Engaging Patients With Advance Directives Using an Information Visualization Approach
Janet Woollen, MS, RN; and Suzanne Bakken, PhD, RN, FAAN

ABSTRACT
Despite the benefits of advance directives (AD) to patients and care providers, they are often not completed due to lack of patient awareness. The purpose of the current article is to advocate for creation and use of an innovative information visualization (infovisual) as a health communication tool aimed at improving AD dissemination and engagement. The infovisual would promote AD awareness by encouraging patients to learn about their options and inspire contemplation and conversation regarding their end-of-life (EOL) journey. An infovisual may be able to communicate insights that are often communicated in words, but are much more powerfully communicated by example. Furthermore, an infovisual could facilitate vivid understanding of options and inspire the beginning of often difficult conversations among care providers, patients, and loved ones. It may also save clinicians time, as care providers may be able to spend less time explaining details of EOL care options. Use of an infovisual could assist in ensuring a well-planned EOL journey. [Journal of Gerontological Nursing, 42(1), 16-20.]

A n advance directive (AD) is beneficial to patients and care providers in guiding end-of-life (EOL) care; however, ADs are often not completed, largely due to patients’ lack of awareness (Rao, Anderson, Lin, & Laux, 2014). A recent survey found that approximately 75% of participants did not have an AD, with the top reason for not having one being “I don’t know what ADs are” (Rao et al., 2014,

ABOUT THE AUTHORS
Ms. Woollen is PhD Student, Department of Biomedical Informatics, and Dr. Bakken is Alumni Professor of Nursing and Professor of Biomedical Informatics, Department of Biomedical Informatics and School of Nursing, Columbia University, New York, New York.
The authors have disclosed no potential conflicts of interest, financial or otherwise. Ms. Woollen is supported by Reducing Health Disparities Through Informatics (T32NR007969) and Dr. Bakken is supported by the New York City Hispanic Dementia Caregiver Research Program (R01NR014430).
Address correspondence to Janet Woollen, MS, RN, PhD Student, Department of Biomedical Informatics, Columbia University, 622 W. 168th Street, VC-20, New York, NY 10032; e-mail: jw3024@columbia.edu. doi:10.3928/00989134-20150804-63
The current article summarizes reasons for this lack of awareness and explores the literature for pivotal ways information visualizations (infovisuals) can improve understanding, dissemination, and engagement of ADs.

WHY ADVANCE DIRECTIVES ARE DESIRABLE

Completion of an AD has been associated with greater use of palliative care, decreased stress during EOL, shortened length of hospital stay (Wu, Newman, Lasher, & Brody, 2013), improved communication between providers and health care surrogates, and a significant decrease in health care costs (Trustees of Dartmouth College, 2015). Failure to discuss, understand, and complete an AD can result in confusion, distress, and guilt in family members, as well as increased patient suffering and unwanted procedures (Weitzen, Teno, Fennell, & Mor, 2003) that proffer questionable value (Valente, n.d.). Moreover, the absence of an AD often causes clinicians to face moral distress and conflict with their medical judgment and family members (Hawkins, Ditto, Danks, & Smucker, 2005). Furthermore, relying on family members or clinicians to guess patients’ EOL preferences has proven unreliable; studies revealed that neither families nor clinicians accurately predict patients’ EOL preferences (Coppola, Ditto, Danks, & Smucker, 2001; Shalowitz, Garrett-Mayer, & Wendler, 2006).

BARRIERS TO ADVANCE DIRECTIVE AWARENESS

Health care providers operate under great pressure in a system that does not provide incentives or adequate training to discuss EOL options with patients and their families. Discussing EOL care is generally difficult for physicians (Periyakoil, Neri, & Kraemer, 2015). Most are reluctant to discuss ADs because they (a) lack the necessary training to do so, (b) think that ADs are not urgent for patients who are not terminally ill, (c) fear that it will induce anxiety, or (d) do not get paid for or have the time to spend discussing the topic (Morrison, Morrison, & Glickman, 1994). Patients often wait for their health care providers to bring up the subject, whereas many health care providers assume patients will bring it up (Ramsaroop, Reid, & Adelman, 2007).

The Advance Directive Form

Patients must be able to read and understand AD forms before signing them. However, AD documents often fail to provide detailed, practical guidance, and are therefore misinterpreted (Lynn, 1991). Moreover, research indicates that ADs are usually written in language above the average patient reading level (Ott & Hardie, 1997). Increased ethnic and cultural diversity of the population and varying levels of health literacy present additional barriers to the understanding of ADs by patients and their surrogates. Moreover, there are strong indications that many individuals increasingly resist reading documents that are of medium length or longer (Liu, 2005), which is the primary format in which ADs are presented to patients. Despite clinician efforts to explain ADs to patients, researchers discovered that the majority of patients complete ADs without understanding them (Upadya, Muralidharan, Thorevska, Amoateng-Adjepong, & Manthous, 2002). This is troubling for a number of reasons, in part because patients rated clear communication of EOL options as one of the highest concerns of EOL care (Steinhauser et al., 2000). Furthermore, some EOL experts question whether patients would consent to certain EOL treatment if they truly understood what the words in ADs represented. Some physicians consider certain forms of EOL care torture for the patient (Rauch, 2013).

CAN WORDS ALONE CONVEY END-OF-LIFE INFORMATION?

Although a number of issues plague AD procurement and understanding, words are the vehicle with which AD information is primarily organized, presented, and disseminated. Can health care providers effectively convey the details of EOL treatment to patients using words alone? Evidence would suggest otherwise (Ramsaroop et al., 2007). To help patients and families discern pertinent EOL information, entry points into the text must be provided so that they do not unknowingly consent to spend the last moments of life undergoing interventions that a majority of clinicians would essentially forgo (Periyakoil, Neri, Fong, & Kraemer, 2014). Perhaps a more complete and comprehensible image of EOL options can be provided using an innovative infovisual to enhance interest, understanding, recall, contemplation, and sharing.

PROPOSITIONS FOR HOW INFORMATION VISUALIZATIONS CAN FACILITATE LEARNING OF ADVANCE DIRECTIVES

The following section draws on evidence across a range of academic fields and real-world examples to illustrate how infovisuals can improve AD awareness, dissemination, comprehension, and engagement.

Information Visualizations Enhance Insight, Comprehension, and Learning

Infovisuals have been defined as the use of computers to interactively amplify cognition using visual representation (Fogg, 2002). The primary goal of an infovisual is to provide insight as an experience that is complex, deep, qualitative, unexpected, and relevant (Fogg, 2002). Infovisuals for ADs should aim to impart this type of insight to patients and their families or other health care surrogates to facilitate true, informed EOL planning.
Although various categories and types of infovisuals exist (Pousman, Stasko, & Mateas, 2007), most, if not all, aim to provide insight through visually enabled reasoning of phenomena that are not obvious or observable. An applicable infovisual for an AD could arrange, organize, and present various informative elements (e.g., text, images, videos) to effectively elucidate EOL interventions.

Studies have found that the addition of visualization to instructions improves patient comprehension, recall, and interest, and causes deeper and more accurate understanding of medical information in older adults and in individuals with low health literacy (Volandes et al., 2008). These effects tend to be greater among patients who are women or non-White, or have no more than a high school education. This cohort is also the target population for AD education and procurement, as they are the least likely to have completed an AD (Rao et al., 2014).

Addressing the literacy gap of ADs is of ethical interest, as studies indicated that due to the misinterpretation and incomprehension of ADs, patients naively consent to EOL treatment that may be different from their true wishes and values (Upadaya et al., 2002). Visual representations of EOL options can ameliorate this problem by serving as a visual universal language. Images of EOL care appeal to the more objective faculty of vision rather than to incomplete or biased interpretations of EOL care described in texts. For example, a video/visual capture of what EOL treatment is like may be more informative than a textual description, particularly to individuals with low health literacy or limited English proficiency. Infovisuals, in effect, support more equitable medical care. Visualizations increase accessibility of information in high-risk populations while fostering the interest of patients at all levels of reading ability.

**Information Visualizations Help Dissemination, Communication, and Collaboration**

Embedding AD information in an infovisual has great potential to increase awareness and knowledge. Information contextualized and encapsulated in an infovisual makes it appealing, easily disseminated, and accessible to anyone with an Internet connection, and can serve as a shared interface and point of reference about EOL options, promoting clear informed communication among patients, families, and health care providers. Researchers have demonstrated that shared interactive visualizations are effective in communicating and developing insights, supporting awareness, and establishing common ground between collaborators (Heer & Agrawala, 2008). If knowledge of ADs increases, it may spur individuals to broach the subject with their health care providers or at least be knowledgeable about ADs if health care providers broach the subject with them. Furthermore, because infovisuals typically include the entire context needed within the visualization, they could help focus and circumscribe patients’ attention on, and interaction with, vetted information provided in the visualization. This could save time and facilitate improved communication, as patients are known to spend time browsing online for medical information without knowing if the sources they find are trustworthy.

Every individual has various experiences, ideas, and wishes for their EOL care that are hard to predict. These unique, diverse preferences cannot be well accommodated by static, fixed text describing EOL options. However, a mixed media, interactive infovisual can accommodate such preferences: it is flexible, yielding, and versatile, offering multiple facets and nuances of EOL information that accommodate the subtlety of individual understanding and preferences. It is this ambiguity and open-endedness that offer the
greatest possibilities for conveying information and providing an engaging experience for critical AD decision making.

An AD infovisual could facilitate collaborative knowledge creation by serving as an anchor on which patients and family members could gather (asynchronously or synchronously) to discuss each individual’s understanding of EOL options. An AD infovisual could facilitate communication between the clinician (i.e., the expert in EOL care options) and patient (i.e., the expert in what constitutes a “good death”) (Gustafson, 2007) to collaboratively devise a plan for EOL care. This may be particularly important in situations where the clinician and patient differ in cultural background or other aspects of common ground.

Infovisuals are made to be shared—they are usually networked, often public, and by their digital nature can be quickly, economically, and automatically distributed across a network. Although AD text can also be made digital and shared over the Internet, it lacks the engaging aesthetic and artistic appeal that infovisuals wield.

How Aesthetics of Information Visualizations Promote Interest and Engagement

Discussing EOL wishes with loved ones and health care providers has been identified as key to ensuring EOL plans will be followed. However, as discussed previously, individuals often find broaching the topic awkward and challenging. The design and aesthetics of an infovisual may provide an entry for discussion.

The aesthetics of an AD infovisual could induce emotional responses to pique interest, curiosity, and engagement. For example, Burmester, Mast, Tille, and Weber (2010) found that good aesthetic design was a major factor inspiring curiosity and interest in visualizations. Aesthetics persuade the user to unconsciously choose to become involved (Fogg, 2002) and can reduce perceptions of response effort and increase arousal and interest (Casey & Poropat, 2014). Proper construction of aesthetic elements can entice the senses to arouse intellect, intuition, and personal experience, in concert with new information, to provide an experience that is deep and engaging (Holsanova, Holmberg, & Holmqvist, 2009).

An AD infovisual with good aesthetic design could foster a desire to return to view, remember, or share the visual and possibly spark a conversation about EOL care. This would be desirable for ADs, as studies show EOL preferences can change over time (Forrow, 1994). Good aesthetic design may positively affect user experience, memory, and interest in AD infovisuals. AD documents are currently pushed onto patients and their families; an aesthetically well-designed AD infovisual has the potential to engage them.

IMPLICATIONS FOR NURSES

The medical community is currently focused on precision medicine (i.e., “prevention and treatment strategies that take individual variability into account” [Collins & Varmus, 2015, p. 793]). Although this initiative has primarily focused on caring for the unique genetic and physical nature of an individual, it could be argued that precision medicine, as it pertains to EOL treatment, should take into account the unique psychological and emotional nature of an individual. Although researchers may eventually find that these elements are closely related (Vedhara et al., 2015), health care providers must act now to address what patients have expressed—that along with more information, the largest unmet needs in EOL care are emotional, psychological, and spiritual (Adams, Bailey, Anderson, & Docherty, 2011).

Nurses play a crucial role in providing support that addresses these specific needs, but they are challenged by time and communication constraints (Beckstrand, Callister, & Kirchhoff, 2006). Perhaps an AD infovisual accessible online could help make time and improve nurses’ ability to support patient-valued needs. Communicating EOL options to patients or family members who have various emotional and psychological needs may be improved through use of adaptable, immersive visuals (Kamvar & Harris, 2011), which better speak to the emotional psychology of an individual than words alone (Bechera, 2004).

In addition to the roles of supporter and advocate, numerous studies reported that nurses also play a central role in EOL decision making as information broker to physicians, patients, and family members (Adams et al., 2011). Although providing physicians with updates on patients’ clinical, emotional, and psychological statuses and expressed wishes, nurses, in tandem, educate, update, clarify, and interpret medical information to patients and family members (Bach, Ploeg, & Black, 2009). Nurses mediate and serve as an important source of information to aid physicians and family members in EOL decision making (Scherer, Jezewski, Graves, Wu, & Bu, 2006). A time-constrained information broker may benefit from an AD infovisual to enhance his or her ability to disseminate and facilitate understanding of EOL options to patients and family members.

CONCLUSION

Better communication tools are needed to promote reflective insight into EOL care options and to increase awareness of ADs. Patients and families lack access to information on what to expect, what to look for, and what their options and rights are at the EOL (Heyland, 2013). They know the principles, but need ready access to pertinent information presented in a way that facilitates a deeper understanding of specifics.

Leveraging infovisuals to visually articulate and support textual
ADs could improve understanding, help broach often difficult conversations, increase dissemination, and better engage patients with EOL care options. Ultimately, AD infovisuals could help true patient preferences be respected and, in doing so, help patients live the end of their lives on their own terms.

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