

# Early Initiation of Advance Care Planning for Veterans With Chronic Illnesses

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When treating patients with chronic illnesses, health care providers should involve patients in the decision-making process.

Every day, health care providers (HCPs) care for patients with advanced chronic illnesses. At times, HCPs make critical treatment decisions without input from the patient. As a result, patients are often confused about their disease trajectory, prognosis, benefits and burdens of treatments, and outcome preferences.<sup>1</sup> Unfortunately, limited research has been conducted on patients who have chronic illnesses, such as congestive heart failure (CHF) and chronic obstructive pulmonary disease (COPD), regarding early discussion of advance care planning (ACP) and advance directives (ADs). This gap in the knowledge base has contributed to a delay in the initiation of ACP for patients with COPD or CHF, especially for those with end-stage illness.

## BACKGROUND

The Patient Self-Determination Act (PSDA) was passed in 1990 to inform patients of their rights about health care choices while in the hospital, but the completion rate for ADs re-

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mains poor.<sup>2</sup> The 3 key elements include the right of patients to facilitate their own health care decisions, the right to refuse or accept treatment, and the right to make an AD.

One of the reasons for the poor AD completion rate may be increased confusion about the difference between ACP and an AD.<sup>3</sup> Advance care planning is a discussion about overall goals of care related to health care and progression through the life cycle. Advance directives focus on more specific information, including who will be designated as health care proxy, which health care interventions would be requested and which would be declined, and decisions regarding code status and organ donation.

A case study was conducted at a long-term care facility to test beliefs that residents who made their wishes known through ACP would have a positive experience at the end of life (EOL).<sup>3</sup> The study allowed the residents to provide direction on what are and are not acceptable treatments at EOL. Before this study, most residents did not have a health care proxy and had not discussed the topic of EOL care with their HCP. Treatment choices were also not designated.<sup>3</sup> Results demonstrated that ACP had positive outcomes for residents and family members, including

documentation of an AD, autonomy in decision making, person-centered approaches to care, and dying with dignity.

Much of the research regarding ADs has been conducted with seniors, hospitalized patients, and those with critical or terminal illnesses. A study by Jackson and colleagues examined attitudes, experiences, and preferences about ADs among adults of all ages. The study used an age-stratified random sample of patients from a large managed care organization.<sup>4</sup> Findings revealed that older subjects were likely to be comfortable with and complete an AD. The most valuable outcome was the discussion of personal wishes with family and loved ones. Overall, the findings of this study concurred with the findings of other studies demonstrating that patients wanted control over EOL care decisions or wanted family members or loved ones to make those decisions. Consequently, patients not only believe the decisions are their responsibility, but also feel comfortable if their HCP initiates this conversation.<sup>4</sup>

Open and direct discussion regarding care planning can ease many of the fears related to EOL care. Discussion of an AD is a way to prepare for death and dying, rather than just

a preparation for being incapacitated in the future. The process allows improved communication between patients, surrogates, and HCPs.<sup>3</sup>

The importance of communication with the patient's primary care provider (PCP) regarding discussion of ACP or an AD is demonstrated in a longitudinal study completed by Ramsaroop and colleagues from January 1991 through July 2005. This systematic review of studies was designed to increase the completion of an AD in primary care settings.<sup>5</sup> The study reviewed interventions that were most successful in improving the AD completion rate. The investigators extracted physician and patient barriers to completion of an AD. Findings suggested that the most successful intervention for completion of an AD were conversations that took place between patients and HCPs about ACP and occurred over multiple visits. By contrast, passive education using written materials without any direct counseling was relatively ineffective.<sup>5</sup> The study also demonstrated the importance of completion of an AD in the primary care setting, gauging patient readiness to complete an AD, and having the PCP initiate the AD conversation.<sup>5</sup>

If communication does not occur between patients and HCPs, care preferences are often not documented. Without this documentation many patients do not receive appropriate palliative care services when needed. Palliative care is not available to and therefore often not used with patients with nononcologic diseases.<sup>6</sup> A study by Mahtani-Chugani and colleagues evaluated barriers to providing palliative care to nononcologic patients and proposed strategies to overcome them. Findings suggested 4 barriers: (1) lack of clarity about illness and prognosis; (2) discussion

limited exclusively to the curative approach; (3) avoiding terms such as "terminal illness"; and (4) cheating death, including linking nononcologic disease and death.<sup>6</sup> A strategy to overcoming these barriers highlighted improved communication between HCP and patient and understanding that the communication process is as important as the content of the message. Therefore, equitable palliative care services should be offered to both nononcologic and oncologic patients.<sup>6</sup>

One life-limiting nononcologic disease is COPD. Chronic obstructive pulmonary disease remains a major public health problem. It is the fourth leading cause of chronic morbidity and mortality in the U.S. and is projected to rank fifth in 2020 in disease burden worldwide.<sup>7</sup> Given its prevalence, COPD is found in all adult health care settings.

Among hospitalized veterans in the VHA in 2005, COPD was the fourth most common discharge diagnosis.<sup>8</sup> In the veteran population, a high prevalence for developing COPD also exists due to high-risk factors including tobacco use in the military. According to a study conducted at the Cincinnati VAMC in Ohio, a 40% greater prevalence of COPD existed in this veteran population than in the general U.S. population.<sup>8</sup>

Another nononcologic, life-limiting disease is CHF. Both the prevalence and hospitalization rates for CHF show an upward trend since the 1970s, resulting in a continued increase in CHF death rates.<sup>9</sup> According to 2008 estimates from the National Institutes of Health, there are 5 million CHF patients in the U.S. and hospitalization rates approach 1 million per year.<sup>9</sup> Congestive heart failure affects 2.4% of the adult population and > 11% of

the expanding population aged > 80 years. Existing care may slow the progression of the disease but can rarely reverse it, which usually results in a prolonged period of advanced illness. As a result of the increasing prevalence, there remains a high symptom burden for patients living with advanced CHF.<sup>10</sup>

In managing the high symptom burden of CHF and COPD, patient-centered care must be acknowledged and used. Patient-centered care mandates that beneficial therapies and recommended guidelines be offered and discussed with the patient, giving attention to patient preferences.<sup>10</sup>

## STUDY DESIGN

The theoretical framework for the development and implementation of this project is based on Ruland and Moore's Peaceful End of Life Theory.<sup>11</sup> This theory is based on 2 assumptions. The first is that each person's approach to EOL is personal. The second is that nursing care plays a major role in making EOL a peaceful experience. The 5 outcome measures include: (1) not experiencing pain; (2) the experience of comfort; (3) the experience of dignity and respect; (4) being at peace; and (5) closeness to significant others or other caring persons.

The outcome indicator of the Peaceful End of Life Theory—experience of dignity/respect with its related criteria and prescriptors—provided structure for the development and implementation of this project. The prescriptors related to the experience of dignity/respect include involving the patient and significant others in decision making; treating the patient with dignity, empathy, and respect; and being attentive to the patient's expressed needs, wishes, and preferences.<sup>11</sup>

Due to the increased prevalence of chronic illnesses in the VA system, veterans need encouragement to complete ADs. The VA instituted a national directive guiding education and implementation of an AD.<sup>12</sup> These discussions occur at the first contact a veteran has with the system and at other times when appropriate. The purpose of the directive is to allow veterans to guide the course of their treatment and to assure that they are aware of the ability to refuse treatment at any time.<sup>12</sup>

### INCONSISTENCIES IN ADVANCE DIRECTIVE COMPLETION

Inconsistencies were noted with how ADs were completed at the VA Northern Indiana Health Care System in Muncie. For outpatients, the clinic nursing staff received an electronic medical record (EMR) reminder if the veteran did not have an AD. This reminder prompted the nurse to ask the veteran about completing an AD. If the veteran agreed, a social work consult was initiated by nursing. Of concern, the social worker is usually responsible for several clinics so it is unlikely the process of completing the AD would be accomplished on the day the veteran was already in the clinic.

Discussions in the inpatient setting included a physician, a nurse practitioner, or a social worker and were often disease specific and patient oriented. However, in an acute hospitalization, it was less likely that patients initiated ADs due to acute illness and rapid nature of treatment.

Another concern was related to the amount of clinical knowledge the social worker had about the specifics of each patient's case. Without specifics, a social worker can make the AD discussion very broad. Patients want information regarding disease progression and prognosis

specific to their own condition to be able to make an informed choice regarding ADs.<sup>13</sup>

A study population with the diagnoses of CHF and COPD was selected due to the prevalence in the facility and at the request of facility leadership.

### METHODS

The primary aim of this quality improvement (QI) project was to educate the PCP about the importance of allowing veterans to express their care goals in the form of ADs and to understand that veterans would prefer to discuss these goals with their PCP. A secondary aim was to improve goal-directed care for veterans with COPD or CHF by increasing the number of completed ADs.

By using a systems approach, ACP can be addressed in a uniform manner. This approach allows veterans to discuss their goals of care prior to the need for emergent interventions, avoiding burdensome and unwanted treatments. Through the completion of ADs, veterans are able to designate a surrogate decision maker and identify specific desired treatments and interventions as their illness advances.

Two physicians and 3 nurse practitioners volunteered to contribute to this study. In the participating clinics, veterans with a diagnosis of CHF or COPD were identified. Each veteran had 20 to 30 minutes per appointment to discuss concerns, be examined, have HCPs address concerns, and complete all clinical reminders.

The study design was a QI project focused on evaluating the following process: An EMR reminder alerted the clinic nurse who asked the veteran if he or she was interested in completing an AD. If the patient agreed, a consult was placed to the social worker for completion of the VA national form for AD. The com-

pletion rate for a sample of primary care clinics at the facility was 10% to 12%, with no participation from the PCP in the process.

The providers were educated in 5 areas: (1) the prevalence of CHF and COPD in the U.S.; (2) the difference between ACP and AD; (3) the percentage of ADs completed in the U.S. adult population and in the facility; (4) the importance of addressing ACP early in the disease trajectory of this population; and (5) the use of the EMR reminder and the template to guide discussion of ACP (eAppendix A, available at [www.fedprac.com](http://www.fedprac.com)).

The template was developed following the literature review and addressed the reoccurring themes that patients wanted to discuss concerning their specific diagnosis and treatment. The template was formatted to include 3 components: (1) health care surrogate; (2) code status; and (3) organ donation preference (eAppendix B, available at [www.fedprac.com](http://www.fedprac.com)). When EMR reminders appear, the PCP initiated a discussion regarding COPD or CHF and the likely progression of the illness. The provider opened a separate note entitled AD Discussion and uses the template. The provider could then guide the discussion to the veteran's goals of care.

The natural progression from discussion of goals of care led to the discussion regarding the initiation of an AD. When completed, the note automatically appeared in the Postings section of the EMR, making it easily accessible to all other providers in different care settings.

The project time was 3 months (December 2012 through February 2013). The education was completed and the EMR reminder was turned on at the beginning of the project for veterans with a diagnosis of CHF or

COPD who had not completed an AD. At the conclusion of the project, the PCPs completed a post project survey to provide information regarding their opinions on facilitators and barriers in the AD completion process (eAppendix C, available at [www.fedprac.com](http://www.fedprac.com)). The intervention of the PCP-initiated discussion of ACP was assessed by the percentage increase in completed ADs.

## RESULTS

Five different primary care clinics in 4 different locations throughout the health care system provided a total of 294 veterans with diagnoses of CHF or COPD. On completion of the project, 35 veterans had completed ADs. These 35 veterans represent an additional 12% of patients who previously did not complete an AD despite being approached multiple times. The veterans completed an AD following PCP-initiated discussion due to this QI project.

All 5 providers completed the post project survey and agreed that it would be beneficial to have the information regarding ADs easily accessible in the EMR. Four out of 5 providers admitted to cutting corners by not opening a new note every time to complete the AD template. They reported completing the EMR reminder within the clinic note, making it difficult to locate the information. Providers also reported on the various facilitators and barriers to AD discussion with patients (Table).

## DISCUSSION

The completion of an AD remains an important part of health care that is often neglected. When patients receive care and treatments, they often do not desire an AD, because the goals of care have not been clearly communicated and clearly documented. This can lead to poor

**Table. Provider-Identified Facilitators and Barriers to Advance Directive Discussion**

Barriers	No. of Providers
Not adequate time	5
Discomfort on the part of the provider	1
Discomfort on the part of the patient	1
<b>Facilitators</b>	
A template to guide discussion	3
The veteran initiating the discussion	1
A family member initiating the discussion	1
Education regarding discussing goals of care and advance care planning	2
Brochures to accompany discussion	3

quality of care with increased dissatisfaction and burden on the patient and health care system.<sup>14</sup> However, if goals of care are discussed and documented, the veteran may avoid these burdensome treatments, and health care will be congruent with patient wishes. Better communication and documentation promotes increased patient satisfaction and improved quality of health care.<sup>1</sup>

This project endorses findings from a previous case study that demonstrated better patient-centered, goal-directed care results when patients have the opportunity to complete an AD, thereby improving health care quality and patient/family satisfaction.<sup>3</sup> Previous studies suggested one way to increase the AD completion rate involves the PCP initiating a discussion with the patient.<sup>5</sup> This project supports that conclusion.

## LIMITATIONS

All the project providers expressed support regarding the importance of discussing ACPs with their patients.

The major limitation identified by the project providers was time constraints in a busy primary care clinic. One provider suggested initiation of an EMR reminder once per year to prompt discussion. The same provider also recommended rescheduling an additional clinic visit to have an in-depth discussion regarding ACP.

Another limitation to this project involved the EMR. Currently, there is no way to have information in the postings section without a separate note. The project providers all agreed that it was not always possible to open a new note to use the template due to limited clinic time. This allowed information regarding health care surrogates and discussions regarding code status and organ donation to be embedded in a clinic note, which can make it difficult for other providers at different levels of care to effectively locate. Incorporating a method to allow information from an EMR reminder to be automatically placed in the postings section would alleviate this limitation.

A further limitation involved the setting. The VA provides care only to veterans. The project can be generalized to other VA primary care clinics, but generalizability beyond the VA may be limited.

This QI project took place over 3 months, another potential limitation due to the limited study period. Also, due to the short time frame of the project, a small sample size was used. Further investigation of this topic by expanding the time frame and sample size would further develop this body of knowledge.

The VA uses an EMR that is accessible to all VA providers locally and nationwide. Due to the nationwide network, expansion of the project would be possible with the support of facility leadership and the EMR reminder staff. By using the education and the template for discussion, the project could be replicated throughout the system.

## CONCLUSION

Advance care planning and ADs should be a regular part of the health care process, especially for veterans with noncancer diagnoses, such as CHF and COPD. Clear communication about disease trajectory and prognosis are an important part of this discussion. Primary care providers are in the optimal setting to initiate this discussion.

This project supports previous findings that a PCP initiating or participating in the ACP discussion

would result in an improved completion rate for ADs.<sup>5</sup> Theoretically, improved AD completions result in patient-centered care, leading to higher patient satisfaction. ●

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## Author disclosures

*The authors report no actual or potential conflicts of interest with regard to this article.*

## Disclaimer

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