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### At the end of the Road

In our ever increasing sophisticated technological and complex world of medicine, it is not unusual for patients to receive medical treatment that can prolong the end of the life of a patient. This type of critical care is an integral part of hospital care that is usually managed by an interdisciplinary team of doctors and nurses. However, even as we learn and apply more and more methods on how to prolong life we cannot guarantee that it comes with an equally satisfying quality of life. Essentially, this is what the controversy about end of life care centers around, quantity of life versus quality of life. Therefore, in order to preserve what people say matters the most- comfort, personal dignity, family relationships and spiritual matters- during a patient's last chapter in their lives, greater efforts in advanced care planning are required to ensure that the preferences of the patients prevail and to ensure they receive a satisfactory end-of-life care.

The first step to ensure patients who do have the ability to plan ahead about their end-of-life care would be to inform and educate them about advance care planning. Advanced care planning is when patients identify, clarify, and prioritize factors that influence their decision-making about future medical conditions in the event that they no longer can communicate their wishes when decisions need to be made. (American Medical Association) This includes things from religion to culture to beliefs to matters of the heart and soul. However, one of the critiques of advanced care planning is that often times patients are not knowledgeable enough about their own medical conditions to predict what medical treatments they may want in the future. In addition, health care providers might not have the time or patience to explain treatment decisions to patients, and might even be reluctant to initiate such

conversations due to lack of skill or concern over adverse consequences. (Levi and Green)

Improvements can and should be made in this respect, it is a simple matter of reinforcing communication between the health care providers and the patients while there is time. It could be as simple as the physician starting off by explaining the patient's end-of-life conditions depending their specific medical dilemma and their options for life-sustaining treatments and implications. Treatments could include anything ranging from cardiopulmonary resuscitation (CPR), artificial breathing, artificial feeding, hospice care, and more. (Pace) In fact, based on a survey of 120 adults that compared the effect of a video depiction and verbal description of patients with advanced dementia who were selecting levels of medical care concluded that watching the video significantly changed their preferences for care [all P values were very small decimal values]. (Volandes et al) This survey supports the idea that once people have a more realistic image of what the advanced stages of their illness might be, their views about what medical treatment they would like at those stages might change. As for the adverse consequences this knowledge can cause a patient that health care providers fear, knowledge will not only give the patient the ability to make a more informed decision, but it might even create a greater agreement with the decisions they make. Education in order to make informed decisions about future medical treatments requires good communication with the patient and the health care professionals and is crucial to a successful advanced care plan.

The second major step after advanced care planning is the actual process of making advanced directives. An advance directive is a formal document that states the patient's wishes on what should be done about their medical care if he/she becomes incapacitated and therefore unable communicate it themselves. (American Medical Association) Many of the critiques that surround advance directives are centered around issues of communication and logistics. An advanced directive can be compared to that of a will. Therefore, there will often be times when even though in the patients eyes he has been clear about his wishes those wishes may seem opaque to someone else who is trying to interpret them.

However, by creating an advance directive one of the values of medical ethics, the value of autonomy, or the right of the patient to refuse or choose their treatment, can best be kept. (American Cancer Society) Also, by composing a written document in which the patient tries to make his/her wishes clear, it opens a door for discussion with the health care providers and relatives about what is to be done in the end. In the long run, the patient is given the opportunity to communicate his point of view and desires better if he goes through the process of creating an advanced directive. Another problem to consider is, about how accessible and useful advance directives are when trying to make medical decisions at the bedside. There are some who would say that, “respect for patient autonomy is misguided, and that when individuals are at their most vulnerable our primary responsibility should be to protect them from harm, not engage in a quixotic quest to discern their exact, authentic wishes regarding health care.” (Levi and Green) This argument is stating that for those patients that lose the ability to make autonomous decisions, as a rule, the wishes of the patient should be disregarded for paternalistic reasons. However, as mentioned before, the accepted standard is autonomy. Only when there is no reliable information about a patient's wishes can medical staff or relatives make decisions about what is best for the patient. First and foremost are the parents wishes, however, if those are not readily available then alternatives can be considered. The importance of the creations of advanced directives cannot be more emphasized.

The last preventative step a patient can make is to chose a spokesperson in the case that they can no longer speak for themselves. When choosing a surrogate, there has to be ample communication between the elected individual, the patient, and the health care professionals. It can be this lack of communication that often leads to confusion and disputes about what it was the patient really would have wanted. For example, religious views can come into conflict with medical practices because religion shapes attitudes about death, dying, end-of-life care, and religious views and beliefs are different from patient to the patient's family to the clinicians. “In Israel, for example, orthodox Jewish

law allows life-sustaining treatments to be withheld, but withdrawal of continuous interventions is forbidden because it is regarded as an act to shorten life. However, withdrawal of intermittent life-sustaining treatments is permitted because it is seen as the next treatment being withheld rather than the withdrawal of the present one.” (Randall and Jean-Louis) Personal beliefs and moral views on life and death are very important factors that come into play in end-of-life care, and if the patient takes the time to find a surrogate with whom he can discuss them with the more satisfactory his care will be. In the most extreme cases where a decision cannot be agreed on by the patients and the physicians, then the last resort is to go to the court and a decision is reached guided by what the patient would have preferred as best as it can be determined. (American Medical Association) The importance of having an individual that the patient trusts and who can best relay his wishes or what could best be his wishes is ideal in the last part of advanced care planning.

In cases where the patient has not had the opportunity to plan this far ahead, then interdisciplinary communication between the medical staff and communication between the clinician and family is key. Sadly enough, collaboration between all members of an interdisciplinary team is often poor and varies greatly in different countries. In a questionnaire that was conducted in several countries, they found that in the United States 28% of the physicians would involve nurses in end-of-life decisions when the patients had no family. (Randall and Jean-Louis) These kind of situations are difficult on the medical staff and the patient, because if the patient's family was around, they would mostly likely be the primary and most important source of information about the patient's values and treatment preferences. However, if the family is available then for the benefit of the patient is is very important for the physicians to inform and include family into the medical conditions to come to a decision that would most closely resemble that of what the patient's wishes might have been. The more increased the communication among the medical staff and between the staff and the family of the patient the more improvement of the quality of care for the patient.

Undoubtedly, the nature of critical care and end-of-life treatments contain a variety of difficult decisions for the patient, family, and health care professionals. There is also no doubt that as we discover more and more technologically advanced-sustaining treatments, patients will have a wider variety of options to choose from when they are deciding about their end of life treatments. It is for these reasons that educating patients and encouraging them to think about advance care planning might help with the decisions needed to be made about life-sustaining treatments, not only for the probability of survival but for the quality of life associated with survival. More efforts should be made while the patient is still in the condition to relate his/ her wishes, to plan for a desirable treatment. In this manner, the patient's end-of-life care can be better improved and help them be more comfortable in as many aspects as possible of his life in his remaining time.

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