Advance Directives and Advance Care Planning

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Editorial

There continues to be a growing trend toward providing life-prolonging therapy unless there are expressly and legally refused by a competent patient or their legal representatives [1]. Up to 76% of patients will be unable to participate in some or all of their own decisions at the end of life [2].

The complex social and emotional environments within which End of Life (EOL) planning is initiated and auctioned are not sufficiently embedded within standardized Advanced Care Planning. The notion that ACP is concerned principally with the right to self-determination through control over treatment choices at the EOL may misrepresent the way that ACP actually occurs in Palliative Care [3].

Those patients who agreed to complete an AD did not die earlier than those who did not complete them, and furthermore significant economic costs were saved in medical care [4]. ADs also decrease moral burdens among health care teams [5].

When a dying patient’s family members have more time to prepare for the loss, they are less likely to suffer complicated grief during the bereavement process. ADs relieve feelings of guilt and grief for patients’ families [4-6].

Patients willing to talk with their doctors about ADs had lower levels of stress, depression and anxiety, than those who did not want it. Patients who had earlier discussions about EOL care were less likely to receive aggressive measures before death [4,7,8].

Choosing a surrogate decision maker is widely accepted as one of the most important aspects of ACP. Allowing surrogates leeway in decision making may decrease burden on loved ones and may help to prevent conflict. However, not all patients want to grant leeway, with the greatest concern, being a desire to prevent surrogate burden. Deciding how much leeway to give and discussing the reasons behind granting leeway may go a long way in preventing conflicts that often occur when surrogates’ wishes and prior ADs do not agree [6].

Some of the reasons clinicians have avoided starting advance care plan discussions include: the topic may cause distress to the patient or to the medical staff, the patient lacks sufficient knowledge to address the issue, the conversation might encourage suicide, the clinician denies responsibility to broach the topic, discussing death conflicts with the clinician’s personal values, or insufficient time to hold the conversation [7].

Nurses perceived that doctors did not want to take this responsibility; and also recognized that doctors did not fully explain the possible consequences to patients and their families when conversations Happened [5].

Some nurses considered that promoting ACP was within scope of practice and recourses of others, and they did not want to be responsible. Other nurses, however, believed that promoting ACP was in their own scope of practice, but was not their priority [5].

Nurses’ personal beliefs and values, personal experiences, attitudes, knowledge and skills in ACP conversations, and their relationships with individual family members could either be helpful, or could hinder the process of implementing ACP. Nurses reported that they found ACP related terminologies difficult to understand, and even more difficult for the public [5,9].
The use of passive informative material (posters, leaflets or videos) in isolation does not significantly increase AD completion rates. However, when interactive informative interventions are employed, the AD completion rate increases [10].

Nurses believe that they need knowledge of ACP, ADs, related legal issues and related resources for enriching their expertise through regular in-service education and workshops. In the processes of implementing ACP, nurses need to balance their own demands and needs with those of others. They have to adjust and balance sensitive emotions in their professional and private feelings because nurses sometimes also suffer when prolonging patients’ lives and respecting their wishes. Nurses think that they need to be authorized and protected by organizational policies or national laws to make them more accountable [8].

The goals of an advance directive can be accomplished by asking two questions by Del V-Pérez et al. [4]:
1) If you cannot, or choose not to participate in healthcare decisions, with whom should we speak?, and
2) If you cannot, or choose not to participate in decision making, what should we consider when making decisions about your care?

At least three of every four patients at the end of their lives are unable to participate in decision making that affects them directly. Each patient's values and needs are highly individual. Clinicians cannot make high-quality treatment recommendations or offer sound guidance through the decision-making process without incorporation of the patient's and surrogates' values and needs. Therefore communication between patients and surrogates before a medical crisis is crucial to in-the-moment decision making [2,11].

End-of-life issues and quality of care will become imperative in the upcoming years for the aging Baby Boom generation and their parents. Clinicians should exercise judgment and flexibility in engaging patients and family members in these discussions, recognizing that determining goals of care is a process [7,12].

People should be encouraged to engage in a dialogue about what they consider to be the main conditions that would make life worth living for them, and share them with proxies and/or loved ones, as well as with their attending healthcare team. Even though these narratives and value histories can be useful, they will not be easily translated into technical medical choices. In order to minimize its arbitrary nature, this translation should be discussed during an ad hoc meeting, where the different members of the healthcare team, the patient’s surrogate engage in a thorough deliberation process [13,1].

The ACP is an important topic in today's palliative care agenda. ADs are considered an important tool for providing care consistent with patients wishes, which also guarantee better quality of life and respect of their autonomy but, unfortunately, their use is limited and yet poorly valued due to the interaction of the different factors [8].

Some of these factors are associated with ethical and legal issues, but other barriers are due to a lack of knowledge about ADs and lack of competency in EOL care. Overcoming legal and ethical barriers may be difficult; however, those related to lack of knowledge and confidence may be more easily addressed [14-16].

References


