

# Public Health Need Paper

## Advance Care Planning

Contessa Stroda

August 9, 2017

Medical care and technology advances in the 20<sup>th</sup> century have made tremendous progress in prolonging life expectancy in the United States. Delaying death is always a desired outcome, but often the quality of life and experience of death itself is abated. For some Americans, these advancements have allowed them to survive illnesses or traumatic injuries that previously would have been fatal. For others, medical technology prolongs their existence with a poor quality of life. However, some disabled individuals have reported that healthcare overvalues their quality of life and their suggestions to withhold life-prolonging treatment is not what the patient themselves might want.<sup>1</sup> Extensive literature shows evidence that at the time of death, people receive more aggressive treatment than what they desired or wished to receive.<sup>1</sup> When asked, many people wish to die at home<sup>1,2</sup> but less than a quarter of patients actual do.<sup>2</sup> These differences of opinions and views on dying only exemplifies the public health need to improve end-of-life documentation in the United States.<sup>2</sup>

Talking about death and how we want to die is often a very uncomfortable topic to discuss amongst our family and friends let alone with medical professionals. Each person has their own right to an opinion on how they want to approach and experience death. This topic is often not breached especially amongst those that are healthy with no active threat to their lives. Their end of life plans, wishes, and desires go unreported. To increase advance care planning rates, primary care providers should discuss and educate middle age patients about end-of-life measures and options<sup>3,4</sup>.

The public health need for legal end-of-life documents has been recognized by the US government since the 1960's.<sup>5</sup> To prevent difficult legal and emotional situations once patients lost their health care autonomy, the US congress passed the Patient Self-Determination Act

(PDSA) in 1990<sup>6</sup>. This law gave creation and recognition of the Advance Directive form and its delegation of a medical proxy. The law allowed people the right to make their own decisions about their health care, to accept or refuse medical treatment, and the opportunity to complete an advance health care directive<sup>6</sup>. This law also requires health care personnel to reiterate that it is the patient's right to make their own medical decisions, to ask if the patient has an Advance Directive, and if not, ask if the patient would like to complete one<sup>6</sup>. The POLST concept was initiated in 1991 when the Center of Ethics in Health Care leaders at OHSU noticed advanced directives were not consistently being honored<sup>7</sup>. By 1995 the "Physician Orders for Life-Sustaining Treatment" (POLST) form was first released in Oregon. This form consists of direct physician's order making it clear to EMS and other medical personnel what resuscitation measures the patient wants implemented<sup>7</sup>. Other medical governing bodies such as the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) requires hospital staff to provide information about advance care planning to all patients and to document evidence of an Advance Directive<sup>4</sup>. Even with these government implemented strategies, Advance Directive and POLST completion rates in the US remain relatively low<sup>4</sup>.

There are important, fundamental difference between an Advance Directive and POLST that requires both of them to be completed by a patient in order to have efficient end-of-life care wishes documented. An Advance Directive is similar to a living will in that it contains specific legal instructions regarding patients preference for what they would and would not want done to stay alive when they become unable to make a decision for themselves<sup>8</sup>. The Advance Directive addresses medical decisions during specific situations like terminal illness, significant injury, coma, late stages of dementia, tube feeding, dialysis, comfort care, or organ donation<sup>8</sup>. An important part of the Advance Directive is that it allows the patient to name a person that they

feel comfortable making decisions about their medical care when they are incapacitated<sup>7</sup>.

Depending on the state, these people are called health proxy, health surrogate, health representative, or power of attorney<sup>8</sup>. This document should be filled out by healthy people 18 years and older and should be updated periodically<sup>8</sup>. The Advance Directive packet can be filled out and signed by themselves and witnessed by a non-relative. It is up to the patient to make sure it is retrievable when needed to make a medical decision<sup>8</sup>. The essential downfall of an Advance Directive is that it is not a medical order and cannot be used in the event of an emergency<sup>8</sup>. This is why the POLST form needs to be completed as well when patients near the end of their lives.

POLST forms are a medical order which gives instructions to medical teams to ensure the patient receives the treatment and resuscitation they prefer<sup>7</sup>. Since the POLST is an order, it must be filled out and signed by the patient's physician, physician assistant, or nurse practitioner. POLST forms should be filled out when individuals become seriously ill, frail, or near the end of life. The POLST includes details about which certain treatments can be used, how long the treatments can be used, and when treatment should be withdrawn<sup>8</sup>. Specific issues include orders on resuscitation, mechanical ventilation, tube feeding, use of antibiotics, requests not to be transferred to the emergency room or hospital, and pain management<sup>8</sup>. POLST forms should be updated with a provider when a patient's health status changes. This document becomes part of the Oregon POLST Registry and is accessible by all medical staff in the case of an emergency<sup>7</sup>.

Twenty years after the PDSA was initiated and regulatory bodies such as JCAHO have promoted Advance Directives, the completion rate of end of life documentation is still low. This can be seen in a retrospective cohort study conducted across 5 counties in Oregon in 2010. The

study analyzed patient's POLST status before being found by EMS providers in an out-of-hospital cardiac arrest event<sup>9</sup>. Researchers found that of 1,577 patients found in out-of-hospital cardiac arrest, only 82 had previously signed POLST forms<sup>9</sup>. Only 5% of the patients being treated by the EMS for an acute cardiac arrest event had a POLST order on file. The CDC estimates that 20 years after implementing the PSDA law, only 5-15% of the adults in the United States has a completed Advance Directive<sup>10</sup>. There was, however, a higher prevalence of Advance Directives completed amongst adults living in long-term care populations including home health care patients, nursing home residents, and discharged hospice care patients<sup>10</sup>. To be enrolled in the previous long-term facilities or programs, they most often require patients to file an Advance Directive before admittance. This establishes the need to increase advance care planning practices amongst a younger, healthy population before hospitalization occurs<sup>11</sup>.

A goal made by Healthy People 2020 advocates to increase the proportion of older adults utilizing clinical preventative services<sup>12</sup> which can include counseling about advance care planning. Having an Advance Directive and POLST on file can help dictate where you die which has an influence on *how* you die.<sup>13</sup> Having a comfort care or hospice order written in your advance care plan lessens the extent of stay in hospitals, decreases the amount of care you originally receive<sup>13</sup>, and lessens the chance of an in-hospital death<sup>14</sup>. In a study that was done at OHSU, 70% of family members of those receiving home hospice services rated their experience as excellent<sup>13</sup>. Of family members of those dying in a hospital or nursing home, 50% of them ranked their experience as excellent<sup>13</sup>. When one is dying in a hospital, they are subjected to increased medicalized treatment which can prolong life but often at the cost of losing their quality of life. By completing and reregistering a POLST form, 93.6 % of Oregonians died in their homes, or long-term care versus 61.9% of those without POLST forms died in their homes

or long-term care. With a POLST form on record, there is a 32 % increased chance of dying at home or in long term care versus dying in a hospital<sup>13</sup>. This proves to the patient that if completed, the patient's wishes will be carried out as ordered.

One location where preventative medicine, including advance care planning, should be implemented is within primary care services<sup>4</sup>. Patients have a unique opportunity to have a personal relationship with their family provider where the provider can attain morals and values from the patient. This can provide the patient and their family satisfaction and peace of mind knowing that their medical care aligns with their wishes<sup>14</sup>. However, medical providers have poor track record of discussing Advanced Directives with their patients. It has been reported that under a quarter of patients learn about Advance Directives from medical providers; More often they learn about them from their family and friends<sup>15</sup>. Prior studies have found that patients want their primary care providers to initiate advance care planning and that it is the providers' responsibility to do so<sup>4,16</sup>.

Many interventions have been attempted to promote engagement in advance care planning and completion of Advance Directives. They have included changing individuals health behavior, or physicians practice patterns<sup>1</sup>. A study in the Journal of American Geriatric Society completed a systematic review that evaluated studies on their method to increase Advance Directive completion in the primary care setting<sup>4</sup>. They found that the most effective intervention to Advance Directive completion used direct counseling from the provider over multiple visits<sup>4</sup>. The use of only handouts and distributed written material *without* direct counseling from medical staff was found to be ineffective in the primary care setting<sup>3</sup>. The systematic review also considered the practicality of strategy implementation and the amount of time used for increasing

completion. In one study, they found that even if patients were given written information and were counseled for an extra 3-5 minutes about Advance Directives, completion rates equaled 44%<sup>4</sup>. One limitation to this study was that it was published in 2007. Recently a new strategy was implemented to increase Advance Directive completion. As of January of 2016, Medicare and Medicaid will pay for a 30 minute advance care planning appointment or if it is addressed during a wellness visit<sup>17</sup>. CPT codes have been constructed to file claims for advance care planning services to reimburse providers for the time they spent educating<sup>17</sup>. This will give providers incentive to have a face-to-face conversation with the patient, family member and/or surrogate to explain and discuss Advance Directives and POLST forms<sup>17</sup>. As simple as a few extra minutes and a piece of paper seems, there are many barriers that do not allow this interaction between provider and patient.

There are multiple barriers that can prevent providers and patients from engaging in conversation about the patient's advance care plans. Common provider related barriers include lack of time, lack of useful instructional information, and ineffective communication<sup>14</sup>. Patient related barriers could include health literacy, lack of interest, lack of reliable proxy, and waiting for the physician to initiate the discussion<sup>3</sup>. There are also studies that show cultural, racial and ethnic factors also influence Advance Directive completion<sup>3</sup>. African American patients have a lower completion rate of filing Advance Directives and often prefer more aggressive measures at end-of-life<sup>3</sup>. It is important for providers to be aware of their own barriers and those of their patients to overcome them while implementing Advance Directives.

Too often people are hospitalized with a serious illness and are too incapacitated to participate in medical decision making which then falls to their family and loved ones<sup>18</sup>.

The first stage of life that interactive Advance Directives discussions should be implemented by a primary care provider should begin in a routine patient visits of those 50-65 years of age<sup>3</sup>. By initiating an advance care plan conversation with a healthy patient, a provider can establish the patients initial values and foster a discussion about preventive issues as well<sup>3</sup>. It is important to talk to this population before they encounter an acute sickness or accumulate chronic comorbidities<sup>18</sup>. Healthy middle-aged individuals are the most ideal patient because they are in a stable state of mind where they can keep their autonomy about end-of-life measures before they happen<sup>19</sup>. In the event of an emergency accident, having an Advance Directive and POLST form on file can be extremely beneficial for the patient and their family.

Advanced care planning and the implementation of an Advance Directive and POLST gives patients the autonomy to communicate and record end of life wishes during emergencies and unforeseen, critical illness. Too often people are hospitalized with a serious illness and are too incapacitated to participate in medical decision making which then falls to their family and loved ones<sup>18</sup>. Without written acknowledgement of the patient's end of life wishes, this can increase the amount of medicalized care the patient receives from EMS or within a hospital<sup>20</sup>. Having an understanding of patient's end-of-life wishes can decrease unnecessary, expensive medical treatment that often sacrifices quality of life<sup>20</sup>. The primary care setting is the ideal location to target the quintessential audience of healthy middle-aged adults to initiate advance care planning discussions. With new reimbursement codes, new research is required to see if it is an effective intervention to increase Advance Directive completion. Providers need to be aware of the many barriers to implementing advance care planning and should actively practice overcoming them. This topic is pertinent to every single patient since we all grow older. All



providers young and old should have advance care planning dialogue in their care plan to give their patients a full and meaningful health care management.

### Topic Connection

This topic was chosen to discuss because I felt uneducated about advance care planning. This topic is important because it should eventually be discussed with every single one of my patients since none of us can escape death. I feel that it is important that patients are presented the opportunity to discuss and record how they prefer to die. As shown by the studies above, there is a need to promote advance care planning in the primary care setting. Implementing advance care planning is as simple as bringing up the conversation and taking the time to talk with patients. The knowledge about the new reimbursement CPT codes needs be shared especially amongst my classmates. It would be great practice to start advance care planning at the beginning of our career to become well versed in a subject that will be discussed often.

### **References:**

1. U.S. Department of Health and Human Services Assistant Secretary for Planning and Evaluation Office of Disability AaL-TCP. ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING:REPORT TO CONGRESS. 2008.
2. Muramatsu N, Hoyem RL, Yin H, Campbell RT. Place of death among older Americans: does state spending on home- and community-based services promote home death? *Med Care*. 2008;46(8):829-838.
3. G. David SPOELHOF M, Barbara Elliott P. Implementing Advance Directives in Office Practice. *American Directives in Office Practice*. 2012;85(5):461-466.
4. Ramsaroop SD, Reid MC, Adelman RD. Completing an advance directive in the primary care setting: what do we need for success? *J Am Geriatr Soc*. 2007;55(2):277-283.
5. Sabatino CP. The evolution of health care advance planning law and policy. *Milbank Q*. 2010;88(2):211-239.
6. Advance Directives Expressing Your Health Care Wishes. In: States CHAotU, ed2015.
7. Advance Directives. 2017; <http://oregonpolst.org/advance-directives>. Accessed July 11, 2017.
8. Living wills and advance directives for medical decisions. *Healthy Lifestyle Consumer Health* 2014; <http://www.mayoclinic.org/healthy-lifestyle/consumer-health/in-depth/living-wills/art-20046303?pg=1>. Accessed July 19, 2017.

9. Richardson DK, Fromme E, Zive D, Fu R, Newgard CD. Concordance of out-of-hospital and emergency department cardiac arrest resuscitation with documented end-of-life choices in Oregon. *Ann Emerg Med*. 2014;63(4):375-383.
10. Adrienne L. Jones AJM, Lauren D. Harris-Kojetin, Ph.D. . Use of Advance Directives in Long-term Care Populations. *NCHS Data Brief* 2011; <https://www.cdc.gov/nchs/data/databriefs/db54.pdf>. Accessed July 19, 2017.
11. Donahue E. Improving Advance Directive Completion Rates in the Primary Care Setting. *Nursing Commons*. 2013.
12. Older Adults. <https://www.healthypeople.gov/2020/topics-objectives/topic/older-adults/objectives>. Accessed June 28, 2017.
13. Fromme EK, Zive D, Schmidt TA, Cook JN, Tolle SW. Association between Physician Orders for Life-Sustaining Treatment for Scope of Treatment and in-hospital death in Oregon. *J Am Geriatr Soc*. 2014;62(7):1246-1251.
14. Lum HD, Sudore RL, Bekelman DB. Advance care planning in the elderly. *Med Clin North Am*. 2015;99(2):391-403.
15. Duke G, Thompson S, Hastie M. Factors influencing completion of advanced directives in hospitalized patients. *International journal of palliative nursing*. 2007;13(1):39-43.
16. Horne SG, Anderson RN, Burwash I, Koilpillai C, Johnstone DE, Smith ER. Differences in ventricular septal motion between subgroups of patients with heart failure. *Can J Cardiol*. 2000;16(11):1377-1384.
17. Services CfMM. Advance Care Planning. *Medicare Learning Network* 2015; <https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/AdvanceCarePlanning.pdf>. Accessed 09/23/17.
18. Berns SH, Camargo M, Meier DE, Yuen JK. Goals of Care Ambulatory Resident Education: Training Residents in Advance Care Planning Conversations in the Outpatient Setting. *J Palliat Med*. 2017.
19. Kellogg E. Understanding Advance Care Documents: What the Nurse Advocate Needs to Know. *Journal of emergency nursing: JEN : official publication of the Emergency Department Nurses Association*. 2017.
20. Salmond SW, David E. Attitudes toward advance directives and advance directive completion rates. *Orthopedic nursing*. 2005;24(2):117-127; quiz 128-119.