

# Feasibility and Patient Perceptions of Video Declarations Regarding End-of-Life Decisions by Hospitalized Patients

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## Abstract

**Background:** A videotaped declaration by patients of their advance care planning preferences could be an opportunity to supplement advance directive forms and be a source of information for family, caregivers, and clinicians, yet research is needed to examine the content and acceptability of making declarations among patients.

**Objective:** To evaluate the content and acceptability of ‘video declarations’: the process of patients videotaping themselves describing their advance care planning preferences.

**Design:** We showed a brief video describing three approaches to end-of-life care and then invited participants to use an iPad to videotape themselves making a declaration about their wishes.

**Setting/Subjects:** Hospitalized patients from a large urban U.S. safety net hospital.

**Measurements:** We interviewed participants about the acceptability of the declaration process. Declarations were transcribed and coded by a team, with multiple stakeholder input.

**Results:** There were 16 participants; mean age was 60 (SD=14) years. One participant declined. Out of 15 declarations, most were able to express their wishes for CPR ( $n=12$ ) and intubation ( $n=13$ ). Participants frequently discussed their family structure ( $n=11$ ), religious/spiritual well-being ( $n=8$ ), legacy/dignity issues ( $n=6$ ), and physical symptoms ( $n=6$ ). Nine declarations had directives judged to be unclear. The majority (66%) thought that this process was quite a bit or extremely helpful.

**Conclusions:** Findings show that asking hospitalized patients to make videos describing their advance care planning preferences was feasible and acceptable. While the majority described their wishes around CPR and intubation, a fair amount of uncertainty remained. Further research is needed to support patients in describing their wishes clearly and test the effectiveness of video declarations to promote care concordant with preferences.

**Keywords:** advance care planning; underserved populations; video

## Introduction

ADVANCE CARE PLANNING is one means by which patients communicate with members of the healthcare team, family members, and friends about their preferences for end-of-life care. However, advance care planning can be complex. There is evidence that patients completing advance directives may have low comprehension of their options and provide inadequate detail about their wishes to their providers and families; furthermore, patients from racial/ethnic

minority groups and those with limited health literacy are at particularly high risk for not having advance directives.<sup>1–9</sup> Future research should seek models of care that address these factors.

Delivering care at the end of life that is consistent with the treatment preferences of seriously ill patients is a critical component of high-quality medical care.<sup>10–13</sup> There is an extensive literature of decision support tools that have been developed to help patients make informed decisions by clarifying benefits and risks for a wide variety of medical

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interventions.<sup>14,15</sup> Video is an increasingly utilized health-care information technology, which can improve decision making by providing visual information to capture complex medical and emotional scenarios.<sup>16,17</sup> The use of video decision support tools also has the potential to better inform patients by improving the quality and effectiveness of patient–physician communication.

An innovative use of videos in the advance care planning process would be for patients to document their own goals of care and advance care planning wishes. Such video declarations could (1) assist patients, families, and providers in characterizing patients' wishes in advance directive forms; (2) help clinicians and family members understand how to apply a patient's advance directive to a given clinical situation; and (3) be accessed at a later time if/when the patient may not be able to communicate and direct care in collaboration with providers. Observing an individual express their preferences for advance care planning on a video declaration also has the potential to be perceived as more trustworthy by family members compared to a standardized form. Before these applications to clinical care can be realized, research is needed about video declarations to better understand their feasibility, including the content of the videos and their acceptability to patients. Recent research by Mirarchi et al. evaluated whether videos would increase consensus in decision making among providers reviewing information in simulated scenarios. They found that adding video testimonials/messages of hypothetical patients to Physician Orders for Life-Sustaining Treatment (POLST) and living will documents resulted in increased consensus for code status and resuscitation decisions versus POLST and living wills alone.<sup>18</sup> To our knowledge, there has not yet been an investigation of the feasibility of video declarations conducted by patients. Thus, there is a gap in the literature for research that examines the feasibility of having actual patients produce their own video declarations, which would yield important information about the utility of these videos in real-life clinical settings.

The objective of this pilot study was to examine the content and acceptability of video declarations made by hospitalized patients at a large urban U.S. safety net hospital. Findings from this study will be used to refine our video declaration procedures and inform the development of a larger trial in which the effectiveness of video declarations to facilitate communication of advance care planning between patients and family and medical providers will be examined in clinical settings.

## Methods

### Setting and participants

We recruited hospitalized patients from Medicine admissions at Boston Medical Center, a large urban safety net hospital, for participation. A research assistant identified potentially eligible patients by speaking with attending physicians and nurses on medicine inpatient units and asking them to recommend potentially eligible patients (i.e., speak English, 21 years old or older, not on contact precautions, and not blind, deaf, or unable to give consent due to mental status). A nurse then approached patients to ask if they would be willing to speak to the research team. If the patient agreed, the research assistant entered the room to describe the study. Written informed consent was obtained from all participants.

The study protocol was approved by the Boston University Medical Campus Institutional Review Board.

### Data collection

We began by conducting an interviewer-administered survey [prevideo survey]. Then, a qualitative interviewer showed the patient a six minute video describing three general goals of care approaches: Life-Prolonging Care, Limited Medical Care, and Comfort Care.<sup>19</sup> At the start of the study, we were flexible on showing this video if we felt the participant needed further information about goals of care, yet we determined early on to show this video to all participants. Thus, the first two participants were not shown this video. After viewing the goals of care video, the interviewer read a brief script inviting the patient to make a video of him or herself describing their advance care planning preferences and used the iPad as a video recording device for this purpose. When the recording was complete, the interviewer played the video for the patient to see if they felt it accurately represented their wishes and/or if they would like to refilm their declaration. The patient was able to refilm as many times as they wanted. Afterward, the interviewer asked a series of open-ended questions about the participant's experience [postvideo survey].

### Measurements

The prevideo survey contained questions adapted from surveys used in other studies.<sup>20,21</sup> First, we asked questions about demographics, including age, race/ethnicity, education, marital status, and religious affiliation. A knowledge assessment contained six questions, and patients were scored on the total number correct. It included mostly true or false questions, including *Cardiopulmonary resuscitation (or CPR) is a medical procedure that is done on patients whose heart stops beating in an attempt to restart their heart*. Preferences for end-of-life care included questions regarding the patient's preference for life-prolonging care, limited medical care, or comfort care; preferences for CPR and ventilation; and decisional conflict (*Now I would like to ask you how you feel about your decisions. Do you feel sure about what to choose?* Responses: yes, no, or not sure).

The postvideo survey contained questions rated on Likert scales about patients' experiences with making their video, after which the interviewer asked the patient to expand on their answer. Questions included: *Was it helpful for you to make this video?*; *Was it easy for you to make this video?*; *Would you recommend that others make a video like this one?* with five responses ranging from "not at all" to "extremely"; and two open-ended questions: *Who would you recommend this to?* and *Who would you like to see your video?*

### Data analysis

Quantitative data from the pre- and postvideo surveys were examined using descriptive statistics. Qualitative data were obtained from both the content of the patients' video and responses to the open-ended questions on the postvideo survey. Using a narrative research qualitative inquiry approach, we examined the content of the videos to describe the participant's perceptions around advance care planning.<sup>22</sup> Our approach to narrative research included collection and analysis of both participants' lived experiences and predictions of

TABLE 1. SOCIODEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS (N=15)

Characteristic	n (%)
Age, mean years (SD)	60.1 (14.6)
Gender, male	8 (53.3)
Hispanic ethnicity	2 (13.3)
Race	
American Indian/Alaskan Native	1 (6.6)
Black or African American	5 (33.3)
White	5 (33.3)
More than one race	2 (13.3)
Other, specify	2 (13.3)
Education	
Never attended school or kindergarten only	0
Elementary, grades 1–8	1 (6.6)
Some high school, grades 9–11	2 (13.3)
High school graduate, grade 12 or GED	6 (40)
Some college or technical school	4 (26.6)
College graduate	1 (6.6)
Post graduate, masters, PhD	1 (6.6)
Religious affiliation	
Catholic	8 (53.3)
Christian noncatholic denomination	7 (46.6)
All others	0
Marital status	
Married or with partner	5 (33.3)
Widowed	2 (13.3)
Divorced	2 (13.3)
Single, not widowed or divorced	6 (40)
Self-rated health	
Excellent	0
Very good	2 (13.3)
Good	3 (20)
Fair	3 (20)
Poor	7 (46.6)
Had a prior advance directive conversation	
Yes	9 (60)
No	6 (40)
Not sure	0
Advance directive conversation with	
Healthcare worker	2 (13.3)
Family and/or friends	4 (26.6)
Both	2 (13.3)
Other	1 (6.6)
Have advance directive	
Yes, living will	0
Yes, healthcare proxy	5 (33.3)
Both	2 (13.3)
MOLST <sup>a</sup>	0
No	7 (46.6)
Not sure	1 (6.6)
Knowledge about advance care planning	
Total number correct out of 6, mean (SD)	3.6 (1.2)
Preferences <sup>b,c</sup>	
Life-prolonging care	6 (40)
Limited medical care	1 (6.6)
Comfort care	9 (60)
Not sure	0
Receive CPR	
Yes	12 (80)
No	2 (13.3)
Not sure	1 (6.6)

(continued)

TABLE 1. (CONTINUED)

Characteristic	n (%)
Ventilation	
Yes	8 (53.3)
No	6 (40)
Not sure	0
Decisional conflict <sup>d</sup>	
Yes	12 (80)
No	1 (6.6)
Not sure	1 (6.6)

<sup>a</sup>%s may not add to 100 due to missing data.

<sup>b</sup>As has been done in most states, Massachusetts has adopted a uniform order system for advanced care planning to be respected across all sites of care. While most states call this program POLST, in Massachusetts this is called MOLST. MOLST dissemination has been supported with mandatory education requirements for licensure. In accordance with Joint Commission requirements, clinicians are instructed to ask all patients on admission to the hospital if they have a healthcare proxy and if they are DNR (Do Not Resuscitate) or DNI (Do Not Intubate).<sup>25</sup> However, there is no formal process for when, how, or for whom MOLST forms are completed. This is at the discretion of each clinician.

<sup>c</sup>n = 16 because one participant selected two preferences.<sup>d</sup>“Yes” answers indicate less decisional conflict.

CPR, cardiopulmonary resuscitation.

what they would want in the future. To examine the videos, we began by transcribing the patient-recorded videos verbatim. Drawing from an existing conceptual framework of palliative care<sup>23</sup> and integrating additional concepts from a subset of transcripts, one team member (L.M.Q.) created a preliminary coding framework and reviewed it with team members. To enhance the trustworthiness of our analysis,<sup>24</sup> we held two peer debriefing meetings to review the coding framework and analysis decisions with team members who had different but important perspectives on advance care planning. Peer debriefers included team members, which included primary care physicians, the director of the palliative care service at the hospital, a patient navigator, and a palliative care nurse practitioner with graduate training in religious studies. This group was shown the transcripts and the codes applied and were asked for their feedback. After several iterations of adding new codes, collapsing coding categories, and deleting codes, a final coding framework was created. A systematic team-based approach was then undertaken by three team members who coded all video transcripts (L.M.Q., J.E.M., P.B.V.), and any discrepancies were resolved through team discussion. Codes were entered into NVivo version 11 qualitative software to assist in data management.

The qualitative interviewer (L.M.Q.) recorded patients' responses in shorthand at the time of the interview onto the postvideo survey, and these were later entered into a database. Two team members (L.M.Q. and J.E.M.) examined these responses and summarized themes. Responses were initially examined according to patients' preferences for CPR and intubation, but responses did not appear to differ substantially. Thus, responses are combined for all participants below.

## Results

Sixteen participants were enrolled, with one participant who declined to make their own video after watching the goals of care video because they thought making their own

TABLE 2. SUMMARY OF THEMES AND ILLUSTRATIVE QUOTATIONS FROM THE VIDEO DECLARATIONS OF HOSPITALIZED PATIENTS<sup>a</sup>

<i>Category</i>	<i>Theme</i>	<i>n</i>	<i>Illustrative quotation</i>
Advance care planning	Life-prolonging care	2	“I would like prolonged care. Life-term prolonging care which means if my heart were to stop beating I would want CPR, if I couldn’t breathe, I would like to be on a respirator.” Participant M (44, Female)
	Limited medical care	4	“I am thinking that limited care is an approach that I thought, in the beginning when I first heard the video, was something that I wanted. But in hindsight I see that this approach won’t work for me.” Participant F (63, Female)
	Comfort care	5	“I don’t know, I’ve had second thoughts though. I thought I was going to be resuscitated and all that but upon watching this video I think I’d prefer to go the comfort route.” Participant G (62, Male)
	CPR	13	“I would like to be revived by CPR—in that way.” Participant I (41, Male) “Interviewer: So if you were to get very sick, would you want chest compressions...” Participant: “No” Participant H (70, Female)
	Breathing tube	13	“I prefer to, if possible, to avoid the [motions to his mouth], being intubated.” Participant N (66, Male)
	Unknown/unclear	1	“I’d prefer to live as long as I can. The limited care with a measure of prolonged care is what I prefer for my life.” Participant F (63, Female) “...unless it was something very easily corrected I’d want that to be the way of my life.” Participant G (62, Male) “I would also like comfort measures if that was necessary to keep me alive” Participant M (44, Female)
Acute issues	Mental health symptoms & addiction	3	“And I was fine when I was on the street tellin’ you that I was doing cocaine, smoking it I could function. Stop doing it I can’t function.” Participant E (67, Male) “Tomorrow is the day I get out of the hospital and stay clean.” Participant K (68, Male)
	Physical symptoms/ function	13	“My heart is a pretty good ticker. My blood pressure is wonderful. My weight’s up though. My weight is up. I do have fluid in my knees, my legs.” Participant C (59, Female)
	Prognosis	3	“I’ve been told I have less than two years to live” Participant E (67, Male)
Psychosocial issues	Insurance concerns	1	“But as far as death, I don’t have medical insurance for death. What I have is nothing.” Participant C (59, Female)
	Family structure/ history	20	“...if I am sick, yes I would like my families and friends to know what is going on.” Participant J (49, Female) “I’d like to be there for my three children, they’re my world and if I’m gone then they don’t have anybody. They have my family but they don’t have me.” Participant D (29, Female)
	Caregiver support	2	“But the only one that will, uh, go by my wishes is my sister. My sister [name], that’s the only one. She will go by my wishes” Participant A (67, Male)
	Financial concerns	2	“The rest of ‘em, they’ll be hollerin’ about money. Too much money to ship the body all the way down South.” Participant A (67, Male)
	Knowledge	3	“...the intelligence I have, I’m not a dumb person.” Participant E (67, Male) “And because I don’t know and I don’t believe that a person knows what’s going on...” Participant L (72, Female)
	Patient provider interactions	5	“And I have trust and faith in the doctors here because I have been here quite a few times.” Participant N (66, Male)
	Remorse/making amends	7	“... I’m sorry for everything I’ve put them through. It wasn’t intentional.” Participant D (29, Female)
After death wishes	Funeral planning	5	“Spread my ashes in Atlantic Ocean.” Participant B (56, Male)
	Organ donation	3	“And I would like to donate my organs” Participant M (44, Female)

(continued)

TABLE 2. (CONTINUED)

Category	Theme	n	Illustrative quotation
Existential and spiritual issues	Meaning, legacy, dignity	12	<p>“Anything I can do, I would be thankful for being able to do it and I am thankful for this opportunity, pray that maybe in some way somehow it will help someone else. Thank you.” Participant L (72, Female)</p> <p>“I’d like to just go off into the sunset with a minimum of fuss.” Participant G (62, Male)</p> <p>“...[Recently] I had my first great great grandchild. I plan to be around to have a second one and I wanna be able to have some fun with them. If she comes up here she has a medical kit, she’s smart as a whip. She follows what the doctors do she sees the doctors come in with their stethoscopes she comes up and puts the stethoscope on my heart, it makes me cry.” Participant E (67, Male)</p>
	Hope	2	<p>“... hopefully I’ll get through it and be there for you guys.” Participant D (29, Female)</p>
	Religious and spiritual well-being	16	<p>“Because if I stop breathing the good Lord let me stop breathing. I just rather go home to the Promise Land.” Participant A (67, Male)</p> <p>“If it’s my time to go it’s my time to go.” Participant G (62, Male)</p>

<sup>a</sup>Before making a video declaration, the interviewer said to the participant: “Imagine you were very sick and you weren’t able to talk to your doctors or family. We would like you to make a video about your wishes for medical care so your doctors and family can understand your wishes. Please try to be specific. For example, if your heart stopped beating would you want chest compressions? Would you want CPR? Or if you stopped breathing, would you want to be on a breathing machine? A respirator? I’ll show your video to you when you are done. If you aren’t happy with it, you can record it again. Do you have any questions for me before we get started?”

video would be too emotionally draining. Therefore, the demographic characteristics of the 15 participants who recorded a video are presented in Table 1. Approximately half were black/African American or more than one race, had a high school education or below, and all reported being from a Christian faith tradition. Approximately half of participants reported having had an advance directive conversation, which was spread among healthcare workers and family/friends, and having designated a healthcare proxy/living will or both. No participants reported having had filled out a MOLST form. While 80% reported a preference for receiving CPR, fewer (53%) reported a preference for intubation. The majority reported feeling sure about these decisions (80%).

Average video length was 3:10 minutes. Results of coding the video transcripts are presented in Table 2, along with quotations selected across a range of participants to illustrate the theme. Relating to advance care planning themes, patients generally included their wishes for receiving CPR or intubation on their video. Patients referred to life-prolonging care, limited medical care, or comfort care less frequently. However, a substantial number of instances ( $n = 18$ ) occurred in which we were unable to clearly determine the advance care planning theme the patient was discussing on the video as indicated in the unknown/unclear row. This code was applied whenever we determined that a statement made by the patient was not clear enough to guide a clinical decision. Although primed beforehand to discuss advance care planning, themes having to do with acute medical and psychosocial issues, wishes for after death, and existential and spiritual issues came up frequently. The most common themes were related to physical symptoms and function; family structure and history; meaning, legacy, and dignity; and religious and spiritual well-being.

Results from the postvideo survey and interview demonstrated that the process was generally positive. The majority found the video declaration process to be extremely or quite a bit helpful ( $n = 10$  out of 14), easy ( $n = 7$  out of 14), and were

likely to recommend it to others ( $n = 11$  out of 13). Note that one patient had trouble assigning a Likert scale response to all three of these questions, and one additional patient could not provide an answer to the ‘recommend to others’ question; in these cases only responses to the verbal follow-up questions were recorded. Those who considered the video declaration process to be helpful indicated that the process helped them to consider their mortality and face reality about their current medical condition and consider the impact of their death on their family. Being put front and center and expressing their wishes in their own voice was also seen as a positive aspect, with video being better than expressing wishes through phone calls or in text. Those who remarked that making the video was easy expressed that they were a convenient sample to participate since they were already in the hospital. Those who recommended this process remarked that video declarations could help others decide what to do.

Although less frequent, some patients rated the process less positively in their Likert scale ratings and verbal responses. For example, one patient who rated the helpfulness of this process as ‘a little bit helpful’ indicated that the declaration started the process of formulating their goals of care and realizing that these decisions were not automatic. Those who thought the process was less easy indicated that they wished their appearance in the video was better, and they needed time to think and plan what to say. The fact that these issues are often not discussed and considering their mortality/facing reality made the process less easy. In terms of recommending this process to others, one patient who gave a rating of ‘neutral’ indicated that the video declaration process might not be appropriate for certain people depending on their illness or psychological state.

## Discussion

In this pilot study, 15 hospitalized patients were able to record a video declaration of their advance care planning

wishes after viewing a video describing goals of care options and brief instructional prompting. Examining the content of these videos revealed that while advance care planning topics were discussed, it was common for wishes pertaining to life-prolonging care, limited medical care, and comfort care to be rated as unclear by the research team. This may indicate that additional prompting and education about these topics may be necessary in order for patients to effectively convey their wishes in a video declaration. For instance, we would recommend that an educational session should be conducted before making a video declaration, whether in a video, individual, group visit, or other format. During or shortly after the creation of the video declaration, the interviewer could also ask prompting questions to enable the patient to clarify their wishes on the video or record a new video declaration. Topics of CPR and intubation were more clearly discussed. This may be because these topics may be more familiar to patients, more effectively presented in the video used to trigger the patients' recordings, may be less abstract than discussing general goals of care, and patients may have more developed opinions about them.

Interestingly, patients were equally interested in providing information about acute medical issues, psychosocial issues, after death wishes, and discussing existential and spiritual issues on their videos. While these issues are not technically germane to advance care planning decisions in acute medical situations, they are important to patients to discuss in the context of advance care planning. A main finding of the systematic review by Sanders et al. is that African Americans may prefer more informal discussions and ways of expressing their preferences for advance care planning,<sup>9</sup> something for which video declarations are particularly well suited. The topics might give additional context to family members and clinicians to understand the wishes and values of the patient and may facilitate decision-making during acute medical situations. For example, in our study, even in situations where it was unclear/unknown what the patient's specific preference was toward the three approaches to care, often the patient's stated values and other details and stories given outside of specific discussion of advance care planning preferences provided valuable information to assist in clarifying the person's wishes in a way that you cannot do with standardized forms. Concordance with patient wishes among patients who do and do not make a video declaration could be tested in a future trial.

Several limitations should be addressed. We had no mechanism to systematically measure the portion of patients who refused participation, so we cannot comment on this aspect of feasibility. It is possible that medical providers went beyond our listed eligibility criteria to recommend that we approach specific types of patients who may have been more amenable to speaking with the research team. This may have led to a sample of patients less representative of the general population of hospitalized patients. It is also possible that patients felt pressure to participate when a medical provider, often their nurse, approached them to see if they were interested in speaking to the research team about this study. Given that some patients indicated that they were not willing to speak to us at all or declined participation after we explained the study, we believe that patients generally felt comfortable declining participation. While participants found creating video declarations quite acceptable, the current pilot was done ex-

clusively in English and with a small group of patients. It is certainly possible that there are cultural norms in some populations that would make the process of a video declaration less acceptable. Similarly, the experience of making a video declaration could be influenced by the health status of the patient. The impact of such factors and the utility of video declarations for health providers, family, and friends would be excellent topics for future study.

Future work is needed to specify when, how often, and in which ways it is best to capture and share patient videos about their wishes to empower patients and help patients receive care that is concordant with their wishes. Conducting several video declarations over time would allow researchers to construct a chronology of advance care planning preferences which could also be examined using a narrative inquiry framework. While some people will be prepared to make a video declaration with minimal preparation, other people may benefit from more support and such details need to be examined. In addition, we judged some of the videos to have elements that were vague; this means that there likely are ways to improve patient's preparation for creating their video declaration. This also should be seen as an opportunity to promote beginning or continued discussion among patients, caregivers, and providers using patient's video declarations to expose areas where patients may have ongoing misgivings. Future work could include the development of a guide to accompany the video that could assist family members and providers in asking clarifying questions. In addition, videos can begin to capitalize on the technological advancements created by electronic media. With appropriate protections for privacy, social media sites can ease the process of providing patients with a copy of their video and enabling them to share it. This work provides the pieces necessary to further examine how to implement video declarations in clinical contexts in conjunction with legal documentation to empower patients, caregivers, and providers to provide care that is concordant with patients' wishes.

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### Author Disclosure Statement

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