expressed in his living will. Professor Shepherd opines that the court’s decision may not have respected the patient’s autonomy. She feels that it is problematic that the court determined that the provisions of the boilerplate-filled living will should be given more weight than the directives of the woman the patient was married to for over fifty years. Professor Shepherd’s second example was related to a discussion she had with members of a book club after reviewing changes to North Carolina’s law pertaining to health care agents
and living wills. During her conversation with the members of the book club, Professor Shepherd realized that the statutory revisions had rendered the living wills of some of the women obsolete. She also recognized that the law was too complicated and could not provide for all of the concerns raised by the women.

Professor Shepherd asserts that decisions about end-of-life care should be treated similar to other choices that impact the patient’s health. In the remainder of the article, Professor Shepherd sets forth eight principles she feels health care providers should consider when decisions need to be made. The first articulated principle states that physicians should respect and care for patients by balancing their expressed wishes, values and interests. For example, instead of just relying on what is stated in a form, the physicians should speak to those persons who are closest to the patient to ascertain the actions that would best conform to his or her desires. Professor Shepherd next suggests that every patient should have a surrogate decision maker. Therefore, if a patient does not pre-select an agent, one should be appointed for him or her. She also argues that the law should not give pre-selected agents more deference than the ones appointed by default. Thirdly, Professor Shepherd recommends that the law lessen the formalities currently required for an advanced health care directive to be valid. She feels that this will make it easier for persons to indicate their choices. Some jurisdictions have taken this approach by recognizing holographic wills. Fourthly, Professor Shepherd contends that, if possible, patients should not be treated as if they are obligated to stick to their pre-selected choices. In particular, she states “We must be especially cautious in following advance instructions that are contrary to a patient’s current, individualized best interests or contrary to a patient’s current expressions, even if the patient’s decision-making capacity may appear diminished at the time.” Professor Shepherd’s position acknowledges that patients do not regularly update their advanced directives. Hence, those documents may not be reflective of their changing values or life circumstances.

Professor Shepherd’s fifth principle stems from the concern that some end-of-life decisions are made too quickly. She gives two examples of cases where families and patients were given a short period of time to answer the question or whether or not a patient would want to “live like that.” To decrease the possibility of that happening, Professor Shepherd counsels that, absent an emergency, physicians should slow down the process to give patients the opportunity to embrace the altered state of their health. As a sixth principle, Professor Shepherd states that physicians should be encouraged to have more conversations with their patients about all health care matters. The law should not dictate the content of those conversations. Instead, physicians should be compensated in some manner for taking the time to communicate with their patients. In recognition of the fact that the number of patients with some form of cognitive impairment has increased, Professor Shepherd maintains that suitable safeguards need to be put in place. However, those protections must only be aimed at patients who are shown to lack decision-making capacity. In enumerating her principles, Professor Shepherd concludes by proclaiming that physicians should always recognize the reduction of pain and suffering as a crucial goal of patient care.

In light of medical advances and increasing health care costs, conversations about end-of-life care will continue to occur. A significant portion of the discussion will focus on ways to handle surrogate decision-making. The practical suggestions Professor Shepherd includes in her article could be a valuable part of that dialogue.