The Importance of Discussing Living Wills With Patients With Heart Failure
Sloan Beth Karvera and Jessalyn Bergerb

aProgram Leader, Psychosocial and Palliative Care Program, Moffitt Cancer Center and Assistant Professor of Oncologic Sciences, University of South Florida, Tampa, Florida, United States
bHealth Education and Behavior Masters student, University of Florida, Gainesville, Florida, United States

The concept of the living will is relatively new in medical standards. It is a legal document that allows patients to record their wishes for treatment at the end of their life if they are not able to speak for themselves anymore; it gives patients the opportunity to be a part of the decision making process. In Spain, the introduction of legislation in Catalonia in 2001, started the legal regulation of living wills. It has now been established in all autonomous communities as well as at the state level.1 Encompassed in a rich tradition and history, many Spaniards are unfamiliar with this new medical tool, and therefore have not utilized it to their advantage.

In the recent study conducted by Antolín et al published in this issue of Revista Española de Cardiología, 309 patients with heart failure were given a questionnaire on their knowledge of their disease, what a living will entailed and whether they would be willing to draft one.2 Only 13.3% of the study population knew what a living will was and 4.9% had heard about it from their doctor.3 The study found that patients with heart failure received inadequate information regarding their disease, including its progression, as well as the option to write a living will. The findings also indicated that those patients that were knowledgeable about their condition and options were more likely to know what a living will is as well as to actually draft one.

From this study, one can clearly see that even though legislation has been approved and campaigns have begun to increase the knowledge about living wills, more work is needed. In 2008 the study said that only 50 000 documents had been filed, approximating to only 5% of the total Spanish population.4 For the tool to be better implemented, Spanish doctors need to be educated about the usefulness of a living will as well as how it can help them better treat their patients and make their patients more involved in the overall treatment plan. If they are not suggesting it or educating patients on it, then the low numbers of living wills will stay constant. If physicians did start implementing the living will in their practice of medicine and with all of their patients with heart failure or other serious medical illnesses, then the numbers would exponentially increase, as well as the awareness.

The study also mentioned that there was a correlation between those patients that felt satisfied with the information they were given about their treatment plan and those patients that either knew about a living will or had actually completed one. If physicians, upon diagnosis or soon thereafter, took the time to sit with a patient and share detailed information about that patient’s disease, such as what the prognosis is and what the next steps were, then the number of patients who felt satisfied with the information given would increase and we could expect the number of living wills might increase as well. This would also build trust in the relationship between physician and patient as well as move forward the treatment options. In this study, better communication would have helped patients to feel more comfortable with the decisions taken. The goal would be to have patients specifically asking for information regarding their treatment and the

Correspondence: Sloan B. Karver, M.D.
Program Leader, Psychosocial and Palliative Care Program,
Moffitt Cancer Center,
E-mail: Sloan.Karver@moffitt.org
option of a living will, as well as physicians who spontaneously will offer the information.

In the United States, the field of palliative care and compassionate treatment has grown over the past 20 years and has changed the way doctors speak to their patients as well as treat them. Doctors are now being trained to talk to their patients about the patient’s wishes and how they will play an integral role in the decision making process. If a patient chooses not to be put on life support, then the doctor should comply with that wish. The same goes for a do not resuscitate (DNR) order. The concept of a palliative care team, which is composed of a team of doctors, nurses and pharmacists, social workers and chaplains, is intended to keep the patient comfortable during the end-of-life stage, as well as to discuss further treatment options and prognosis. This is a useful way for a physician to truly understand what the patient wants and to make sure those wishes are made complete. Normally, treating primary physicians are very uncomfortable in having this discussion with their patients since they do not want the patient to feel that they are giving up hope or letting patients know that the end of their life is near. Physicians typically have no formal training in delivering bad news or in having a conversation regarding end-of-life care. If doctors undergo training in how to communicate with their patients, then the quality of care would improve.

Similar to Spain, the United States has not had many case studies where the use of living will documents has proved to be successful. Teno et al examined 688 living wills as part of the Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment (SUPPORT) study. They found that 50% of the orders not to attempt cardiopulmonary resuscitation were not contained in the medical chart, rendering it obsolete, as the doctor had no idea that the order had been made. Furthermore, 87% of those living wills that do make it to the chart are written in vague medical language, making it unclear as to what the patient actually wants. Only 13.3% go beyond general statements and 3.2% refer to current medical conditions.

Patient and doctor communication as well as advanced planning strategies were discussed in the “La Crosse Advance Directive Study” (LADS), which retrospectively reviewed all adult deaths in all local healthcare organizations for an 11-month period in 1995 and 1996. The objectives of the study were to determine the prevalence and type of end-of-life planning and its correlation with treatment decisions. Data were collected from medical records, death certificates, and interviews with attending physicians and healthcare proxies. While other studies have documented low rates of advance directive completion, the LADS results stand in stark contrast. Of the 540 deaths included in the study, the prevalence of written advance directives was 85%, with most of these (95%) found in the medical record. Median time between the recording of the completed advance directive and death was 1.2 years, clear evidence of planning in advance of a medical crisis. And unlike other studies, which have found poor correlation between advance directive preferences and actual treatment decisions, it found that patient preferences to forgo life-sustaining treatment were honored by consistent medical orders reflecting these preferences.

In order to increase the widespread use of living wills, doctors need to be educated on having end-of-life as well as prognosis discussions and to make sure that communication is always shared with the patient. Plans need to be made and treatment options discussed. It should be a doctor’s goal that each patient is always comfortable with the plan of action and understands all that is happening. If none of this happens, then the use of a living will tool will become obsolete.

REFERENCES


