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The Era of “E”: The Use of New Technologies in Advance Care Planning

Michael J. Green, MD, MS, FACP [Professor] and
Departments of Humanities and Medicine Penn State College of Medicine

Benjamin H. Levi, MD, PhD, FAAP [Professor]
Departments of Humanities and Pediatrics Penn State College of Medicine

Abstract

In this paper, we review developments in technology that can help patients, their loved ones, and healthcare providers engage in more effective advance care planning (ACP). We begin with a brief description of ACP and its purpose; then proceed to discuss various electronically available resources for ACP in the U.S.; and finally provide a critical assessment of the achievements, challenges, and future prospects for electronic advance care planning, or “e-planning.”

Introduction

Advance care planning (ACP) is the process of planning for one's medical future so that an individual's values, goals, and preferences can be taken into account even if that person loses the ability to speak for him or herself. Advance care planning is a broadly inclusive term that can encompass everything from informal conversations to legally binding durable powers of attorney, and includes: 1) learning about medical conditions that may occur, as well as treatment options for addressing them; 2) thinking about what goals, beliefs, and/or values are important and relevant for such treatment decisions; 3) formulating one's wishes regarding potential treatment decisions and discussing them with others; 4) communicating those wishes (and ideally the rationale behind them) to those most likely to be involved in making medical decisions on the individual's behalf; and 5) designating someone to serve as a surrogate decision-maker in the event that one is needed (Emanuel, von Gunten, & Ferris, 2000; Gillick, 2004).

The standard mechanism for documenting a person's deliberations regarding advance care planning (ACP) is an advance directive. This formal expression of an individual's wishes (which often includes the designation of a surrogate medical decision-maker) is typically

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Corresponding Author: Michael J. Green, MD, MS, FACP Professor, Departments of Humanities and Medicine Penn State College of Medicine Room C1743 500 University Drive, Hershey, PA 17033 Work Phone: 717-531-8778 Home Phone: 717-602-3358 Fax: 717-531-3894 mjl5@psu.edu.

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Author Disclosure Statement

The authors (MJG & BHL) have intellectual property and copyright interests for the decision aid, Making Your Wishes Known: Planning Your Medical Future (*MYWK*). To encourage individuals to reflectively and systematically engage in advance care planning regarding end-of-life medical decisions, it is anticipated that *MYWK* will be made available free of charge for use by the general public, as well as for education purposes. However, users who wish to archive, revise, and electronically transmit advance directive documents will be charged a modest fee.

completed with a standard paper/pencil form, and is so often the focal point of ACP that it is frequently conflated with the process that gave rise to it. Such overemphasis is in part due to widespread advocacy for individuals to create advance directives, particularly following passage of the 1990 Patient Self Determination Act that required health care facilities to offer patients information about advance directives if they were to receive Medicare or Medicaid funding (Act, 1990). In the past decade, advance directives have come under increasing scrutiny --and criticism-- for their limitations at achieving many of their intended goals (Fagerlin & Schneider, 2004; Teno et al., 1997). We know that only a minority of adults complete advance directives (Jezewski, Meeker, Sessanna, & Finnell, 2007), and that even when they do, the documents are often unavailable when needed. An advance directive locked away in a safety deposit box or a lawyer's office cannot contribute to the care of a patient who arrives in the emergency department at 3:00 am in acute respiratory failure. To know what this patient wants, documentation of their wishes must be available immediately. More importantly, though, concerns have been raised about the very ability of advance directives to accurately reflect a patient's authentic values and preferences (Ditto, Jacobson, Smucker, Danks, & Fagerlin, 2006; Halpern & Arnold, 2008; Loewenstein, 2005). Hence, efforts to promote effective ACP must address these critiques as well as other obstacles that hinder people from reflecting on and planning ahead for important medical decisions. In what follows, we will discuss technology-based efforts to overcome some of the barriers.

Initial Steps

More than a decade ago, Dexter et al. evaluated the use of computer-generated reminders to physicians for increasing advance directive completion rates, and found a six-fold greater completion rate compared with no reminders (4% vs 24%) (Dexter et al., 1998). More recently, Heiman et al. found that among patients with no previous advance directives, physician reminders alone were not associated with greater completion rates (1.5% vs. 1.8% in controls), but reminders plus mailings to patients of advance care planning forms and other materials did increase advance directive completion rates (14% vs. 1.8%) (Heiman, Bates, Fairchild, Shaykevich, & Lehmann, 2004).

Taking this a step further, Tung et al. examined whether an automated protocol to deliver a multimodal educational intervention to older adults who lacked advance directives would improve ACP completion rates (Tung et al., 2011). The authors hypothesized that their web-based Generic Disease Management System would not only identify such individuals, but also increase their understanding of ACP and motivation to complete advance directives. By implementing their intervention, the authors found a 17.5% increase in advance directive completion rates (21.6% vs. 4.1%).

Electronic Advance Care Planning: basic “e-planning”

In recent years, technology has been harnessed to increase the availability of ACP documents, through the development of secure electronic repositories that can store, retrieve, and send advance directives at any time and from any place. In addition to basic data warehousing, most existing repositories provide individuals the opportunity to electronically complete and save a rudimentary advance directive (including designation of a spokesperson). Most also provide static, text-based information on ACP, typically comprising several paragraphs or pages that explain the legal standing of advance directives and surrogate decision-makers, how and when ACP information is used, as well as legal and practical limitations regarding substituted decision-making (Table 1).

Though various registries have been set up to store ACP documents at no cost^{1,2} or a minimal, one-time filing fee³, economic stress has forced some of these operations to shut down. As such, most resources that include electronic storage of ACP documents are

commercial⁴⁻⁸ with some available as smartphone apps⁹. Though there are few data on the efficacy of these online materials, such basic e-resources are generally best suited for individuals who are already well informed, clear about their healthcare preferences, and have limited time to engage in ACP.

Another way technology has been used to improve how people prepare for life-or-death medical decisions is by providing educational material about ACP via the world wide web. Many hospital and organizational websites offer information about advance care planning, ranging from descriptions of what ACP and advance directives are^{10,11} to advice about how and where to complete advance directives¹². In many cases this includes education about requirements for an advance directive document to qualify as a statutory declaration within a particular state^{13,14}.

Several commercial sites also market services for creating a state-specific living will document. Most of these offer cursory education on ACP-related terminology (e.g., permanent unconsciousness, artificial nutrition and hydration, etc.), along with the opportunity for users to express their wishes regarding various life-sustaining medical treatments (mechanical ventilation, cardio-pulmonary resuscitation, kidney dialysis, etc.), designate a spokesperson, and specify which decisions that spokesperson is authorized to make (regarding medical treatment, organ donation, and other decisions regarding care at “end-of-life”). Some sites^{4,7} allow free trials, after which continued access requires a monthly fee. Other sites⁵ charge a fee for the living will in addition to ongoing access and/or accessories such as wallet-size living will alert cards. Some also provide “keyholder” functionality, whereby certain people are authorized to gain access to ACP documents if the individual becomes incapacitated or dies⁶.

Such use of technology may in fact markedly improve what people know about ACP, the chances they will complete an advance directive, and the availability of individuals’ advance directives when needed most. But for these to be meaningful improvements, the decisions that individuals make and document must also accurately reflect their goals and values, *and* be perceived by others as doing so. Consequently, genuine technological solutions to advance care planning must also facilitate good decision-making and effective communication.

In other areas of medicine, decisional support technologies are increasingly seen as ways to overcome vexing challenges in medical decision-making, chiefly by empowering patients to better understand their medical conditions and proposed interventions, and assisting them in choosing from among multiple treatment options (Barry, 2002; Kasper, Mulley, & Wennberg, 1992; Molenaar et al., 2000; O’Connor et al., 1999). In particular, decision aids have been shown to successfully help patients disentangle complex medical decisions and to make healthcare choices that reflect their values and priorities (M.J. Green & Fost, 1997; O’Connor et al., 2007). Technological approaches have also been used to promote communication between patients and their healthcare providers (Blake, 2008; Hsu et al., 2005; Leong, Gingrich, Lewis, Mauger, & George, 2005; Strecher, Greenwood, Wang, & Dumont, 1999). But only recently have such technological innovations been introduced for advance care planning (M. J. Green & Levi, 2009); and in the remainder of this paper, we will review these new and emerging e-resources, which we call “e-planning.”

Enhanced e-planning

Much of the e-planning found on the Internet is very basic, comprising little more than static, text-documents posted online. Sites providing what can be termed *enhanced e-planning* augment these basic materials with additional education in the form of graphics, audio- or video-recordings, answers to frequently-asked-questions¹⁵, and links to online

information related to ACP (e.g., organ donation, issues related to surrogate decision-making, etc.). The enhanced e-resources that include storage and transmittal capabilities are (as mentioned) typically commercial, either as traditional websites¹⁶ or smartphone apps¹⁷. However, most enhanced e-resources are not proprietary, with some of the most helpful being not only free, but quite simple in their construction. One example is a website created by five University of Rochester medical students (with guidance from faculty) whose step-by-step guide helps users create a living will, and allows them to specify the kinds of situations in which they want their living will to apply¹⁸.

In many instances, enhanced e-resources are available through organizations concerned with “advance care” —a newer and broader term intended to replace “end-of-life care.” This includes local agencies^{19,20}, national organizations²¹, as well as many professional societies²²⁻²⁴. Some e-resources are sponsored by organizations for whom ACP is central to their mission^{25,26}, while others are part of regional or national initiatives whose principal aim is to promote ACP²⁷⁻²⁹. Among these, the *National Healthcare Decisions Day* initiative³⁰ is unique in that it brings together hundreds of stakeholder groups (and a wide range of e-resources) to help raise community awareness about ACP.

Interactive e-planning

A more involved level of e-planning extends beyond information delivery by introducing interactive elements to advance care planning. Interactivity can take the form of discussion forums and chat-rooms³¹⁻³³, where individuals have the opportunity to observe and/or engage in exchanges about a wide variety of ACP issues —such as how to discuss one's wishes with family members, choose a spokesperson, and comply with legal guidelines.

Another approach to interactivity involves exercises or “thought experiments” that encourage individuals to reflect on their goals, values, and priorities. Recognizing that it can be difficult to see beyond one's immediate predicament, narratives or clinical vignettes are used to prompt individuals to imagine themselves in various life-threatening conditions with a range of possible outcomes. Such reflective exercises encourage individuals to consider not only what it would be like to live with particular symptoms and/or disabilities, but how these changed circumstances might affect the things that matter most in their lives. Then on the basis of these reflections, individuals are encouraged to formulate their wishes regarding medical treatments they would or would not want under various circumstances, and document them in an advance directive.

One of the most widely used interactive approaches to ACP is the *Five Wishes* program³⁴, which employs scenarios involving brain damage, coma, and “near death” to help individuals articulate their wishes regarding not just medical treatment, but also personal, spiritual, and emotional matters. A more involved and broad-ranging interactive framework is exemplified in the *Respecting Choices* program³⁵, which takes a systems-based approach to foster community-wide dialogue about ACP. To that end, *Respecting Choices* provides multiple online curricula, webinars, and tool-kits that promote ACP as a process, and details how groups and organizations can effectively engage their community in ACP. In addition to this broader focus, *Respecting Choices* also differs from most other e-resources in having published data on its efficacy for improving ACP communication between patients and surrogates, enhancing patient-surrogate concordance regarding treatment wishes, and increasing the completion rate for advance directives (85% vs. baseline of 15%) (B. Hammes & Rooney, 1998; Hickman, Hammes, Moss, & Tolle, 2005; Moorman, Carr, Kirchoff, & Hammes, 2012). Both *Five Wishes* and *Respecting Choices* charge modest fees for their products.

Integrated e-planning

The most recent trend in e-planning uses strategies that combine multi-media materials, tailored education, and decision-support tools to allow individuals to customize the pace, style, learning objectives, and other features of ACP. These integrative approaches not only provide education and information, but can function as true decision-aids that help individuals: 1) break down complex decisions into smaller, more manageable components; 2) identify inconsistencies and/or incompatibilities in stated values and goals (through the use of decision analytic techniques); 3) coherently apply these values and goals to foreseeable clinical situations; and 4) translate this information into comprehensible, practical directives that can be used by surrogates who need to make decisions. As of the writing of this article, there are no publicly available e-resources that fully meet this description, though two are nearing completion.

The U.S. Department of Veterans Affairs (VA) is developing an online program called *Planning for Future Health Care Decisions...My Way* (or *Planning My Way* for short) that uses text, graphics, videos, and voice-overs to educate people about ACP. The program provides interactive tools and worksheets to guide individuals through the process of selecting a spokesperson to speak for them in the event they lose capacity, thinking about what matters to them and why, and initiating conversations with their loved ones and healthcare providers. The program also enables individuals to document their wishes in a personal advance directive. *Planning My Way* was developed by VA's National Center for Ethics in Health Care with input from a broad range of individuals and groups (Pearlman, Starks, Cain, & Cole, 2005). Great care was taken to ensure that the program does not favor any one point of view, that the interface is efficient and easy to use, and that the content is understandable by individuals with limited literacy skills and accessible to individuals with disabilities. While the program is designed to be relevant to everyone, some of the patient stories will have special meaning for Veterans and their families. *Planning My Way* is expected to be available later this year free of charge (personal communication with the National Center for Ethics in Health Care, March 16, 2012).

The program that we (MJG/BHL) have been developing over the past several years, *Making Your Wishes Known: Planning Your Medical Future*³⁶ (M. J. Green & Levi, 2009), likewise uses multi-media to provide tailored education, engage individuals in values clarification and other reflective exercises, and generate a personalized advance directive. It, too, was designed by a multidisciplinary team, including physicians, educators, graphic artists, nurses, decision analysts and lawyers. But what is (to our knowledge) unique about *Making Your Wishes Known* is its use of a sophisticated algorithm (based on multi-attribute utility theory) (Edwards & Newman, 1982) to translate individual values and preferences into a detailed advance directive document. In essence, this algorithm integrates an individual's responses to a broad array of questions and interactive exercises, and systematically converts these values and preferences to a set of general and specific wishes for healthcare (M. J. Green & Levi, 2009; Levi & Green, 2010). To date, this integrated e-planning program has been used exclusively in educational and research settings, where accumulated evidence shows that the program is reliable and accurate in reflecting patient wishes (Levi & Green, 2012; Levi, Heverley, & Green, 2011; Schubart et al., 2012); user-friendly (Hossler, Levi, Simmons, & Green, 2010); and effective at increasing knowledge about ACP, communication between patients and loved ones, and surrogate understanding of patient values and wishes (M. J. Green et al., 2012; M. J. Green & Levi, 2011; Levi, Brothers, et al., 2012; Levi, et al., 2011; Levi, Schubart, et al., 2012). In the near future, it is anticipated that *Making Your Wishes Known* will be made available free of charge to the general public as an educational tool. However, individuals who wish to archive, revise, and electronically transmit their advance directive documents will be charged a modest fee.

Social Media and e-planning

As e-planning matures, the manner in which individuals communicate their wishes will likely evolve as well. Already, health systems are beginning to integrate advance directive documents into the electronic medical record (Bricker, Lambing, & Markey, 2003; B. J. Hammes, Rooney, & Gundrum, 2010; LaPorte, 2008), a phenomenon that will inevitably improve as best practices emerge. However, more dramatic changes are likely to materialize as new generations of electronic tools alter the way people communicate about their medical wishes and concerns. One early effort to integrate social media into advance care planning is Qualtonomy, a social media site aimed at encouraging advance care planning among young people³⁷. Other sites are likely to follow, a phenomenon that will give rise to questions about how we should regard stated preferences about one's healthcare that are not formal advance directive documents, but nevertheless reflect a person's values, goals and preferences. For example, if a person discusses their medical experiences and desires on *Facebook*, *Twitter*, in a chatroom, or on a listserv, are these statements to be considered part of the documentary evidence of their desires, and if so, how should they be catalogued, prioritized, and integrated into surrogate decision-making? No doubt, such questions will need to be addressed as e-planning matures and the medical profession becomes more experienced integrating social media into the medical record.

Achievements, Challenges, and Future Directions

The "era of e" is here to stay. E-planning tools provide a plethora of options for learning about medical and legal issues related to advance care planning, and can do so in private, at the convenience of the user, and tailored to individual needs. Moreover, research shows that the use of technology for ACP is feasible even with patients who have life-threatening conditions (Farace, Levi, & Green, 2010; Farace, Marupudi, Green, Levi, & Sheehan, 2008; M. J. Green et al., 2011; Hossler, et al., 2010), and that computer-based education in general outperforms traditional text-based learning (even with older adults, individuals with low literacy skills, and learners with no prior computer experience) (Fox, 2009; Ogozalek, 1993; Ryhanen, Siekkinen, Rankinen, Korvenranta, & Leino-Kilpi, 2010).

Though basic e-resources provide little more than electronic access to print material, even this can help people begin to appreciate what loved ones, healthcare providers, and others need to make medical decisions on behalf of individuals who lack decision-making capacity. More developed e-resources go further by encouraging people to reflect upon what is important to them, why, and what choices would best promote their values and goals (which often includes easing burdens for loved ones). In so doing, e-resources can help prepare individuals to engage loved ones and healthcare providers in discussions about ACP, if not actually facilitate those encounters. The ability to electronically store and transmit advance directive documents can additionally promote communication as well as increase the likelihood that such documents will be available when they are needed most.

Integrated e-planning tools go still further by helping people articulate their wishes in ways that are more systematic, logically consistent, easily understood by others, and useful for surrogate decision-making. This has particular utility insofar as personal preferences may not be well-formed and/or various values and goals may be in conflict with one another (Ariely, 2009; Ubel, 2005). Well designed decision aids have the potential to identify contradictions and inconsistencies, as well as frame ACP decisions in ways that others find easier to parse.

But of course it is no simple task to improve decision-making that concerns future circumstances, especially when multiple variables are in play. Individuals' predictions for their future selves are frequently inaccurate, and people often change their minds as

situations evolve (Danis, Garrett, Harris, & Patrick, 1994; Fried, O'Leary, Van Ness, & Fraenkel, 2007). The import assigned to future conditions and abilities (and/or disabilities) are often unduly biased — by past experiences, mistaken assumptions, and/or unrealistic comparisons (Forrow, 1994; Koch, 2001). As such, one of the challenges for integrated e-planning is to introduce reflective “affective forecasting” exercises that help people both envision themselves differently and appreciate their ability to adapt. Research suggests that challenging individuals to make *educated* forecasts based on vivid projections of their future selves can result in decisions that more accurately reflect their values (Halpern & Arnold, 2008; Sudore & Fried, 2010). Moreover, it is the premise that this is so (combined with the principle of respect for autonomy) that justifies the practice of informed consent, which forms the basis of advance care planning (Levi & Green, 2010).

A related challenge for e-planning involves presenting information in an unbiased manner. For example, we found several online living will programs in which options for life-sustaining treatments were pre-selected, thereby creating default responses that reflected particular ideological assumptions. Whether such missteps are unintentional or purposeful, they are problematic not only for the imbalance they create, but also for contributing to the politicization of ACP. So, too, care must be taken to account for framing and phrasing biases, or even the order in which options are presented, as these can predispose individuals towards particular responses (Tversky & Kahneman, 1981). Bias can arise further from oversimplifying issues — particularly when significantly different responses would be expected were individuals presented the issues in a more nuanced and context-dependent manner.

The use of technology in and of itself also raises several important concerns. Chief among them is the potential loss of face-to-face interactions, crucial for fostering dialogue and shared understanding (Rhoads, 2010). Over-emphasizing technology risks replacing personal stories with a series of check-boxes and pre-fabricated templates. And particularly for life-and-death issues, there are no shortcuts for establishing human connections that are necessary for fostering intimacy and compassion.

Reliance on technology can also be fraught with significant practical problems. It can be costly and complicated to create and maintain secure electronic access to broad-based ACP services, and we are unaware of any health system that has yet integrated sophisticated ACP into its electronic medical records. Further, it is logistically complex and expensive to provide individuals and institutions the technical support necessary to both facilitate ACP and to prevent paralyzing system failures. There is also ample evidence that high tech solutions are sometimes more burdensome than liberating (Gajic, Herasevich, & Hubmayr, 2010; Lau et al., 2012), and that careful design is needed to prevent technology from becoming overwhelming and anxiety-provoking (Kadry, Sanderson, & Macario, 2010; Luchins, 2010; Rebitzer, Rege, & Shepard, 2008).

As e-resources for ACP continue to develop, critics and champions alike must be mindful that technology is not an end in itself, but rather a tool for achieving particular goals. Technology cannot resolve concerns about making decisions for future selves (Furberg, 2012), or bias in depictions of living with disabilities (Horner-Johnson et al., 2010; Huang, 2005). But as a tool, it can facilitate diverse and sophisticated approaches to decision-making that provide multiple perspectives about issues relevant to ACP. And, when properly designed, e-planning has the potential to achieve such goals in a way that saves healthcare providers time and money while simultaneously meeting the needs and preferences of patients.

Conclusion

The era of e has arrived for communicating about palliative and end-of-life care, and e-resources for advance care planning (ACP) represent an increasingly valuable set of tools for improving this care when patients cannot speak for themselves. Well designed e-resources can help better inform individuals about decisions that might need to be made; challenge them to think deeply about what matters to them and why; encourage dialogue with loved ones, healthcare providers, and others; and promote greater access to a variety of ACP materials and methods. To realize this potential, however, significant investment is needed to develop balanced, nuanced, effective e-resources for ACP, combined with a technological infrastructure that renders these e-resources both portable and sustainable.

Toward this end, future research should focus on the following important questions: (1) Which types of e-planning tools best (and most cost-effectively) achieve patient-centered outcomes such as promoting patient autonomy, improving knowledge regarding life-sustaining medical treatments, decreasing the stress of medical decision making, etc.? (2) When and under what circumstances are e-planning tools best utilized —e.g., home vs. in medical settings, good health vs. acute illness? (3) How can e-resources help decrease the burdens experienced by family caregivers/surrogate decision-makers? (4) How are e-planning tools best integrated into the electronic medical record? and (5) How can social media be effectively leveraged to promote the goals of advance care planning? A multi-faceted research agenda using qualitative and quantitative methods would provide the necessary evidence to inform future recommendations regarding the integration of e-planning into clinical practice.

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References

- Act, OBR. Patient self determination act provisions. US Government Printing Office; Washington, DC: 1990.
- Ariely, D. Predictably irrational: the hidden forces that shape our decisions. Rev. & exp. ed.. Harper; New York: 2009.
- Barry MJ. Health decision aids to facilitate shared decision making in office practice. *Ann Intern Med.* 2002; 136(2):127–135. [PubMed: 11790064]
- Blake H. Innovation in practice: mobile phone technology in patient care. *Br J Community Nurs.* 2008; 13(4):160, 162–165. [PubMed: 18595303]
- Bricker LJ, Lambing A, Markey C. Enhancing communication for end-of-life care: an electronic advance directive process. *J Palliat Med.* 2003; 6(3):511–519. doi: 10.1089/109662103322144880. [PubMed: 14509500]
- Danis M, Garrett J, Harris R, Patrick DL. Stability of choices about life-sustaining treatments. *Ann Intern Med.* 1994; 120(7):567–573. [PubMed: 8116994]
- Dexter PR, Wolinsky FD, Gramelspacher GP, Zhou XH, Eckert GJ, Waisburd M, Tierney WM. Effectiveness of computer-generated reminders for increasing discussions about advance directives and completion of advance directive forms. A randomized, controlled trial. *Ann Intern Med.* 1998; 128(2):102–110. [PubMed: 9441569]

- Ditto PH, Jacobson JA, Smucker WD, Danks JH, Fagerlin A. Context changes choices: a prospective study of the effects of hospitalization on life-sustaining treatment preferences. *Med Decis Making*. 2006; 26(4):313–322. doi: 26/4/313 [pii] 10.1177/0272989X06290494. [PubMed: 16855121]
- Edwards, W.; Newman, JR. *Multiattribute Evaluation*. Sage Publications; Newbury Park: 1982.
- Emanuel LL, von Gunten CF, Ferris FD. Advance care planning. *Arch Fam Med*. 2000; 9(10):1181–1187. [PubMed: 11115227]
- Fagerlin A, Schneider CE. Enough: The failure of the living will. *Hastings Center Report*. 2004; 34(2): 30–42. [PubMed: 15156835]
- Farace, E.; Levi, BH.; Green, MJ. Feasibility of an interactive computer-based decision aid for advance care planning in cancer survivors.. Paper presented at the American Psychological Oncology Society; Anaheim, CA. 2010.
- Farace, E.; Marupudi, N.; Green, MJ.; Levi, BH.; Sheehan, JM. A decision aid for advance care planning in patients with malignant brain tumors.. Paper presented at the The Society for NeuroOncology 13th Annual Scientific Meeting; Las Vegas, NV. 2008.
- Forrow L. The green eggs and ham phenomena. *Hastings Center Report*. 1994; 24(6):S29–S32. [PubMed: 7860277]
- Fox MP. A systematic review of the literature reporting on studies that examined the impact of interactive, computer-based patient education programs. *Patient Educ Couns*. 2009; 77(1):6–13. doi: S0738-3991(09)00078-0 [pii] 10.1016/j.pec.2009.02.011. [PubMed: 19345550]
- Fried TR, O'Leary J, Van Ness P, Fraenkel L. Inconsistency over time in the preferences of older persons with advanced illness for life-sustaining treatment. *J Am Geriatr Soc*. 2007; 55(7):1007–1014. doi: JGS1232 [pii] 10.1111/j.1532-5415.2007.01232.x. [PubMed: 17608872]
- Furberg E. Advance directives and personal identity: what is the problem? *J Med Philos*. 2012; 37(1): 60–73. doi: jhr055 [pii] 10.1093/jmp/jhr055. [PubMed: 22190599]
- Gajic O, Herasevich V, Hubmayr RD. Will the electronic medical record live up to its promise? *Am J Respir Crit Care Med*. 2010; 182(5):585–586. doi: 182/5/585 [pii] 10.1164/rccm.201004-0677ED. [PubMed: 20802167]
- Gillick MR. Advance care planning. *N Engl J Med*. 2004; 350(1):7–8. doi: 10.1056/NEJMp038202 350/1/7 [pii]. [PubMed: 14702421]
- Green MJ, Fost N. An interactive computer program for educating and counseling patients about genetic susceptibility to breast cancer. *J Cancer Educ*. 1997; 12:204–208. [PubMed: 9440011]
- Green, MJ.; Hensel, J.; Farace, E.; Whitehead, M.; Lehman, EB.; Levi, BH. Patients with CHF find decision aid for ACP helpful and computer-generated advance directive accurate.. Paper presented at the ACPEL; Chicago. 2012.
- Green MJ, Levi BH. Development of an interactive computer program for advance care planning. *Health Expect*. 2009; 12(1):60–69. doi: HEX517 [pii] 10.1111/j.1369-7625.2008.00517.x. [PubMed: 18823445]
- Green MJ, Levi BH. Teaching advance care planning to medical students with a computer-based decision aid. *J Cancer Educ*. 2011; 26(1):82–91. doi: 10.1007/s13187-010-0146-2. [PubMed: 20632222]
- Green, MJ.; Schubart, JR.; Farace, E.; Lehman, EB.; Whitehead, M.; Levi, BH. Use of a computer-based decision aid for advance care planning among patients with cancer.. Paper presented at the International Conference on Communication in Healthcare; Chicago. 2011.
- Halpern J, Arnold RM. Affective forecasting: an unrecognized challenge in making serious health decisions. *J Gen Intern Med*. 2008; 23(10):1708–1712. doi: 10.1007/s11606-008-0719-5. [PubMed: 18665428]
- Hammes B, Rooney B. Death and end-of-life planning in one midwestern community. *Archives of Internal Medicine*. 1998; 158:383–390. [PubMed: 9487236]
- Hammes BJ, Rooney BL, Gundrum JD. A comparative, retrospective, observational study of the prevalence, availability, and specificity of advance care plans in a county that implemented an advance care planning microsystem. *J Am Geriatr Soc*. 2010; 58(7):1249–1255. doi: JGS2956 [pii] 10.1111/j.1532-5415.2010.02956.x. [PubMed: 20649688]

- Heiman H, Bates DW, Fairchild D, Shaykevich S, Lehmann LS. Improving completion of advance directives in the primary care setting: a randomized controlled trial. *Am J Med.* 2004; 117(5):318–324. doi: 10.1016/j.amjmed.2004.03.027 S0002-9343(04)00345-6 [pii]. [PubMed: 15336581]
- Hickman SE, Hammes BJ, Moss AH, Tolle SW. Hope for the future: Achieving the original intent of advance directives. *Hastings Center Report Special Report.* 2005; 35(6):S26–S30.
- Horner-Johnson W, Suzuki R, Krahn GL, Andresen EM, Drum CE, Measurement R. E. P. o. H. Structure of health-related quality of life among people with and without functional limitations. *Qual Life Res.* 2010; 19(7):977–984. doi: 10.1007/s11136-010-9664-y. [PubMed: 20467819]
- Hossler C, Levi BH, Simmons Z, Green MJ. Advance care planning for patients with ALS: Feasibility of an interactive computer program. *Amyotroph Lateral Scler.* 2010 doi: 10.3109/17482968.2010.509865.
- Hsu J, Huang J, Fung V, Robertson N, Jimison H, Frankel R. Health information technology and physician-patient interactions: impact of computers on communication during outpatient primary care visits. *J Am Med Inform Assoc.* 2005; 12(4):474–480. doi: M1741 [pii] 10.1197/jamia.M1741. [PubMed: 15802484]
- Huang K. Attitudes of persons with physical disabilities toward physician-assisted death: An exploratory assessment of the vulnerability argument. *J Disability Studies.* 2005; 16:16–21.
- Jezewski MA, Meeker MA, Sessanna L, Finnell DS. The effectiveness of interventions to increase advance directive completion rates. *J Aging Health.* 2007; 19(3):519–536. doi: 19/3/519 [pii] 10.1177/0898264307300198. [PubMed: 17496248]
- Kadry B, Sanderson IC, Macario A. Challenges that limit meaningful use of health information technology. *Curr Opin Anaesthesiol.* 2010; 23(2):184–192. doi: 10.1097/ACO.0b013e328336ea0e. [PubMed: 20084001]
- Kasper JF, Mulley AG, Wennberg JE. Developing shared decision-making programs to improve the quality of health care. *QRB.Quality Review Bulletin.* 1992; 18:183–190. [PubMed: 1379705]
- Koch T. Future states: the axioms underlying prospective, future-oriented, health planning instruments. *Soc Sci Med.* 2001; 52(3):453–465. doi: S0277953600001544 [pii]. [PubMed: 11330779]
- LaPorte M. EMRs aid advance directive documentation. *Provider.* 2008; 34(2):42–43. [PubMed: 19397134]
- Lau F, Price M, Boyd J, Partridge C, Bell H, Raworth R. Impact of electronic medical record on physician practice in office settings: a systematic review. *BMC Med Inform Decis Mak.* 2012; 12:10. doi: 1472-6947-12-10 [pii] 10.1186/1472-6947-12-10. [PubMed: 22364529]
- Leong SL, Gingrich D, Lewis PR, Mauger DT, George JH. Enhancing doctor-patient communication using email: a pilot study. *J Am Board Fam Pract.* 2005; 18(3):180–188. doi: 18/3/180 [pii]. [PubMed: 15879565]
- Levi, BH.; Brothers, A.; Whitehead, M.; Simmons, Z.; Schubart, JR.; Farace, E.; Green, MJ. Advance care planning decision aid improves clinician understanding of wishes of patients with Amyotrophic Lateral Sclerosis.. Paper presented at the ACPEL; Chicago. 2012.
- Levi BH, Green MJ. Too Soon to Give Up: Re-examining the Value of Advance Directives. *The American Journal of Bioethics.* 2010; 10(4):3–22. [PubMed: 20379910]
- Levi BH, Heverley SR, Green MJ. Accuracy of a decision aid for advance care planning: simulated end-of-life decision making. *J Clin Ethics.* 2011; 22(3):223–238. [PubMed: 22167985]
- Levi, BH.; Schubart, JR.; Markham, S.; Whitehead, M.; Farace, E.; Lehman, EB.; Green, MJ. Use of an interactive computer program for advance care planning with African American participants.. Paper presented at the ACPEL; Chicago. 2012.
- Loewenstein G. Projection bias in medical decision making. *Med Decis Making.* 2005; 25(1):96–105. doi: 25/1/96 [pii] 10.1177/0272989X04273799. [PubMed: 15673587]
- Luchins D. The electronic medical record: optimizing human not computer capabilities. *Adm Policy Ment Health.* 2010; 37(4):375–378. doi: 10.1007/s10488-009-0234-y. [PubMed: 19662524]
- Molenaar S, Sprangers MA, Postma-Schuit FC, Rutgers EJ, Noorlander J, Hendriks J, de Haes HC. Feasibility and effects of decision aids. *Med Decis Making.* 2000; 20(1):112–127. [PubMed: 10638544]

- Moorman SM, Carr D, Kirchhoff KT, Hammes BJ. An Assessment of Social Diffusion in the Respecting Choices Advance Care Planning Program. *Death Studies*. 2012; 36(4):301–322. doi: Doi 10.1080/07481187.2011.584016.
- O'Connor AM, Drake ER, Fiset V, Graham ID, Laupacis A, Tugwell P. The Ottawa patient decision aids. *Eff Clin Pract*. 1999; 2(4):163–170. [PubMed: 10539541]
- O'Connor AM, Wennberg JE, Legare F, Llewellyn-Thomas HA, Moulton BW, Sepucha KR, King JS. Toward the 'tipping point': decision aids and informed patient choice. *Health Aff (Millwood)*. 2007; 26(3):716–725. doi: 26/3/716 [pii] 10.1377/hlthaff.26.3.716. [PubMed: 17485749]
- Ogozalek V. The “automated pharmacist”: comparing the use of leaflets, text-based computers, and multimedia computers to provide medication information to the elderly. *J Med Educ Technol*. 1993:6–11.
- Pearlman RA, Starks H, Cain KC, Cole WG. Improvements in advance care planning in the Veterans Affairs System: results of a multifaceted intervention. *Arch Intern Med*. 2005; 165(6):667–674. doi: 165/6/667 [pii] 10.1001/archinte.165.6.667. [PubMed: 15795344]
- Rebitzer JB, Rege M, Shepard C. Influence, information overload, and information technology in health care. *Adv Health Econ Health Serv Res*. 2008; 19:43–69. [PubMed: 19548513]
- Rhoads M. Face-to-face and computer-mediated communication: What does theory tell us and what have we learned so far? *Journal of Planning Literature*. 2010; 25(2):111–122.
- Ryhanen AM, Siekkinen M, Rankinen S, Korvenranta H, Leino-Kilpi H. The effects of Internet or interactive computer-based patient education in the field of breast cancer: a systematic literature review. *Patient Educ Couns*. 2010; 79(1):5–13. doi: S0738-3991(09)00371-1 [pii] 10.1016/j.pec.2009.08.005. [PubMed: 19744817]
- Schubart JR, Levi BH, Camacho F, Farace E, Whitehead M, Green MJ. Reliability of an interactive computer program for advance care planning. *Journal of Palliative Medicine*. 2012 in press.
- Strecher VJ, Greenwood T, Wang C, Dumont D. Interactive multimedia and risk communication. *Journal of the National Cancer Institute Monographs*. 1999; 25:134–139. [PubMed: 10854469]
- Sudore RL, Fried TR. Redefining the “planning” in advance care planning: preparing for end-of-life decision making. *Ann Intern Med*. 2010; 153(4):256–261. doi: 153/4/256 [pii] 10.1059/0003-4819-153-4-201008170-00008. [PubMed: 20713793]
- Teno JM, Licks S, Lynn J, Wenger N, Connors AF Jr, Phillips RS, Knaus WA. Do advance directives provide instructions that direct care? SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *J Am Geriatr Soc*. 1997; 45(4):508–512. [PubMed: 9100722]
- Tung EE, Vickers KS, Lackore K, Cabanela R, Hathaway J, Chaudhry R. Clinical decision support technology to increase advance care planning in the primary care setting. *Am J Hosp Palliat Care*. 2011; 28(4):230–235. doi: 1049909110386045 [pii] 10.1177/1049909110386045. [PubMed: 21057141]
- Tversky A, Kahneman D. The framing of decisions and the psychology of choice. *Science*. 1981; 211:453–458. [PubMed: 7455683]
- Ubel PA. Emotions, decisions, and the limits of rationality: symposium introduction. *Med Decis Making*. 2005; 25(1):95–96. doi: 25/1/95 [pii] 10.1177/0272989X04273143. [PubMed: 15673586]

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Table 1

Examples of e-planning web sites

	Website Name	URL
Basic e-planning		
1	My Living Will – Changing the Way America Plans for End of Life	http://www.mylivingwill.com/
2	West Virginia Center for End-of-Life Care	http://www.wvendoflife.org/e-Directive-Registry
3	California Advance Health Care Directive Registry	http://www.sos.ca.gov/ahcdr/forms.htm
4	Legacy Writer	http://www.legacywriter.com/livingwill2.asp
5	LegalZoom	http://www.legalzoom.com/living-wills/living-wills-overview.html
6	PartingWishes.com	http://www.partingwishes.com/Default.aspx
7	Rocket Lawyer	http://www.rocketlawyer.com/documents/living-will.aspx
8	SmartWillForms.com	http://www.smartwillforms.com/index.asp
9	Living Will	http://itunes.apple.com/hk/app/living-will/id430033397?mt=8
10	Indiana State Department of Health – Advance Directives	http://www.in.gov/isdh/files/advancedirectives.pdf
11	iCAREGIVER.ORG	http://icaregiver.org/advance-care-planning
12	HELPGUIDE.org	http://www.helpguide.org/elder/advance_directive_end_of_life_care.htm
13	DifferenceBetween.net	http://www.differencebetween.net/miscellaneous/legal-miscellaneous/difference-between-living-will-and-advance-directive/
14	Caring Connections	http://www.caringinfo.org/t4a/pages/index.cfm?pageid=3289
Enhanced e-planning		
15	LAWDEPOT.com	http://www.lawdepot.com/contracts/living-will-us/
16	U.S. Living Will Registry	http://liv-will.us/livingwillregistry.com/state.html
17	iLivingWill	http://itunes.apple.com/us/app/livingwill/id435181141?mt=8
18	DoYourProxy.org	http://www.doyourproxy.org/livingwill1.php
19	Hospice & Palliative Care of Western Colorado	http://www.hospicewco.com/t4a/pages/index.cfm?pageid=3633
20	Lower Cape Fear Hospice & Life Care Center	http://www.hospiceandlifecarecenter.org/resources/patient-family/advance-care-planning.aspx
21	AARP	http://www.aarp.org/relationships/caregiving/info-03-2012/free-printable-advance-directives.html
22	American Hospice Foundation	http://www.americanhospice.org/articles-mainmenu-8/advance-care-planning-mainmenu-9/46-medical-issues-to-be-considered-in-advance-care-planning

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	Website Name	URL
23	American Bar Association – Commission on Law and Aging	http://www.americanbar.org/groups/law_aging/resources/health_care_decision_making.html
24	Caring Connections – Advance Directives	http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3284
25	Center for Practical Bioethics – Guidance at the Crossroads of Decision	http://practicalbioethics.org/initiatives/aging-end-of-life-care.html
26	C-TAC Coalition to Transform Advanced Care	http://advancedcarecoalition.org/
27	The Go Wish Game	http://www.gowish.org/index.php?topic=about
28	Speak Up	http://www.advancecareplanning.ca/about-advance-care-planning/national-framework-for-accp.aspx
29	Compassion and Support at the End of Life	http://www.compassionandsupport.org/index.php
30	National Health Care Decisions Day	http://www.nhdd.org/
Interactive e-planning		
31	National Health Care Decisions Day	http://www.nhdd.org/chat/
32	Developing A Trusting Heart	http://trustinghearts.com/job-related-stress/planning-ahead-for-death-is-beneficial-not-unethical-2015.php
33	CaringRoad Support Network	http://www.caringroad.com/
34	My Five Wishes Online	https://fivewishesonline.agingwithdignity.org/
35	Respecting Choices	http://respectingchoices.org/about_us
Integrated e-planning		
36	Making Your Wishes Known	https://www.makingyourwishesknown.com/
Social Media e-planning		
37	Qualtonomy	https://www.qualtonomy.com/

All web sites accessed July 20, 2012