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Technology in Academic Medicine: Technology Promotes Wider Use of Advance Directives

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—By Stephen G. Pelletier, special to the Reporter

When a critically ill patient is unable to communicate directly, prewritten advance directives help caregivers and family members understand the type of care the individual prefers. Typically, these directives name a surrogate who is authorized to make medical decisions on the patient's behalf. Technological innovations may be opening doors for this important tool to be used more widely and effectively.

The Joint Commission, which accredits and certifies health care organizations, advocates advance directives in the context of patients' rights. The federal Patient Self-Determination Act, enacted in 1991, requires many hospitals and other health care providers to inform adult patients about advance directives. A proposal for Medicare to cover planning for end-of-life care originally was part of the Affordable Care Act, but was struck from the bill when foes claimed the law would create what they called "death panels." Efforts are underway to implement the provision, perhaps using the Obama administration's executive authority.

At the state level, California was the first to legislate advance directives when it passed what was called the "natural death law" in 1976. All other states eventually followed suit, concluding with New York in 2010. Laws regarding advance directives vary from state to state, and directives are sometimes, but not always, transferable between states.

One of the fundamental challenges of advance directives is that they are not always accessible to care providers or families when they are needed most. The directives fail their most basic function if they are stuck in a drawer at home when a patient is under hospital care but unable to communicate. Another challenge is that too few people have completed advance directives. A recent study found, for example, that slightly more than 25 percent of Americans have completed advance instructions for their health care. Technology may help address those concerns.

For the past two decades, numerous public- and private-sector entities have created data registries where individual advance directives can be stored and then accessed as needed by authorized parties. Many operate through a code number that users can both store and share with loved ones. A prominent example, the U.S. Living Will Registry serves individual clients and manages advance directive registries for Vermont and Washington. Bioethicist and medical anthropologist Craig M. Klugman, Ph.D., chair of the Department of Health Sciences at DePaul University College of Science and Health, has consulted with other states, including Nevada and Texas, that have created their own registries for advance directives. However, there are no complete data to indicate how extensively registries are used, he noted.

The most recent innovations have been smartphone apps to help individuals write their own advance directives. Klugman helped design the Texas Living Will app, which drives Texans to the website for their state registry. Another app, MyLivingWill, offers users the ability to create a legal living will or advance directive.

The American Bar Association (ABA) takes app technology even further. In April, the ABA's Commission on Law and Aging released "My Health Care Wishes," an app that enables users to store and distribute health care advance directives via their smartphones. A "lite" version of the app stores one person's information, while a "pro" version will store multiple profiles.

"Doing an advance directive and filing it in a drawer somewhere does little good," said ABA President William C. Hubbard, J.D., a partner with the Columbia, S.C., office of Nelson Mullins Riley & Scarborough LLP.

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"Your directive needs to be at your fingertips and at the fingertips of the loved ones and health care providers you choose. That's what the [ABA] app does." Moreover, promotional materials for the ABA app note that "the information is protected because the data reside only on your smartphone, not on any server or cloud service."

One criticism of advance directives is that they can be completed perfunctorily, without careful thought. "Ideally I would want advanced health care planning to be the product of a conversation—an information exchange—between the patient and his or her health care provider," said Marshall B. Kapp, J.D., M.P.H., director of the Center for Innovative Collaboration in Medicine and Law at the Florida State University College of Medicine and College of Law.

Two physicians at Penn State University's Milton S. Hershey Medical Center, Benjamin H. Levi, M.D., Ph.D., and Michael Green, M.D., M.S., are using technology to get people to think carefully about their advance directives. They conceived "Making Your Wishes Known," an online interactive tool that includes personal values, beliefs about quality of life, and particular options for care to help an individual generate a personalized advance directive that can be saved as a PDF file.

The growing push to increase the use of advance directives through technology remains somewhat speculative. "We realize that something needs to be done, and there needs to be a better way to get decisions made," Klugman said. "A lot of different things are being tried, but we don't quite know yet what is going to be effective. So, at this point, I think of [the effort] as an interesting thing to explore."