

Review Article

Lifting Shadows off the End-of-Life Care: Hopes and Beliefs on Video Decision Support Tools for Advance Care Planning

Heon-Jae Jeong, M.D., DrPH.* and Hyecheon Yoon, MHS, CHES[†]

*The Care Quality Research Group, [†]Center for Patient Education, Philadelphia, Pennsylvania, USA

As advance care planning is taking center stage in the field of end-of-life care, various tools have been developed to aid in the often emotional and difficult decision-making process. Video decision support tools are one of the most promising means of assistance, of which the modus operandi is to provide more comprehensive and precise information of medical procedures to patients and their families, allowing them to make better informed decisions. Despite such value, some are concerned about its potential negative impact. For example, video footages of some procedures may be shocking and unpalatable to non-medical professionals, and patients and families may refuse the procedures. One approach to soften the sometimes unpleasant visual of medical procedures is to show less aggressive or more relaxing scenes. Yet another potential issue is that the objectivity of video decision support tools might be vulnerable to the very stakeholders who were involved in the development. Some might argue that having multiple stakeholders may function as checks and balances and provide collective wisdom, but we should provide more systematic guarantee on the objectivity of the visual decision aids. Because the decision of the modality of an individual's death is the last and most significant choice in one's life, no party should exert their influence on such a delicate decision. With carefully designed video decision support tools, our patients will live the last moments of their lives with dignity, as they deserve.

Key Words: Advance care planning, Videotape recording, Decision making, Clinical decision support systems, Palliative care, Terminal care

TWO STORIES FROM THE 21st CENTURY

There is nothing left. It's time to stop, I said to myself over and over. Finally, a black rollerball that used to belong to my father slowly began to draw my signature on a sheet of paper. It was a DNR declaration form for him, who was a terminal stage lung cancer patient in a coma.

It was quiet at 6 AM. Only the beeping sounds from patients' monitoring machines filled the void of the patient room. It felt as if time had stopped. I took a deep breath and paused in my signing, looking back on the past few months. What would be better? A couple of CPR compressions had successfully revitalized the flat line of the

EKG, but that was all. Days in the ICU did not change anything. Literally every single thing that modern medicine could offer had been tried with him. Although we all knew it could not save him, my family and I just believed doing everything we could was the right thing. We did everything for our unconscious patient, my father. Even when we did not understand the procedures, we asked the doctor to please do it for him too.

Now I had decided to end this with his pen. He passed away within a few days.

I think I did the right thing, but sometimes I feel guilty about signing the DNR declaration form. I might have killed him or, at least, expedited his death.

— Heon-Jae Jeong, a lung cancer victim's son, 2006

Received February 21, 2016, Revised February 24, 2016, Accepted February 25, 2016

Correspondence to: Heon-Jae Jeong

The Care Quality Research Group, 1815 JFK Blvd., Philadelphia, PA, 19103, USA

Tel: +1-410-733-2452, Fax: +1-410-955-6959, E-mail: hjeong1@jhu.edu

© This is an Open Access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0>) which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original work is properly cited.

I was watching my father, who was reading a piece of paper. He was concentrating so hard on the paper I could not even speak to him. It had been three years since his diagnosis with terminal colon cancer. The cancer had already metastasized to a few other organs; there was no hope of a cure for him.

It was the first day at a palliative treatment center and the paper had been brought to him by a kind-looking nurse. I still vividly remember every single word on the yellowish paper, which included mostly yes/no questions. “I will not get cardiopulmonary resuscitation (CPR) when my heart stops”, “I will use a mechanical ventilator when I cannot breathe myself”, and so on. I was scared, even terrified. I was looking at my father cautiously and saw a smile cross his face—at least, I thought it was a smile. What was it?

I realized that my father might be happy that he would not have to leave this difficult choice to his daughter and could keep his dignity by choosing how he would die.

— Hyeeyon Yoon, a colon cancer victim’s daughter, 2013

When we were asked to write this commentary, the first thing that came to our mind was the preceding two vignettes—true stories that we experienced ourselves. Therefore, we need to confess that this article might be a bit emotional. However, we decided to take advantage of such experiences and emotions in our writing to better engage ourselves with this discussion. In other words, we will be standing a bit closer to the patient and patient’s family perspective, rather than the authors’ usual standpoint as a healthcare provider or policymaker.

INTRODUCTION: DEATH AS A PART OF HEALTHCARE AND ADVANCE CARE PLANNING

For the past few decades, the location of death has changed tremendously. In-hospital deaths accounted to 35.9% of all deaths in Korea in 2000 and more than doubled to 73.1% in 2014 (1). Indeed, we now can say the majority of end-of-life care currently takes place in the hospital setting, and not surprisingly the cost of such care accounts for a huge portion of the healthcare budget of a community. According to the National Cancer Center (2), the amount of medical expenses for a cancer patient in the last month before death is already

up to 36.3% of the total yearly medical expense. Such data indicate that death and any near-death healthcare have become a critical part of medical care.

As evident in the vignettes presented at the beginning of this paper, providing care to terminal patients is often regarded as a family duty. In Asian countries, the still dominant philosophy of the Confucianism culture asserts that children have an obligation to take care of their parents and ancestors, might play a strong role in providing aggressive end-of-life care (3). However, perceptions of who is responsible for healthcare are changing. Today we put more emphasis on patient-centeredness, meaning that patients and their families—instead of simply trying every possible treatment—are expected to actively participate in determining the kind of care patients receive as their condition worsens. Patients are believed to experience more dignity and better quality of life during their final months of life, which has led to the development of advance care planning (ACP). ACP is “a process whereby a patient, in consultation with health care providers, family members and important others, makes decisions about his or her future health care, should he or she become incapable of participating in medical treatment decisions” (4). A randomized controlled trial concluded that “ACP improves end of life care and patient and family satisfaction and reduces stress, anxiety, and depression in surviving relatives” (5).

Researchers agree that ACP broadly shows positive effects (6,7), and a new method has been developed to improve the ACP process: video decision support tools.

VIDEO DECISION SUPPORT TOOLS

Boeuf bourguignon, a traditional French dish, is described as a stew prepared with beef braised in red wine, yet this description hardly describes the look or taste of this dish. Thus, some restaurants include a photo of the dish in their menu as well; such a visual aid helps customers understand what they will get, which enables them to make the best possible choice.

Medical procedures are the same. Patients and their families may not understand what using a ventilator entails until they can watch a video, which goes a step further than a picture and enables the patient to observe someone breathing with the help of a ventilator mask. Such a video helps the patient

and family make a better decision as to whether to use a ventilator or not in the final moments. These video decision support tools can provide more comprehensive and precision information to patients, thereby leading to better patient-centered care.

Yet do such tools also benefit patients? Our answer is a conditional yes. Many end-of-life care procedures, like CPR, are shocking and even seem aggressive to non-medical professionals. Showing videos of such scenes is highly likely to lead a patient to refuse the procedure, as previous studies have already demonstrated (5). The point here is that showing the video can have a unilateral effect. By providing more information, visual aids might cause people to avoid aggressive procedures. This leads to a philosophically complex issue: Do video decision support tools function solely as an aid or do they actually influence the direction of the patient’s decision?

What makes this situation more complicated is when we provide such visual aids more often to patients facing end-of-life care, rather than other acute care issues. At the macro level, based on the discussion thus far, the rapid development of video aids for end-of-life care procedures might decrease the amount of care demands compared to the other acute cares. Considering that end-of-life care patients are usually older than those seeking acute care, the topography of healthcare resource allocation becomes different. With a little stretch, one might think it is a human rights issue between generations. Although we are not proposing any conflicts in values on this change, we still have to consider the impact of such a change considering both medical and human rights issues.

THREE SOURCES THAT MAY UNDERMINE VIDEO DECISION AIDS

We are certainly not the first people to express concern in

this regard. Volandes, et al (8) reviewed studies of documentary films to extrapolate findings on the objectivity of video decision aid tools. Both documentary films and video decision aids in healthcare depict reality as much as possible (otherwise they are fictional); thus, their approach seems appropriate. The researchers identified three biases that can seriously influence the contents of the decision aids (Table 1).

Volandes, et al. (8) shared the very same concern that we identified: How can we maintain the objectivity of the video decision aids to ensure that they help patients and their families are more informed to make better decisions for themselves? In other words, how can we effectively control the possibility of manipulation—an intentional effort to lead others in a certain direction (e.g., not to choose life-prolonging care or vice versa)?

Probably the most significant concern is stakeholder bias, especially when funding sources are among the stakeholders. For example, what if a researcher developing video decision aids is funded by a not-for profit organization that partners with a for-profit company whose mission includes reducing unnecessary healthcare costs? Can the researcher’s work definitively be free from the influence of the company’s agenda? Are the video aids developed by the research team designed solely to provide objective information for patients and their families, regardless of the nationwide or health system-wide cost reductions? What if the research and resulting video aids developed are directly or indirectly related to healthcare payers or even national or private health insurance?

We are not at all concluding that such cost reductions are bad or should not be pursued. Rather, we are saying the nominal or ostensible cause of video decision aids for ACP should reflect the true agenda of the stakeholders. Because the decision of the modality of an individual’s death is the last and most significant dignity in one’s life, no party can or

Table 1. Three Major Biases that Can Undermine the Objectivity of Video Decision Aids.

Bias	Concerns and examples
Stakeholder bias	Who should decide the content: clinicians, patients, or policymakers?
Selection bias	Considering the short length of the video, much of the recorded footage is ultimately discarded. Who decides what to discard and how?
Editorial bias	Video decision aids are also narratives that have their own point of view. How can we ensure objectivity?

Source: Volandes AE, Barry MJ, Wood F, Elwyn G. Audio-video decision support for patients: the documentary genre as a basis for decision aids. *Health Expect* 2013;16:e80-8.

should exert their influence on such a decision. Death in one's life requires the purest objectivity in information shared with a person making the relevant decisions.

Volandes, et al.'s (8) suggestion for dealing the identified biases is quite straightforward: include many different groups of people and versatile team members in the process. The underlying assumption of such an approach seems to rely on a system of checks and balances and maybe even collective wisdom. However, including different groups on a team can never be a sufficient panacea; rather, it is an oversimplification of the problems and an intentional negligence of the part of the researchers. Group thinking emerges and, more often than not, collective wisdom turns into collective mistakes.

Thus, many obstacles must be overcome to make video decision aids completely free of any overt interests or the underlying agenda of a certain group in the form of bias.

CONCLUSION: OVERCOMING OBSTACLES

Please do not get us wrong. We sincerely encourage medical society's efforts to develop visual aids and improve ACP. Yet someone must play the devil's advocate because ACP is a critical component in ensuring an individual's dignity when making important decisions related to end-of-life care. Video decision aids are by far the most effective supports for such planning if they work as intended. We are concerned that this sacred endeavor is littered with impure interests of healthcare business vultures, whose main focus is not patients and their family members; therefore, we have highlighted the importance of understanding stakeholders' input into video aids that can lead patients and their family in making decisions.

Many difficulties remain in creating informative video aids

of clinical procedures while maintaining absolute objectivity. However, difficulties can never justify ongoing ignorance or negligence. In the history of modern medicine, video decision support tools for ACP are in their infancy; they have huge room for improvement, and the improvement will certainly lead to a better quality of life for both patients and their families. With carefully designed visual decision support tools, we will lift the shadows from the complicated end-of-life care procedures and help patients live the last moments of their lives with dignity, which should be our true goals.

REFERENCES

1. KOSTAT: birth and death statistics [Internet]. Deajeon: Statistics Korea; 2006. [cited 2015 Dec 10]. Available from: <http://kostat.go.kr>.
2. ncc.re.kr [Internet]. Goyang: National Cancer Center; 2006 [cited 2015 Dec 10]. Available from: <http://www.ncc.re.kr>.
3. Hofstede G, Hofstede GJ, Minkov M. Cultures and organizations: software of the mind. 3rd ed. New York, NY:McGraw-Hill;2010.
4. Singer PA, Robertson G, Roy DJ. Bioethics for clinicians: 6. Advance care planning. CMAJ 1996;155:1689-92.
5. 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.
6. Gillick MR. Advance care planning. N Engl J Med 2004;350:7-8.
7. Simon JE, Ghosh S, Heyland D, Cooke T, Davison S, Holroyd-Leduc J, et al. Evidence of increasing public participation in advance care planning: a comparison of polls in Alberta between 2007 and 2013. BMJ Supportive & Palliative Care. In press 2016.
8. Volandes AE, Barry MJ, Wood F, Elwyn G. Audio-video decision support for patients: the documentary genre as a basis for decision aids. Health Expect 2013;16:e80-8.