

Educating Healthcare Employees about Advance Care Planning

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ABSTRACT

The objective of this descriptive article is to provide a background of current research and data on advance care planning. Additionally, a proposed and detailed education initiative for increasing completion and understanding of advance care

planning documents is presented.

Key words: Advance care planning, advance directives, durable power of attorney, education, end-of-life

Introduction

Advance care planning (ACP) is a dynamic process involving many discussions whereby individuals anticipate and discuss future health states and preferred treatment options.^[1] The Medical Code of Ethics opinion 5.1 states that despite the popular opinion of ACP being applied to terminally ill patients, end-of-life decision-making is applicable to every patient served, including young, healthy, and all others.^[2] Population-based data show that the majority of adults have not had proper education about end-of-life planning.^[3] According to a recent study conducted in the United States, less than half of all adults

over the age of 65 and roughly a third of adults under the age of 35 have any sort of advance care directives.^[4] In addition, in a study of Germany emergency department cases, of 1047 patients, only 127 had advance directives (AD) and 44 had a durable power of attorney (DPOA).^[5] These data suggest that completion rates may be even lower in certain populations. ACP is applicable to all individuals in all stages of life, regardless of medical necessity. A recent study that used a mail panel in the United States reaffirmed that the majority of the population still do not participate in ACP because only 26.3% of individuals reported having an

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AD.^[3] Statistical data are variant throughout the literature, but consistently represent a rate lower than would be ideal for providers, patients, and families to make adequate care decisions.

Included in ACP are living wills, AD and DPOA which allow an individual's wishes to be carried out, should they become unable to verbalize their wishes [Table 1]. For the purpose of this article, authors are referring to DPOA for healthcare, not the alternative for financial decision-making. A living will is a statement about the kinds of medical care a person does or does not want under certain specific conditions (often terminal illness) if the patient is no longer able to express those wishes.^[1] DPOA for healthcare "identifies the person (the healthcare agent) who should make medical decisions in case of the patient's incapacity". This name may vary by state: proxy, healthcare representative, etc.^[1] Individuals completing a DPOA should elect someone as their healthcare agent who is trusted, organized, and will carry out decisions in their best interest. The proxy knows the individual well and becomes their voice when they are unable to verbalize decisions. This may be a best friend, chaplain, colleague, family member, or any trusted individual. Whoever is selected, it is key they understand their role in advance.

A study was conducted at a regional senior welfare center in Korea among older adults aged 60 years or older and researchers found that most participants (79.32%) agreed that AD completion was necessary.^[6] Main characteristics influencing increased agreement and support that AD are necessary were high education level, problems with self-care, poor physical functioning, and death-related experiences.^[6] It was found that especially discussions of end-of-life care with family members and those closest to the patient increased the willingness of the patient to complete an AD.^[6] A recent cross-sectional study examined barriers of ACP uptake in an aging community of Singapore.

The authors noted that ACP is not practiced in the community due to perceived cultural taboos.^[7] Based on this original pilot study data, ACP awareness was reported in approximately 20% of the population.^[7] These cross-cultural studies support the notion that ACP is not discussed in daily life and that education is necessary to promote end-of-life decision-making.

The current research is focused on ACP for older adults or adolescents with cancer. ACP is not necessarily a one-time decision; it can be an ongoing process as people grow.^[8] Family practice care could be the ideal place to begin the conversation between physician and patient due to preexisting relationships^[8] and presumably, an understanding of current health care concerns and future risk. During primary care visits or in times of good health, patients usually have a more clear mind to make the important decisions of ACP in comparison to after or during the diagnosis of a serious illness when patients and families are attempting to cope with the stress and emotions that go along with it. Research suggests that individuals may be more responsive and proactive in completing various forms of ACP when a health promotion focus is taken, as opposed to the intimidating thought of imminent death.^[9]

There have been multiple efforts to promote the education and completion of advance care directives, one being educating healthcare providers. National Healthcare Decisions Day (NHDD), which is recognized each year on April 16th, began through an initiative called "The Conversation Project" [Appendix A] which seeks to highlight the importance of education and empowerment in ACP. The vision of NHDD is that every healthcare facility will participate as the main forum for the public engagement of end-of-life care.^[10] Another initiative called "ISaidWhatIWant" [Appendix A] represents more than 700,000 nurses across 20 nursing specialty organizations with the sole purpose of encouraging nurses to complete their own ACP so that they can educate their patients to do the same.^[11] Although most nurses are familiar with ACP, surprisingly, many do not already have a plan in place, and this initiative encourages nurses to create their own ACP.

The purpose of this paper is to describe an initiative completed at a medical center in the Midwest in the United States in which healthcare workers approached staff with information on end-of-life care with the hopes they would disperse this important education to the patients. In an opinion poll in Canada, only 9% of individuals reported discussing ACP with healthcare providers.^[12] The hope is that with healthcare professionals having more knowledge on ACP and their own directives completed, it will result in an increase in conversations and education with patients on ACP. ACP and all relevant documents are designed to

Table 1: Legal documents

Concept	Definition
DPOA	Identifies the person (the healthcare agent) who should make medical decisions in case of the patient's incapacity. This name may vary by states: proxy, healthcare representative, etc. ^[1]
AD	Advance directive, typically in the form of living wills and healthcare powers of attorney, is a document that offer patients a way to avoid unwanted care in the event of serious illness or incapacity. An advance directive is a formal legal document specifically authorized by state laws that individuals complete to be invoked if they become seriously ill and unable to make decisions ^[4]
ACP	Advance care planning is a dynamic process involving many discussions whereby patients anticipate and discuss future health states and preferred treatment options ^[1]
Living will	A statement about the kinds of medical care a person does or does not want under certain specific conditions (often terminal illness) if the patient is no longer able to express those wishes ^[1]

DPOA: Durable power of attorney, AD: Advance directive, ACP: Advanced care planning

allow individuals to maintain autonomy and direct their own health care, including end-of-life care, to meet their wishes and preferred quality of life which aligns with the belief of healthcare providers to maintain patient-centered care. The values of patient autonomy and individual choice fall under the moral principle of respect for autonomy.^[13] Based on this professional perspective, these decisions should be approached at a time when a person is of sound mind and emotional stress is not impacting decision-making status. It has been reported that 70% of patients needing to make end-of-life decisions are incapable of making those decisions.^[1] Without current legal documentation, providers and family members confront ethical dilemmas and high levels of stress in what is a presumably challenging situation impacting the decision-making process. Although this topic has been studied over time, it appears that results are inconclusive and steps continue to be missed in promoting completion of ACP. This demonstrates a need for increased investigation and education in how stakeholders can increase completion of ACP. This may also impact issues such as quality of life, medical expenses, and grieving in families. A strategy to decrease these burdens and increase completion of ACP is through healthcare professionals implementing interventions aimed to educate the public.

Education Initiative

An initiative developed by nurses from the cancer center associated with a large academic medical center in Midwestern United States was a unique approach taken to provide education to the medical center staff about the importance of healthcare provider completion of DPOAs. The goal of this initiative was to educate hospital staff, including all disciplines and roles, on the importance of ACP. By informing staff, this information could potentially become more widespread based on each individual's sphere of influence and interactions with patients. The initiative encouraged healthcare staff to complete their own ACP documents, with the hopes that their familiarity with the process would influence increased patient education and ACP completion.

Subjects

Individuals included all employees of a large academic medical center in the Midwestern United States receiving or interested in receiving benefits, both licensed and nonlicensed. A total count of individual employees interested in ACP at the fair was to be calculated by the number of forms dispersed. This number was not accurately obtained as several employees requested multiple copies for family members and friends. During a 5-day employee benefits fair in 2018, a total of 709 DPOA forms were dispersed. Flyers marketing their booth at the employee fair were distributed through e-mail and displayed in all

of the hospital campuses. Nurses hosted ACP booths at the benefits fairs in the 2 years before 2018; however, data were not as thoroughly tracked in these previous attempts.

Instruments

Several resources were available to employees during this process. A front and back copy with a DPOA and AD on either side was dispersed to employees for completion [Appendix B]. This form is utilized and acknowledged as a legal document throughout the United States. Handouts were available that identified online resources for employees and the public to access for assistance in decision-making [Appendix C]. This compilation of web resources was used to make individuals aware of free public education tools from credible sources. In addition, "GoWish" cards [Appendix A] were utilized with employees to facilitate conversation regarding their wants and wishes in end-of-life care.^[14] The staff members that supervised the booth were well educated on information involving ACP which included state notary requirements, available links and resources, and the document completion process.

Methods

The nurses completing this education initiative set up a booth regarding ACP at an employee benefits fair. This academic medical center holds an annual system-wide employee benefits fair, available at four hospital campuses. At the benefits fair, vendors provide information and access to different benefits, options, and resources, such as retirement, financial assistance, and healthcare coverage. The cancer center nurses occupied a booth providing education and forms for ACP, such as DPOAs, ADs, and handouts with resources on ACP. On three of the 5 days, a notary was present [Figure 1]. This medical center borders two states, one requiring two witnesses for the DPOA to be legal and the other state requiring notarization. Having

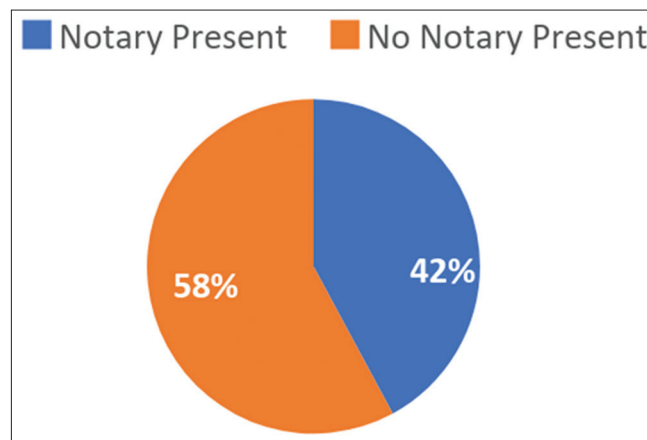


Figure 1: Notary Hours. *40 total hours at employee benefits fair, *Total of 69 combined Registered Nurse hours for supervision of booth

a notary present at the benefits fairs was preferred, since numerous other areas and states require notarization and notarization would allow the DPOA to be transportable across state lines. Employees were also provided with instructions to have their documents placed in their electronic medical record (EMR).

Results

Initial impressions from data

The nurses from the academic medical center hosted ACP booths in years 2016, 2017, and 2018. Each year, the benefits fair was held over a 5 day period which encompassed a total of 40 hours. The 2018 data were not as robust as 2016 when a total of 170 employees completed ACP documentation; with full time notary support available. Unfortunately, the data from 2017 were lost. Antidotally, the 2017 event resulted in low DPOA completion with minimal notary support. The results displayed [Tables 2 and 3] are from the 2018 employee benefits fair. Nursing staff clocked a total of 69 hours, and a notary was present for 13 hours. Table 2 offers a breakdown of 5 days' worth of data collection. With 709 total DPOA forms dispensed, 147 were completed [Table 3]. Overall, approximately 20% of individuals completed DPOA forms on-site, with the hope that individuals that took them home would complete them on their own time. In addition, contact information was provided for those taking forms home for scanning and uploading the completed document into their individual

EMR. A reported 108 hospital employees conveyed already having a DPOA in place. Several individuals received multiple forms for family and friends, including one individual who took home 10 forms adamant about each of her family members completing one.

Each state has different regulations for whether a notary is required [refer to Appendix A to find a specific state]. Individuals overseeing this initiative felt as though all forms should be notarized so that they can be honored in most states. A nurse responsible for this initiative has already completed notary requirements to allow for a notary to be present full time at future employee benefits fairs. Over the three years, outcomes suggest that having a notary present increased the amount of DPOA forms completed.

Qualitative objective information was also tracked throughout the events regarding comments made by a variety of employees, including licensed professionals. Comments were noted regarding assumptions as to why a DPOA was not appropriate for them and indicated a lack of knowledge regarding healthcare decision-making. Reasons for not needing to complete a DPOA included fear of putting stress on loved ones and no imminent risk of death. During the employee benefits fair, several individuals noted that family deaths made them aware of how important it was to complete ACP.

Discussion

ACP can be useful for all individuals to complete and is appropriate regardless of age or health status. A study completed in Singapore demonstrated a willingness of individuals in their community to discuss end-of-life discussion making; however, there is still low completion due to limited awareness.^[7] Based on this initiative and interpretations of other studies, fostering these discussions about ACP is both wanted and needed to equip individuals and their loved ones with the knowledge that their decisions are protected and a plan is in place. Current literature suggests that ACP is not typically considered until an individual is already in a compromised state of health. Therefore, the number of individuals who have any form of ACP documentation (DPOA, AD, etc.) completed is surprisingly low. A woman, who had recovered from a brain aneurysm, attended the employees benefits fair and reported she had completed her DPOA just a few days before the incident. She is now fully recovered but felt that completing a DPOA was a valuable part of her getting the care she desired. It is even more crucial that those who work in the healthcare setting are comfortable discussing such topics like end-of-life care planning with their patients.

One way to educate healthcare staff is to encourage the staff to complete a DPOA themselves so that they

Table 2: 2018 work and data breakdown across 5 days of benefits fairs

Data category	Day 1	Day 2	Day 3	Day 4	Day 5
Total hours	4	4	12	8	12
Hours with notary	0	4*	4.5	0	4.5
DPOA dispensed	47	116	192	172	182
DPOA completed	0	64	37	4	42
DPOA not completed	47	52	155	168	140
Reported having DPOA	7	28	17	12	44**
Conversation starter kit	30	64	50	25	24
ACP resource packets	0	17	25	25	20

*Two notaries present for 1 hour of day, **Due to high number of interactions, it is anticipated that this number is underreported as it was difficult to keep accurate count. ACP: Advanced care planning, DPOA: Durable power of attorney

Table 3: 2018 Total Durable Power of Attorney data

Material type	Count
DPOA forms dispensed	709
Completed DPOA forms	147
DPOA forms not completed	562
Individuals reported having DPOA	108
Conversation kit dispensed*	193
ACP resources dispensed**	87

*See Appendix A for conversation kit, **See Appendix C for ACP resources. ACP: Advanced care planning, DPOA: Durable power of attorney

become comfortable with the wording and process of filling one out. As it has been done at this large academic medical center in the Midwestern United States, this can be coordinated through an employee fair, new employee orientation, or other opportunities, such as in education programs for medical students and allied health. It is important to discuss and document public awareness for ACP to become part of mainstream patient care. It is also necessary to discuss the steps to complete ACP from start to finish to safeguard patient decisions across the care continuum. If healthcare members are familiar with the process themselves, it will be much more efficient to walk a patient through it. Other public engagement campaigns promote having “kitchen table” discussions. One campaign called “Death Over Dinner” encourages participants to gather family and friends to discuss end-of-life planning through an online-facilitated discussion [Appendix A]. The idea is to have end-of-life care discussions with family and friends to further these proactive conversations in a relaxed and nonthreatening environment.

Another key factor to providing information on ACP is by taking an interprofessional approach. Providing education to healthcare practitioners, as well as nonhealthcare workers, allows the information to spread organically to patients and their families. Information about ACP should not only come from one’s physician but also nursing and therapy staff, front-desk staff, chaplains, insurance specialists, social workers, and more. As this team has discussed in their initiative, even the nonlicensed employees of a hospital (maintenance, administration, etc.) have a sphere of influence by which they can disperse information. By educating patients and their families in an interprofessional way, the ACP completion gap, through dispersal of information over longer periods of time, can be minimized.

Regardless of the benefits of ACP, the uptake is slow despite professional opinion. It is also important to note that there is limited literature and research on ACP completion. Due to limited research and circulating information, many healthcare professionals do not have any ACP in place. Even in this initiative, response rates were low and the discussion around ACP was largely uninformed, which is a problem coming from providers. Some remarks heard at the fair indicate misinformation from healthcare members, including registered nurses, about ACP. If providers cannot demonstrate an understanding of the purpose and importance of ACP, then it is expected that patient completion would be low because the healthcare staff educating patients may not be equipped to have this discussion. The chief barriers to ACP completion are the societal/cultural taboo of discussing the dying process, lack of understanding, and

inexperience with the completion process. ACP requires forethought and planning which can pose a challenge to healthy individuals who may not be ready to have discussions about their mortality. Despite these barriers, there is strong evidence from multiple systematic reviews to suggest that multicontextual interventions addressing ACP, such as this education initiative, can further the discussion and increase completion of ACP documents.^[15,16]

With regard to education of healthcare providers on ACP, next steps would be to introduce education initiatives throughout healthcare settings, including hospitals, to increase the knowledge of the general public. Healthcare organizations could participate in education days with volunteers and a notary ready to assist individuals in the completion of their DPOA. This would require some planning, coordinating, and individual interest and time commitment. Educational initiatives can engage individuals beyond patients, families, and immediate healthcare providers. Furthermore, pastors, nonclinical health care workers, office assistants, and more can be part of this educational initiative to ensure a comprehensive approach is taken. The original two nurses from this medical center in the Midwestern United States will be repeating the intervention at the benefits fair in the fall of 2019 to continue to promote further education in hopes that more individuals will complete their DPOA.

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Nil.

Conflicts of interest

There are no conflicts of interest.

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Appendixes

Appendix A: Relevant links

National Healthcare Decision Day: <https://www.nhdd.org>

The Conversation Project: <https://theconversationproject.org>

Conversation Starter Kit: <https://www.theconversationproject.org/starter-kits>

#ISaidWhatIWant: https://advancingexpertcare.org/HPNA/Leadership_Advocacy/Advance_Care_Planning.aspx?hkey=40a15ea1-b378-492c-8eb8-6da1d318ef34 and WebsiteKey = b1bae5a7-e24a-4d4c-a697-2303ec0b2a8d

The Go Wish Game: <http://www.gowish.org>

State DPOA Laws: <https://statelaws.findlaw.com/health-care-laws/durable-power-of-attorney.html>

Death Over Dinner: <https://deathoverdinner.org>

Five Wishes Advance Care Planning Program: <https://fivewishes.org/five-wishes/health-care-systems>

Appendix B: DPOA/AD Forms

Available from: <https://practicalbioethics.org/files/caring-conversations/durable-power-of-attorney.pdf>

Appendix C: Resource flyer used at benefits fair

Advance Care Planning—Selected Resources for the Public. Centers for Disease Control and Prevention 2017. Available from: <https://www.cdc.gov/aging/pdf/acp-resources-public.pdf>