

Early experience with digital advance care planning and directives, a novel consumer-driven program

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Fine, Robert L., Zhiyong Yang, Christy Spivey, Bonnie Boardman, and Maureen Courtney (2016), "Early Experience with Digital Advance Care Planning and Directives, A Novel Consumer-Driven Program," *Baylor University Medical Center Proceedings*, 29(3), 263–267. <https://doi.org/10.1080/08998280.2016.11929430>

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Abstract:

Barriers to traditional advance care planning (ACP) and advance directive (AD) creation have limited the promise of ACP/AD for individuals and families, the healthcare team, and society. Our objectives were to determine the results of a digital ACP/AD through which consumers create, store, locate, and retrieve their ACP/AD at no charge and with minimal physician involvement, and the ACP/AD can be integrated into the electronic health record. The authors chose 900 users of MyDirectives, a digital ACP/AD tool, to achieve proportional representation of all 50 states by population size and then reviewed their responses. The 900 participants had an average age of 50.8 years (SD = 16.6); 84% of the men and 91% of the women were in self-reported good health when signing their ADs. Among the respondents, 94% wanted their physicians to consult a supportive and palliative care team if they were seriously ill; nearly 85% preferred cessation of life-sustaining treatments during their final days; 76% preferred to spend their final days at home or in a hospice; and 70% would accept attempted cardiopulmonary resuscitation in limited circumstances. Most respondents wanted an autopsy under certain conditions, and 62% wished to donate their organs. In conclusion, analysis of early experience with this ACP/AD platform demonstrates that individuals of different ages and conditions can engage in an interrogatory process about values, develop ADs that are more nuanced than traditional paper-based ADs in reflecting those values, and easily make changes to their ADs. Online ADs have the potential to remove barriers to ACP/AD and thus further improve patient-centered end-of-life care.

Keywords: advance care planning | advance care directives | digital planning tools

Article:

Knowledge of patient treatment preferences in the setting of terminal or irreversible illness leaving a person unable to communicate is important for young and old alike. The young and

healthy may suddenly experience a catastrophic event permanently impairing all communication (Terri Schiavo is but one example). Serious illness impairing communication is naturally more common among elders, whose numbers are expected to double by 2030 (1), and 70% will lack decision-making capacity at the time decisions near the end of life are needed (2). In response to these realities, advance care planning (ACP) leading to advance directives (ADs) has been encouraged by law since the Patient Self-Determination Act of 1990. Yet, the 2014 Institute of Medicine report *Dying in America* (3), while also encouraging ACP, noted that the promise of ACP has not been met, with estimates suggesting that 30% or fewer individuals have an AD (4–6), and even when an AD is created, it is not easily available. Chiarchiaro, Arnold, and White recently proposed “next-generation” ACPs utilizing web-based technologies (7). We report on early experience with one such technology.

BENEFITS AND BARRIERS: THE CURRENT STATE OF ADVANCE CARE PLANNING

Seriously ill patients have distinct value preferences about treatment near the end of life, such as freedom from pain, peace with God, having their affairs in order, and dying at home as opposed to in the hospital (8). In the setting of terminal illness, 77% of persons indicated that they would not want to be placed on a mechanical ventilator to gain 1 month of life, and 86% preferred to die at home (9). Yet, 58% of patients die in the hospital, another 20% in nursing homes, and only 22% die at home (10).

This discordance between what patients want and what they get near life’s end is associated with high suffering (11) and unwanted and nonbeneficial treatments that prolong dying (12). Such “wrong medicine” also imposes significant costs on patients and families (13, 14) as well as society, with 25% to 30% of Medicare funds spent on the 5% of the Medicare population in the last year of life (15). These costs are not sustainable long term, as we currently take \$3 out of Medicare for every \$1 we pay in (16).

On the other hand, treatment preferences for life’s last chapter are more likely to be followed with lower family stress, anxiety, and depression in the presence of an AD (17, 18). Serious illness ACP conversations between physicians and patients lessen intensive treatment and lower expenditures, yet do not increase mortality (19). ACP benefits in the nursing home setting are similar (20), and AD utilization correlates with significantly lower levels of Medicare spending, a lower likelihood of in-hospital deaths, and increased hospice use in regions characterized by higher levels of end-of-life spending (21).

With end-of-life treatment deficits so clear and the ability of ACP to improve those deficits, why don’t most people have ADs? Reasons include lack of awareness, the falsehood that families know the person’s wishes anyway, the equating of ADs with limiting treatment, or a belief that creating an AD is complicated, expensive, or requires a lawyer or physician (2, 22). None of these statements is true.

For example, the Institute of Medicine notes the success of Respecting Choices (www.gundersenhealth.org/respectingchoices), an ACP program relying on trained community volunteers rather than physicians (3). However, such facilitated ACP is resource intense (7).

Might a user-friendly digital platform, not necessarily requiring physician involvement, empower consumers/patients to create their own advance care plans on their own time?

DEVELOPMENT OF DIGITAL PLATFORMS FOR ADVANCE DIRECTIVES

Various organizations and companies have experimented with web-based solutions to the deficits in ACP. For example, PREPARE (<https://prepareforyourcare.org/>) focuses primarily on elderly patients and the process of ACP, but it does not actually create an AD. On the other hand, the US Living Will Registry (<http://www.uslivingwillregistry.com/>) allows a person to download a living will, complete it as a paper document, scan it, purchase online storage, and send it on request to healthcare providers.

This article reviews experience with another online ACP/AD platform, MyDirectives (www.mydirectives.com), designed to overcome many of the barriers and obtain more of the benefits of ACP/AD creation. To the best of our knowledge, MyDirectives is the first digital ACP/AD platform combining the elements of patient values and reflection on treatment preferences with a living will and medical power of attorney. Each AD is generated based on the unique user responses to questions presented in a process similar to an actual interview. The platform explores why the person is creating an AD and then queries the person's values *before* delving into specific treatment preferences. Some representative questions are: 1) What best describes your current medical condition and why are you creating an AD? 2) What is important to you if you are seriously ill and can't make your wishes known? 3) If your health ever deteriorates due to a terminal illness, and your doctors believe you will not be able to interact meaningfully with your family, friends, or surroundings, which of the following statements best describes what you'd like to tell them? 4) Which of the following statements best describes your thoughts on cardiopulmonary resuscitation (CPR)? and 5) If it were possible to choose, where would you like to spend your final days? The MyDirectives platform allows users to request the most intensive medically appropriate treatment, comfort-only treatment, or any nuanced variation in between. Users may incorporate audio and video messages into their ACP.

The result is an individualized ACP created, stored, and retrievable from the cloud at any time and from any place with Internet access, and the consumer is not charged for these services. The site prompts annual review of the directive, and to our knowledge, MyDirectives is currently the only digital ACP tool that can digitally integrate into any electronic health record, health information exchange, or patient portal.

METHODS

We analyzed a deidentified dataset provided by the company containing aggregated information from 900 US users of MyDirectives, randomly sampled proportionate to the population of each state, to represent the experience across multiple states. Responses were summarized through descriptive statistics. In addition to the ACP responses, data regarding demographics and revision of the ACP were gathered.

RESULTS

Respondents had an age range of 18 to 92 years (mean 50.8 ± 16.6). In this sample, 47.1% were <50 years old, and 84.3% of the men and 91% of the women were in self-reported good health.

Table 1 summarizes respondents' choices related to the last stages of life. A standard definition of palliative care is offered within the MyDirectives software, and most (94%) of the sample wanted their physicians to consult a supportive and palliative care team, an option not typically available in most ADs. Close to 85% of respondents preferred stopping all life-sustaining treatments during their final days, 76% preferred to spend their final days at home or in a hospice facility, and only about 3% preferred to die in a hospital. There was no significant difference between men and women in this dimension.

Table 1. Responses from a sample of 900 US individuals on the main questions in the online advanced directives

	Combined	Male	Female
<i>Life-sustaining treatments</i>			
Stop all life-sustaining treatments	759 (84.3%)	353 (86.7%)	406 (82.4%)
Keep trying life-sustaining treatments...	71 (7.9%)	28 (6.9%)	43 (8.7%)
For selected period	9 (12.7%)	7 (25.0%)	2 (4.7%)
Indefinitely	12 (16.9%)	4 (14.3%)	8 (18.6%)
Let healthcare agent decide	50 (70.4%)	17 (60.7%)	33 (76.7%)
Neither of the options works for me	70 (7.8%)	26 (6.4%)	44 (8.9%)
<i>Cardiopulmonary resuscitation (CPR)</i>			
Want CPR attempted with limitations	62(69.9%)	288 (70.7%)	339 (68.8%)
Do not want CPR in any circumstance	76 (8.4%)	37 (9.1%)	40 (8.1%)
Let healthcare agent decide	150 (16.7%)	60 (14.7%)	90 (18.3%)
Want CPR attempted in all circumstances	44 (4.9%)	21 (5.2%)	24 (4.9%)
Not sure	1 (0.1%)	1 (0.3%)	0 (0.0%)
<i>Consulting a supporting and palliative care team</i>			
Yes	846 (94.0%)	371 (91.2%)	475 (96.4%)
No	54 (6.0%)	36 (8.9%)	18 (3.7%)
<i>Where to spend the final days</i>			
At home	574 (63.8%)	276 (67.8%)	298 (60.5%)
Hospice care at home	486 (84.7%)	228 (82.6%)	258 (86.6%)
In the hospital	29 (3.2%)	14 (3.4%)	15 (3.0%)
Consultation with a palliative care team	21 (72.4%)	11 (78.6%)	10 (66.7%)
In a hospice facility	116 (12.9%)	45 (11.1%)	71 (14.4%)
Not sure	181 (20.1%)	72 (17.7%)	109 (22.1%)
<i>Autopsy</i>			
Want an autopsy if my doctor thinks it will help others	282 (31.3%)	134 (32.9%)	148 (30.0%)
Want an autopsy only if there are questions about my death	254 (28.2%)	104 (25.6%)	150 (30.4%)
Do not want an autopsy	147 (16.3%)	69 (17.0%)	78 (15.8%)
Want the person who's designated by law to make this decision to decide after I die	174 (19.3%)	84 (20.6%)	90 (15.3%)
Not sure	43 (4.8%)	16 (3.9%)	27 (5.5%)
<i>Organ and tissue donations</i>			
Donate organs	554 (61.1%)	247 (60.7%)	307 (62.3%)
Do not donate	346 (38.4%)	160 (39.3%)	186 (37.7%)

Fifteen percent of respondents preferred one of several other options not typically available on most ADs. Of those who wanted to “keep trying life-sustaining treatment” at that stage, over 70% preferred to let their healthcare agent decide how long to keep trying. Within this group, women (76.7%) were more likely than men (60.7%) to defer decisions to their healthcare agent.

Among the respondents, 70% wanted CPR attempted unless their physician indicated they were terminal, they had a serious brain injury, CPR would do more harm than good, or CPR would not work. In contrast, 8% did not want CPR attempted in any circumstance, and 5% wanted CPR attempted in all circumstances, and these were often the same persons who wanted to maintain intensive treatment in the face of terminal illness. Only 15% preferred to rely on a healthcare agent to decide. No significant gender difference was detected for these decisions.

Most respondents indicated they would want an autopsy under the following conditions: 1) their physicians thought it would help others (31.3%), 2) there were questions about their death (28.2%), or 3) the person who was designated by law decided to do so (19.3%) (Table 1). Finally, 62% of the respondents indicated that they would like to donate their organs.

We also examined participants’ responses to the question “What is important to you?” As shown in Table 2, quality of life was the most important concern for the last stage of life (e.g., avoiding prolonged dependence on machines, 85.3%; being free of pain, 84.2%; avoiding prolonged dependence on artificial or assisted nutrition through tubes, 78.4%). Another important factor was not being a burden to family, either financially (79.3%) or physically (79.2%). About 75% preferred to be with family in the last days of life.

Table 2. Responses from a sample of 900 US individuals on issues important to them in advance care planning

	Combined	Male	Female
Avoiding prolonged dependence on machines	768 (85.3%)	334 (82.1%)	434 (88.0%)
Being free from pain	758 (84.2%)	332 (81.6%)	426 (86.4%)
Not being a financial burden to my family	714 (79.3%)	316 (77.6%)	398 (80.7%)
Not being a physical burden to my family	713 (79.2%)	320 (78.6%)	393 (79.7%)
Avoiding prolonged dependence on artificial or assisted nutrition through tubes	706 (78.4%)	313 (76.9%)	393 (79.7%)
Being with my family	670 (74.4%)	282 (69.3%)	388 (78.7%)
Being able to feed, bathe, and take care of myself	610 (67.8%)	275 (67.6%)	335 (68.0%)
Being at peace with my God	332 (36.9%)	128 (31.5%)	204 (41.1%)
Dying at home	307 (34.1%)	130 (31.9%)	177 (35.9%)
Resolving conflicts	194 (21.6%)	81 (19.9%)	113 (22.9%)
Other things that are very important to me about life and health	106 (11.8%)	37 (9.1%)	69 (14.0%)

About 12% of people changed their ADs at least once (with a range of 1 to 4 changes). Most of these changes (75%) were made more than 1 day after the initial AD creation, with about 30% of changes made more than 4 months after AD creation.

DISCUSSION

The MyDirectives data suggest that online AD platforms can help individuals from a wide range of ages and conditions engage in an interrogatory process about values and then develop an AD reflecting those values. According to Rao et al, AD completion among US adults is associated with older age and an increased likelihood of having a chronic disease (4). This early experience data set from MyDirectives suggests that an online approach can encourage younger people to participate in ACP earlier than society would normally engage them; in addition, the approach corrects the misconceptions that ADs are only relevant to the old and sick and that the elderly can't use the Internet. The emotional harm to patients and their families occurring when young persons have an unexpected and sudden irreversible health event leaving them unable to communicate—as occurred with Quinlan, Cruzan, and Schiavo—serves as a reminder of the importance of ACP at a younger age than is typical under current practice.

Many patients, families, and healthcare professionals erroneously believe that a living will is meant only to limit life-sustaining treatment, and most state living will forms allow only that preference. However, truly patient-centered ADs must allow a preference for intensive and/or prolonged treatment in terminal or irreversible illness. Our data suggest that while most participants preferred cessation of life-sustaining treatment if terminally ill, 16% preferred a more nuanced approach, including 1.2% who preferred indefinite, unlimited treatment in the setting of terminal illness.

One advantage of a digital ACP tool is its ability to ask novel questions and offer definitions, video tutorials, and links to additional information. Such additional information about palliative medicine may help explain the 94% preference rate for palliative care consultation, a relatively new concept in medical care. This result is consistent with findings from the Center to Advance Palliative Care, which noted that when patients understand what palliative medicine is, they want to receive it when needed (23).

The autopsy question is another novel aspect of this ACP platform. Despite the benefits of autopsy (24, 25), nonforensic autopsy rates are around 5% (26). The reasons for the low percentage are multiple, but at least one is physician attitude and discomfort in asking for an autopsy (27). This discomfort may be unfounded because <17% would not want an autopsy. If these data hold true in a larger future sample size, perhaps physicians will be more willing to request an autopsy, especially when they see it as part of the patient's AD.

Finally, nearly 124,000 persons are awaiting organ transplant in the United States (28), and as of 2012, 42.7% of the US population was a registered organ and/or tissue donor. The percentage of those using this online ACP/AD platform wishing to be donors was nearly 50% higher. Reasons are unclear, but we speculate that contemplating one's own death increases empathy for others, thus encouraging the "gift of life." Linking end-of-life care with after-death care (organ/tissue donation and autopsy rates), as done with MyDirectives, has obvious potential to favorably impact other spheres of medical practice.

The historical policy push to motivate consumers to just get something on paper is becoming a movement to underscore that ACP is not a one-time task for only the sick or elderly, but an iterative process spanning one's whole life (29). Baylor Scott & White Health, the healthcare system in which one of us works, promotes universal ACP and AD creation as an important

preventive care strategy for all, using a number of mechanisms to actively encourage utilization of MyDirectives, bypassing the historical barriers of physician time constraints and lack of communication training. A physician recommendation to a patient to engage in digital ACP requires neither significant physician time nor extensive training.

In conclusion, early experience with this digital ACP platform indicates that individuals acting on their own can complete an AD more nuanced than the typical paper-based directive. The ability and motivation of the patient/consumer to create a digital AD online is further supported by our recent research demonstrating that some people consider end-of-life issues too personal to discuss with a nonfamily member such as a physician (30). This early experience with digital ACP demonstrates that the reengineering of ACP suggested by Chiarchiaro and others is already happening. It is time to further expand the model.

Notes

1. Morhaim DK, Pollack KM. End-of-life care issues: a personal, economic, public policy, and public health crisis. *Am J Public Health* 2013; 103: e8–e10.
2. Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med* 2010; 362: 1211–1218.
3. Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, DC: Institute of Medicine, September 2014.
4. Rao JK, Anderson LA, Lin FC, Laux JP. Completion of advance directives among U.S. consumers. *Am J Prev Med* 2014; 46: 65–70.
5. Sabatino C. *Advance Directives and Advance Care Planning: Legal and Policy Issues* [Report 10]. Washington, DC: Office of Disability, Aging and Long-Term Care Policy, Office of the Assistant Secretary for Planning and Evaluation, US Department of Health and Human Services, 2007.
6. Kirschner KL. When written advance directives are not enough. *Clin Geriatr Med* 2005; 21: 193–209, x.
7. Chiarchiaro J, Arnold R, White DB. Reengineering advance care planning to create scalable, patient- and family-centered interventions. *JAMA* 2015; 313: 1103–1104.
8. Steinhauer KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000; 284: 2476–2482.
9. Barnato AE, Herndon MB, Anthony DL, Gallagher PM, Skinner JS, Bynum JP, Fisher ES. Are regional variations in end-of-life care intensity explained by patient preferences? A study of the US Medicare population. *Med Care* 2007; 45: 386–393.
10. Colello KJ, Mulvey J, Sarata AK, Williams ED, Thomas KR. *End-of-Life Care: Services, Costs, Ethics, and Quality of Care* [Report 7-5700]. Washington, DC: Congressional Research Service, 2009.
11. The SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). *JAMA* 1995; 274: 1591–1598.
12. Wennberg JE, Fisher ES, Goodman DC, Skinner JS. *Tracking the Care of Patients with Severe Chronic Illness: The Dartmouth Atlas of Health Care 2008*. Lebanon, NH: Dartmouth Institute for Health Policy and Clinical Practice Center for Health Policy Research. Available

- at https://www.dartmouth.edu/~jskinner/documents/2008_Chronic_Care_Atlas.pdf; accessed October 1, 2015.
13. Kelley AS, McGarry K, Fahle S, Marshall SM, Du Q, Skinner JS. Out-of-pocket spending in the last five years of life. *J Gen Intern Med* 2013; 28: 304–309.
 14. Hogan C, Lunney J, Gabel J, Lynn J. Medicare beneficiaries' costs of care in the last year of life. *Health Aff (Millwood)* 2001; 20: 188–195.
 15. Riley GF, Lubitz JD. Long-term trends in Medicare payments in the last year of life. *Health Serv Res* 2010; 45: 565–576.
 16. Steuerle CE, Rennane S. *Social Security and Medicare Taxes and Benefits over a Lifetime*. Washington, DC: The Urban Institute. Available at <http://www.urban.org/UploadedPDF/social-security-medicare-benefits-over-lifetime.pdf>; accessed October 1, 2015.
 17. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ* 2010; 340: c1345.
 18. Tilden VP, Tolle SW, Nelson CA, Fields J. Family decision-making to withdraw life-sustaining treatments from hospitalized patients. *Nurs Res* 2001; 50: 105–115.
 19. Zhang B, Wright AA, Huskamp HA, Nilsson ME, Maciejewski ML, Earle CC, Block SD, Maciejewski PK, Prigerson HG. Health care costs in the last week of life: associations with end of life conversations. *Arch Intern Med* 2009; 169: 480–488.
 20. Molloy DW, Guyatt GH, Russo R, Goeree R, O'Brien BJ, Bédard M, Willan A, Watson J, Patterson C, Harrison C, Standish T, Strang D, Darzins PJ, Smith S, Dubois S. Systematic implementation of an advance directive program in nursing homes: a randomized controlled trial. *JAMA* 2000; 283: 1437–1444.
 21. Nicholas LH, Langa KM, Iwashyna TJ, Weir DR. Regional variation in the association between advance directives and end-of-life Medicare expenditures. *JAMA* 2011; 306: 1447–1453.
 22. Span P. Why do we avoid advance directives? *New York Times*, April 20, 2009.
 23. Public Opinion Strategies. *2011 Public Opinion Research on Palliative Care*. New York: Center to Advance Palliative Care, 2011. Available at https://www.capc.org/media/filer_public/18/ab/18ab708c-f835-4380-921dfbf729702e36/2011-public-opinion-research-on-palliative-care.pdf; accessed October 1, 2015.
 24. Lundberg GD. Low-tech autopsies in the era of high-tech medicine: continued value for quality assurance and patient safety. *JAMA* 1998; 280: 1273–1274.
 25. McPhee SJ. Maximizing the benefits of autopsy for clinicians and families. What needs to be done. *Arch Pathol Lab Med* 1996; 120: 743–748.
 26. Shojania KG, Burton EC. The vanishing nonforensic autopsy. *N Engl J Med* 2008; 358: 873–875.
 27. Nemetz PN, Tanglos E, Sands LP, Fisher WP Jr, Newman WP 3rd, Burton EC. Attitudes toward the autopsy—an 8-state survey. *MedGenMed* 2006; 8 (3): 80.
 28. Donate Life America. Statistics. Available at <http://donatelife.net/statistics/>; accessed October 1, 2015.
 29. Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy. *Advance Directives and Advance Care Planning: Report to Congress*. Washington, DC: US Department of Health and Human Services, 2008.

30. Brown T, Spivey C, Courtney M, Yang Z, Boardman B. *A Pilot Study: The Effect of Message Framing about Family Burden on Advance Directive Promotion* [Working paper] Arlington, TX: University of Texas at Arlington.