What If I Get Seriously Ill? A Virtual Workshop for Advance Care Planning During COVID-19

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Abstract

The coronavirus disease 2019 (COVID-19) has brought public attention to questions regarding the type of care individuals would want to receive in the event of becoming suddenly critically ill. Advance care planning (ACP) is one way to help individuals and families address these questions. However, social distancing, stay-at-home orders, and hospital visitor restrictions have raised new barriers to facilitating these conversations. Here, we describe the implementation and evaluation of a novel, public-facing, 2-part virtual ACP workshop. Participants were recruited through electronic communication, and evaluations were collected through surveys administered after each part of the workshop. We found that utilizing a virtual format allowed us to reach a large, geographically diverse audience. Participants were likely to recommend the workshop to friends and family. There was no change in advance care planning engagement between the post-session surveys between the first and second parts of the workshop.

Background:
The coronavirus disease 2019 (COVID-19) has placed a new spotlight on human mortality and has focused national attention on questions about wishes for being hospitalized, transferring to the intensive care unit, and receiving mechanical ventilation in the event of becoming seriously ill.

Advance care planning (ACP) is one way to respond to the public's questions and concerns about becoming critically ill from COVID-19, and it has been noted as a critical component in the response to the pandemic.[1]

Getting patients and families to participate in ACP has historically been challenging.[2] Now, social distancing, stay-at-home orders, hospital visitor restrictions, and a transition to telemedicine have made communication more challenging and require novel methods for providing guidance to patients, families, and the public.

Here, we present a novel format for a public-facing, 2-part virtual ACP workshop and a practical paradigm for promoting ACP discussions during a pandemic.

Intervention:
The 2-part virtual ACP workshop was developed at Stanford Health Care, a suburban, academic health system in northern California affiliated with Stanford University. The workshops were supported through a partnership between the clinical Section of Palliative Medicine and the Department of Patient Experience.

A 2-part workshop, as opposed to a single educational intervention, was chosen based on findings that successful ACP interventions provide multiple interactions over time.[3] Content was modelled after an in-person 2-part ACP workshop that demonstrated improved advance directive (AD) completion.[4]

The first part of the workshop (P1) was a webinar consisting of a lecture-style presentation and question and answer (Q&A) session. Content included defining ACP, providing a framework for considering one's health status, values, and how those values inform healthcare decisions. Considerations for COVID-19 were discussed, including overall and ICU-based case-fatality rates based on data available at the time.[5,6] Finally, a 4-step process to start ACP was recommended including 1) talking with your doctor, 2) considering what matters most, 3) assigning a health care proxy, and 4) completing an advance directive.

The second part of the workshop (P2) consisted of a small-group discussion and Q&A session. Each follow-up workshop was limited to 30 participants. In these sessions, presenters reviewed commonly used terms in ACP and demonstrated how he/she would think through completing an AD using the PREPARE for Your Care AD.[7] A recording of P1 and the slides for both P1 and P2 can be found at http://med.stanford.edu/palliative-care/COVID19.html.

To recruit participants, we used email announcements in both a university-wide daily newsletter and our hospital's daily COVID-19 email. We tweeted about the event through the palliative care department and the health system's health library. The event was posted on electronic calendars for the university, hospital, and hospital employee wellness program. Participants were also recruited through several local religious organizations. Finally, 5768 patients who receive primary care at our institution received an invitation through the electronic patient portal. Participants in P2 were recruited from the email addresses of participants in P1.

Measures:

Participation in the workshops was tracked by monitoring the number of accounts logged in to each session. Post-session surveys were emailed after each session through Qualtrics (Qualtrics, Provo, UT). Surveys asked participants their age, race, ethnicity, and gender along with the likelihood of recommending the session to a friend or family member. Participants were also invited to provide qualitative feedback by responding to the following prompts, "the best part of this event was" and "this event could be improved in the future by." Advance care planning engagement was measured using a validated, 4-item Advance Care Planning Engagement Survey, which assesses readiness to participate in various ACP actions on a 5-point Likert scale (1=I have never thought of it, 2=I have thought about it, but I am not ready to do it, 3=I am thinking about doing it in the next 6 months, 4=I am definitely planning to do it in the next 30 days, 5=I have already done it).[8] We calculated a mean score for each ACP action using the 5-point Likert scale, and we calculated an overall mean ACP engagement score by averaging the scores across all ACP actions. We used 2-tailed t-tests to compare means.

Outcomes:

We conducted two initial webinars for P1 and seven follow-up workshops for P2. Five hundred seventy-seven (577) accounts registered for P1 and 413 (71.5%) accounts logged in to participate. From those participants in P1, 91 accounts (22%) participated in P2. Ninety-eight (24%) and 39 (43%) participants completed a post-session survey after P1 and P2, respectively.

The mean age of survey respondents in P1 was 62.4 years (SD 14.3, median 64, range 24-91). Age was not collected for participants in P2. Race, ethnicity, and gender was similar across P1 and P2. Of the respondents who provided information about race (n=86 in P1, n=35 in P2), ethnicity (n=57 in P1, n=21 in P2), and gender (n=93 in P1, n=37 in P2), the majority were white (83.7% in P1, 82.9% in P2), non-Spanish/Hispanic/Latinx/Mexican (91.2% in P1, 100% in P1), and female (80.6% in P1, 89.2% in P2).

The mean likelihood to recommend score for P1 was 4.0 (SD 1.4, median 5) and 4.2 (SD 1.4, median 5) for P2. The mean overall ACP engagement score after P1 was 4.0 (SD 0.8) and 3.8 (SD 0.7) after P2 (p=0.02). Based on the individual ACP Engagement survey items, mean scores were the highest for readiness to sign papers to name a surrogate medical decision maker (4.3 after P1, 4.1 after P2) and lowest for readiness to talk to a physician about future health care wishes (3.4 after P1, 3.2 after P2). There were no differences in ACP engagement between P1 and P2 (Table 1).

There were 83 comments about the “best part” of the initial webinar. The most frequently mentioned components included having a reminder of the importance of ACP (25%), presentation style of the presenters (22%), the presence of or the specific content discussed in the Q&A (14%), and getting information specific to COVID-19 (11%). There were 41 comments for “ways to improve” the webinar. The most common comments were wanting more information (32%), wanting more time (10%) and having more presenters to provide different perspectives (10%). Examples of comments are included in Table 2.

There were 34 comments about the “best part” of the follow-up workshops (P2). Most respondents appreciated hearing one of the presenter’s personal perspective on how she would complete her AD (65%). There were 15 comments for “ways to improve” that included allowing for more time and requests for additional information on a variety of specific topics.

Conclusions/Lessons Learned:

Based on the number of attendees and the positive qualitative comments from our post-session surveys, we found that a virtual 2-part ACP workshop was a successful way to engage the public about ACP during COVID-19. Notably, 22% of initial participants deepened their engagement through a follow-up workshop. In addition, our webinar was posted on YouTube and has accrued 718 views over approximately 3 months. After the turnout for our initial webinar, we shared our experience with colleagues at a neighboring institution, and their nearly identical webinar attracted 338 participants.

We found many benefits to using a virtual platform. First, we were able to reach a large, geographically diverse population, with participants from 48 U.S. cities across 16 states. Second, producing the virtual workshops required a smaller administrative effort compared to similar in-person workshops. Third, the virtual platform allowed us to provide educational content during stay-at-home orders. Fourth, easier access through an online workshop may have allowed the attendance of those who would otherwise not be able to attend an in-person event (e.g. homebound individuals). Fifth, the ability to ask questions anonymously may have provided a unique opportunity for more individuals to ask difficult questions compared to an in-person event.

Despite these benefits, there were challenges to hosting a virtual event. Using electronic methods for recruitment and requiring either phone or computer access likely limited the diversity of participants. The virtual format also limited the ability of presenters to “read the room” during the presentation, which made determining engagement challenging.

There were several limitations to the evaluation of this intervention. First, our results represent a single institution’s efforts and marketing strategy. Our ability to track the number of participants was restricted to the accounts that logged in, which could underrepresent the actual number of participants. Evaluations of ACP engagement were only performed after our interventions, and thus, we do not know if the high levels of ACP readiness among participants can be attributed to our intervention. Because this intervention was public facing, we were unable to track completion of ADs or documentation of ACP in an electronic health record.

Future endeavors could include evaluating participants ACP engagement both prior to and after participating in the webinars, tracking participants' completion of ACP documentation or ADs in the electronic medical record, and targeting a more diverse participant population.

In conclusion, a public-facing, 2-part virtual ACP workshop was able to reach a large, geographically diverse population and participants found many benefits to participating during the COVID-19 pandemic.

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Table 1. Advance Care Planning Engagement*

Advance Care Planning Task	**P1** **Mean (SD)**	**P2** **Mean (SD)**	***p-value***
Readiness to sign papers naming a medical decisions maker?	*N=98* 4.3 (0.9)	N=39 4.1 (0.9)	p=0.5
Readiness to talk to medical decision maker about wishes?	*N=98* 4.2 (1.0)	N=39 4.1 (0.9)	p=0.5
Readiness to talk to MD about wishes?	*N=97* 3.4 (1.2)	*N=38* 3.2 (1.1)	p=0.3
Readiness to sign papers about your wishes?	*N=98* 4.1 (1.1)	*N=39* 3.8 (0.9)	p=0.3
Overall Advance Care Planning Engagement	*N=97* 4.0 (0.8)	*N=38* 3.8 (0.7)	p=0.2

P1 = Initial webinar, P2 = Small-group discussion

*1 = I have never thought of it, 2 = I have thought about it, but I am not ready to do it, 3 = I am thinking about doing it in the next 6 months, 4 = I am definitely planning to do it in the next 30 days, 5 = I have already done it

Table 2. Sample Comments from Part 1 and Part 2 of the Workshops

	The best part of the event was:
P1	*"I noted how the presenters used very compassionate, understanding language. Appreciated that it addressed current situation. Questions at end were helpful: good that coordinator selected those with multiple or more general usefulness, rather than giving time to someone with an important but ultra-specific question."* *"I finally got around to completing my advance health directive because of this event. I'd been meaning to but this was just the push I needed."* *"Overall, I thought it was done well and the fact that it was focused around COVID-19 made it very timely. I enjoyed the Q&A because many of the questions were questions I had."*
P2	*"Hearing the presenter talking through the form and vocalizing the different factors that she used to weigh into her decisions, in addition to balancing family situation and spouse preference. I really appreciated the candor and sensitivity that both presenters brought to the sessions."* *"I think it was really helpful to hear someone talk about how they would actually make these personal decision[s] and what they would need to do to feel comfortable making them."*
	This event could be improved in the future by:
P1	*"We want to better understand, in more detail, the long-term consequences of extended intubation and sedation that characterize the treatment of the more severe cases."* *"Please add an attorney to your panel to answer the legal questions about the AHCD form, that was asked during Q&A."* *"For those questions that went unanswered, consider answering them on your website."*
P2	*"Perhaps more discussion and ideas about choosing a decision maker for single people or those who don't feel their family members may be up to playing that role."* *"I'm usually very critical, for example, I barely remember the first seminar presented about the topic, but this particular workshop was very helpful and well done. Maybe there could have been a little discussion about how to make it legal and where to put it once completed, although I notice in the paperwork itself it goes into that a bit."*

P1 = Initial webinar, P2 = Small-group discussion