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Engaging Patients with Advance Directives using an Information Visualization Approach

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Abstract

Despite the benefits of advance directives (AD) to both patients and care providers, they are often not completed due to lack of patient awareness. The purpose of this paper 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 engaging patients to learn about their options and inspire contemplation and conversation regarding patients' 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 between 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.

Keywords

information visualization; advance directives; end of life; dissemination research

INTRODUCTION

An 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.⁽¹⁾ A recent survey found that around 75% of participants did not have an AD, with the top reason for not having one being "I don't know what advance directives are".⁽¹⁾ This paper summarizes reasons for this lack of awareness and explores the literature for pivotal ways information visualizations 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 stay,(2) improved communication between providers and healthcare surrogates, and a significant decrease in costs.(3) 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 (8) that proffer questionable value.(4) Moreover, the absence of an AD often causes clinicians to face moral distress and conflict with their own medical judgment and with family members.(7) Furthermore, relying on family members or clinicians to guess patients' EOL preferences has proven unreliable. Studies reveal that neither families nor clinicians accurately predict patients' EOL preferences.(5,6)

BARRIERS TO ADVANCE DIRECTIVES AWARENESS

Healthcare 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.(9) Most are reluctant to discuss ADs because they lack the necessary training to do so, think that ADs are not urgent for those not terminally ill, fear that it will induce anxiety, or do not get paid for, nor have the time to spend, discussing the topic.(10) Patients often wait for their healthcare providers to bring up the subject, while many healthcare providers assume patients will bring up the subject.(11)

The advance directives 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.(12) Moreover, research indicates that ADs are usually written in language above the average patient reading level.(13) The 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 people increasingly resist reading documents that are of medium length or longer,(14) which is the primary format in which ADs are presented to patients. Despite clinician efforts to explain AD to patients, researchers discovered that the majority of patients complete ADs without understanding them.(15) 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.(16) Furthermore, some EOL experts question whether patients would consent to certain EOL treatment if they truly understood what the words in ADs actually represented. As one physician puts it: certain forms of EOL care are close to torturing a patient.(17)

QUESTION

While there are a number of issues plaguing AD procurement and understanding, here we focus on the vehicle in which AD information is primarily organized, presented and disseminated: words. Can healthcare providers effectively convey the grave details of their

EOL treatment to patients using words alone? Evidence would suggest otherwise.(11) In order 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 even a vast majority of clinicians would electively forgo. (18) 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 INFOVISUALS CAN FACILITATE LEARNING OF ADVANCE DIRECTIVES

In the following paragraphs, the authors draw on evidence across a range of academic fields and real-world examples to illustrate how infovisuals can improve AD awareness, dissemination, comprehension and engagement.

Infovisuals enhance insight, comprehension and learning

Infovisuals have been defined as the use of computers to interactively amplify cognition, using visual representation.(27) The primary goal of an infovisual is to provide insight. Insight as an experience that is complex, deep, qualitative, unexpected, and relevant.(27) Infovisuals for ADs should aim to impart this type of insight to patients and their families or other healthcare surrogates in order to facilitate true informed EOL planning.

While there are various categories and types of infovisuals,(19) most, if not all, infovisuals 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, pictures, images, videos) to effectively elucidate EOL interventions. An example of such an infovisual may be inferred by the interactive infovisual about President John F. Kennedy (found here: http://nvcn.nbcnews.com/_util/jfk50/#). Figure 1 is a screenshot of the interactive infovisual that houses short video clips and network diagrams displaying connections between interviewees.

A mixed-media infovisual such as this would furnish many potential tools to aid comprehension and serve as an enhanced communication application. 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 the elderly and in individuals with low health literacy.(20) This effect tends to be larger among patients who are female, nonwhite, 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.(1)

ADs have been found to be difficult to comprehend for those with low health literacy.(20) Addressing the literacy gap of ADs is of ethical interest, as studies indicate that due to the misinterpretation and incomprehension of ADs, patients are naively consenting to EOL treatment that may be different from their true wishes and values.(15) 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 those 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.

Infovisuals communicate information quickly and effectively

The human brain processes images faster than it does written text.(22) When it comes to quick, clear communication aimed at a heterogeneous audience, the airline industry is very experienced. Airlines use visuals, instead of textual explanations, on their emergency information pamphlets because visuals facilitate rapid communication and comprehension of information with little cognitive effort compared with texts.(23) Lessons from the airline industry may be applicable to support EOL decision making. Many individuals find themselves having to make EOL decisions in the heat of the moment. They stress a need for better tools to access and understand care options.(24) An infovisual could quickly and effectively convey pertinent information to patients and family members, while helping time constrained clinicians who face numerous challenges in communicating EOL options.

Infovisuals 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. It can serve as a shared interface and point of reference about EOL options, promoting clear informed communication between patients, families and healthcare providers. Researchers have demonstrated that shared interactive visualizations are effective in communicating and developing insights, supporting awareness, and establishing common ground between collaborators.(25) If knowledge of ADs increases, it may spur individuals to broach the subject with their healthcare providers, or at least be knowledgeable about AD if healthcare providers broach the subject with them. Furthermore, because an infovisual typically includes the entire context needed within the visualization, an infovisual 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 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, which offers 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 person's understanding of EOL options. An AD infovisual could facilitate communication between the clinician (the expert in EOL care options) and the patient (the expert in what constitutes a "good death"),(24) to collaboratively devise a plan for the patient's finale. This may be particularly important in situations in which the clinician and patient differ in cultural background or other aspects of common ground.

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

How aesthetics of infovisuals promote interest and engagement

Talking about EOL wishes with loved ones and healthcare providers has been identified as key to ensuring EOL will be followed. However, as discussed previously, people often find broaching the topic awkward and challenging. The design and aesthetics of an infovisual may provide an entry for people to discuss the difficult topic.

The aesthetics of an AD infovisual could induce emotional responses to pique interest, curiosity, and engagement. For example, Burmester, Mast, Tille and Weber (26) found that good aesthetic design was the major factor inspiring curiosity and interest in their study's visualizations. Aesthetics persuades the user to unconsciously choose to become involved. (27) Aesthetics can reduce perceptions of response effort and increase arousal and interest. (28) 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.(29)

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.(30) Good aesthetic design may positively affect user experience, memory and interest in AD infovisual. AD documents are currently *pushed* onto patients and their families; an aesthetically well-designed AD infovisual has the potential to *pull* patients and families in.

HOW INFOVISUALS COULD HELP NURSES

The medical community is currently focused on precision medicine – "prevention and treatment strategies that take individual variability into account."(31) Though this initiative has primarily focused on caring for the unique genetic and physical nature of an individual, one might argue that precision medicine as it pertains to EOL treatment should take into account the unique psychology and emotional nature of an individual. While researchers may eventually find that these elements are closely related,(32) healthcare 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.(33)

Nurses play a crucial role in providing support that addresses these specific needs, but they are challenged by time and communication constraints.(34) Perhaps an AD infovisual accessible online could help free-up time and improve a nurse's 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,(35) which better speak to the emotional psychology of an individual than words alone.(36)

In addition to the roles of supporter and advocate, numerous studies report that nurses also play a central role in EOL decision making as information broker to physicians, patients and family members.(33) While providing physicians with updates on patient clinical, emotional, psychological status, and expressed wishes, nurses, in tandem, educate, update, clarify, and interpret medical information to patients and family members.(37) Nurses mediate and serve as an important source of information to aid physicians and family members in EOL decision making.(38) 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.(39) They know the principles, but they need ready access to pertinent information presented in a way that facilitates a deeper understanding of the 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 life on their own terms.

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Figure 1.