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Feasibility of a Webinar for Coaching Patients With Chronic Obstructive Pulmonary Disease on End-of-Life Communication

Lynn F. Reinke, PhD, ARNP^{1,2}, Randall G. Griffith, DNP, RN², Seth Wolpin, PhD, RN², DorAnne Donesky-Cuenca, PhD, ARNP³, Virginia Carrieri-Kohlman, DNS, RN³, and Huong Q. Nguyen, PhD, RN²

¹Department of Veterans Affairs, VA Puget Sound Health Care System, Health Services Research & Development

²University of Washington, Seattle, WA

³University of California, San Francisco, CA

Abstract

Rationale—Previous research has shown that patients with chronic obstructive pulmonary disease (COPD) desire conversations about end-of-life wishes. However, most clinicians do not initiate these discussions. We explored whether educating patients via Web conferencing (webinar) would equip them with knowledge and skills to engage in conversations about end-of-life care.

Results—Prewebinar, 6 of the 7 patients had completed advanced care planning forms but only half had shared these with their clinicians. Most patients felt confident about discussing end-of-life preferences. At 3 months, all participants had taken further action on end-of-life planning. Five felt the webinar was an acceptable option if unable to participate in person. All patients voiced that adding a video stream would have promoted interaction in the context of these sensitive conversations.

Conclusions—This pilot project demonstrated that a webinar to educate patients on end-of-life communication was acceptable for the majority of patients. Improvements in audio and video bandwidth may facilitate more interaction among virtual participants. This may be particularly useful for patient education on sensitive topics.

Keywords

webinar; end-of-life communication; chronic obstructive pulmonary disease; patient education; advanced care planning; technology

Introduction

Chronic obstructive pulmonary disease (COPD) is the fourth leading cause of death in the United States and in 2005 was responsible for more than 120 000 deaths.¹ By the year 2020,

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Corresponding Author: Lynn F. Reinke, VA Puget Sound Health Care System, University of Washington, 1100 Olive Way, Suite 1400, Seattle, WA 98101, USA reinkl@u.washington.edu.

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COPD is expected to be the third leading cause of death in the United States.² Despite the progressive nature of COPD, less than 20% of patients with COPD have advance directives³ and less than one third have discussed their end-of-life wishes with their clinician.⁴

There is a growing trend to encourage end-of-life planning for all patients regardless of diagnosis or stage of disease. Reducing unnecessary or ineffective care and care that may conflict with patient wishes are some of the benefits of end-of-life care planning.^{5–7} Gaps in patients' desires for care at the end-of-life and what they actually receive are well documented,^{5,8,9} yet there is little research to improve end-of-life planning for patients with COPD. Studies have found that 55% to 75% of patients with COPD would elect not to be put on a ventilator if there were little hope of recovery.^{9,10} Despite these findings, patients with COPD are more likely to die while receiving aggressive treatments such as mechanical ventilation than patients with other life-threatening illnesses.⁵ Curtis and colleagues found that physicians often fail to discuss prognosis and what dying may be like with their patients with COPD as well as with family members of their patients.¹¹

Advanced planning and communication about end-of-life care is critical for patients with COPD to ensure concordance of treatment goals. However, few studies have investigated the potential benefits of empowering patients with COPD to initiate discussions about their end-of-life wishes with their clinician.^{12,13} Thus, research to investigate novel interventions to achieve this goal is indicated. The purpose of this exploratory study was to test the feasibility and preliminary efficacy of an interactive Web-based seminar to equip patients diagnosed with COPD with the knowledge and skills to engage in conversations about their end-of-life care wishes. Results will be used as a foundation for larger studies on the effectiveness of using communication technologies to facilitate end-of-life communication-coaching for patients who are geographically distributed.

Methods

Design

We used a single-group pre–post test study design to assess the effects of a webinar entitled, “Difficult Conversations” on 7 patients with severe to very severe COPD.¹⁴ The study was approved by the institutional review board at the University of Washington. Informed consent was obtained on all study participants prior to any data collection.

Sample

Recruitment letters were mailed to participants (N = 29) who completed an ongoing Internet-based dyspnea self-management study (R01 NR008938) and had expressed interest in receiving end-of-life planning information. Inclusion criteria included patients with severe to very severe COPD (GOLD Stage III–IV), previous participation in the dyspnea self-management program, who voiced interest in learning more about end-of-life issues, and access to a computer with broadband Internet connection with microphone and earphones. Exclusion criteria included dial-up Internet service, inability to establish an audio connection to the webinar application, and lack of comfort with the webinar format.

Procedures

Adobe's Connect Pro Live (CPL) was used as the webinar platform. The Web screen included the following features: a still picture of the discussion facilitator (LFR) and research assistant (RGG), an attendee list with names of all participants, a text chat tool, and a main presentation window. Live videos of the discussion facilitator and participants were not used to optimize the bandwidth for audio quality. A research assistant with computer and technical experience provided training via telephone to each participant on how to access

and navigate the webinar application to each 1 to 2 weeks prior to the webinar. The training sessions averaged 60 minutes per participant. Each participant was contacted again 1 to 2 days prior to the webinar to review their computer setup, login procedure, and use of the Web conferencing application. In addition, 3 open group sessions were conducted prior to the webinar to allow participants the opportunity to interact with each other. The total estimated time dedicated to training and technical troubleshooting for all participants was 15 hours.

Three days before the webinar, participants were e-mailed a link to the prewebinar Web survey described below. Upon completion of the survey, a link was provided to a New York Times article on end-of-life issues that participants were asked to review prior to the webinar.¹⁵ The webinar lasted 60 minutes and was recorded. At the conclusion of the webinar, e-mail links to the postwebinar Web survey were sent to participants.

The interactive webinar content was designed by an end-of-life content expert (LFR) and included 5 main topics: (1) importance of end-of-life conversations; (2) tools available to facilitate these discussions; (3) communicating end-of-life preferences; (4) feelings related to discussing end-of-life preferences; and (5) tips for initiating end-of-life conversations. Following the webinar, a list of Internet resources related to end-of-life issues was e-mailed to participants.

Measurements

Participants were asked to complete a prewebinar Web survey that consisted of 7 questions to assess their knowledge and attitudes regarding end-of-life issues. The survey used multiple-choice questions and Likert scales to measure the participants' current state of end-of-life planning.

A postwebinar Web survey that consisted of 23 questions was administered immediately after the webinar. The questions were designed to assess knowledge and attitudes about end-of-life issues discussed during the webinar and obtain feedback on the use of Web-conferencing technology. Question formats included short answer, multiple-choice, and Likert scales. Both surveys were developed by the investigators (HQN, RGG, LFR) and reviewed by a content expert (DDC) to assess for face validity.

All participants were contacted by phone 3 months after the Webinar to assess whether any changes had occurred in their end-of-life care planning. We asked the participants whether any changes had been made on advanced care planning forms, whether they had shared copies with anyone or discussed their end-of life wishes with anyone, or experienced any adverse emotional responses as a result of the Webinar.

Analysis

Descriptive statistics were used to describe the sample characteristics and the prewebinar and postwebinar results. No inferential statistics were performed due to the small sample.

Results

Of the 29 participants who were invited to participate in the study, 7 (24%) agreed to participate, 11 (38%) declined, and no response was received from 11 (38%). As seen in Table 1, the age of participants ranged from 64 to 72, 3 were female. All study participants were Caucasian, with the exception of 1 African American. More than half (57%) were educated at the college level or beyond. The average forced expiratory volume in 1 second (FEV₁) percentage predicted was 33%, indicating severe to very severe pulmonary disease.

Four participants were on supplemental oxygen therapy. All participants reported being comfortable with Internet browsing and had used the Internet for at least 1 year.

Prewebinar Results

The majority of study participants ($n = 6$) reported having a living will and 5 reported having an advance directive. Fewer used the Medical Durable Power of Attorney (MDPA; $n = 4$) and Physicians Orders for Life-Sustaining Treatment (POLST; $n = 3$) forms. One of the participants was not familiar with either of these 2 documents. Of the participants with completed forms, 5 had shared them with their family and significant friends and 4 had shared them with a designated spokesperson. Only 3 participants had shared the forms with their clinicians (Table 2).

End-of-Life Discussions

All participants reported having had end-of-life discussions with their family/significant friends and 6 participants had these discussions with their clinicians. The majority of participants ($n = 6$) said they were very confident discussing end-of-life issues with family/significant friends and their clinicians and felt their end-of-life treatment would be consistent with their wishes.

Other Information Related to End-of-Life Care

Four participants reported having all the information they needed about end-of-life documents to effectively discuss their end-of-life preferences. Other types of information participants expressed the desire to know more about to facilitate end-of-life care discussions included what dying may be like; end-of-life treatment options such as medications, intubation, oxygen, tube feeding, IV fluids; end-of-life care options such as palliative care, hospice, hospital care; and information about end-of-life financial issues such as insurance and out-of-pocket expenses.

Postwebinar Results—Immediate

Few changes were noted between the pre- and post-webinar survey results (Table 2). Confidence about discussing end-of-life issues with designated spokespersons increased for 2 participants. Two respondents noted having more fear and anxiety regarding end-of-life issues after the webinar. These 2 participants did not offer additional information on the rationale for their increase in fear and anxiety nor did they report adverse outcomes. A majority of patients ($n = 4$) reported that they would have liked to have more discussion in 3 areas: symptoms they may experience at the end of life, treatment options, and care options.

Qualitative Feedback Related to Interpersonal Dynamics

Most participants expressed that the webinar format lacked interpersonal dynamics, such as social presence and visual and aural communication cues, which are important features for the nature of this topic. One participant commented:

I'm not sure this technology is suitable for this type of discussion. One of the people at the beginning said that it was difficult to discuss something like this when you couldn't see people's faces and I think that was an excellent comment on the whole experience. It would have been interesting to hear different people's opinions and to be able to listen to what they were saying without so much effort.

Webinar/Technology Feedback

Overall, 5 participants felt the technology was very easy to use. All participants felt it was easy to log onto the webinar and felt it was moderate to very easy to get their microphone

working on the day of the webinar. Despite the extensive training and technical troubleshooting prior to the webinar, audio feedback was the most problematic technical issue, especially for participants who used a laptop computer. All participants felt that having a live video of the discussion facilitator and the ability of see other participants would have made it easier to them to follow the discussion. Six participants felt the webinar format was a very acceptable alternative if they were unable to participate in person.

Qualitative Feedback Related to Technical Difficulties

One participant reported difficulties with his microphone and said that by the time he was able to express his point, the discussion had moved on. This made him feel unable to actively participate. Another participant's microphone failed on the webinar day and was therefore limited to participating in the discussions via text chat. Comments from other participants included:

It didn't feel like it was a discussion because you couldn't tell who was speaking and you couldn't respond to questions.

I couldn't hear the other patients very well and missed too much of the moderators conversation. I was unable to read the information on screen.

Postwebinar Results—3-Month Follow-Up

Participants reported making no changes on advanced care planning documents related to their end-of-life wishes. However, all participants had taken some form of action since the webinar, including communicating with either their clinician or family members about end-of-life wishes, sharing copies of the documents, learning more about the death and dying process, and symptom management options. None of the participants reported any adverse outcomes as a result of the end-of-life content or discussions.

Discussion

The focus of this study was to determine the feasibility of using Web conferencing to coach patients with COPD on end-of-life communications. The literature suggests that educating patients about end-of-life issues improves end-of-life planning. However, participants in this study were well prepared regarding advanced planning as evidenced by the large percentage that had advanced directives prior to the webinar. This may account for the small changes in survey responses prewebinar and postwebinar. Interestingly, at the 3-month follow-up, all participants took some additional form of action by communicating with clinicians and family about their end-of-life care wishes and planning. This implies that patients are willing to initiate end-of-life conversations or follow-up to previous conversations with their providers and family members. Clinicians need to be aware of the importance of giving patients and families adequate time to think about these personal issues before making decisions and to revisit this topic on a regular basis.

Research has demonstrated that patients with COPD desire to have discussions about their end-of-life care with their clinicians,⁴ but these discussions rarely take place.¹¹ Barriers to this communication come from both patients and providers.^{4,12,16} Patients with COPD report a desire to focus on staying alive and maintaining hope.⁴ Providers express concern that discussing end-of-life may reduce hope.¹⁶ Catalysts for discussing end-of-life issues endorsed by patients include death of a family member or friend and trust in their physician. Physician-endorsed facilitators for these discussions include a long history of providing medical care to the patient and having a large number of patients with COPD.^{4,17} The qualitative comments shared by our study participants during the webinar and 3-month follow-up telephone call reinforce these barriers and facilitators. Placing emphasis on the

facilitators may promote improved end-of-life communication among patients, families, and providers.

Technical issues associated with Web conferencing, for example, poor audio quality, appeared to distract from the practical benefit associated with the discussion itself. Nonetheless, it appeared that participants saw value in the peer-to-peer interaction that took place during the webinar. One participant commented that the best part of the experience for her was “the few moments that I got to hear other folks like me discuss their particular situation and where they are in this process of life.” These findings confirm and are consistent with study findings related to the benefits of patient support groups.^{18,19} One participant commented that a series of interactive forums, rather than a single session, would allow an opportunity to establish rapport with their online peers and provide sufficient time for each person to express their viewpoints. Our study participants displayed a desire to use technology to expand their education and connect with others who share their condition. This desire should support continued efforts by researchers and practitioners to test various communication tools to facilitate patient education, engagement, and social networking and peer support.

Limitations

This study has several limitations. The sample size was small and the study lacked a control group. Participants were already well-versed on end-of-life planning, which may have affected the intervention results. Lastly, our participants represent a small segment of the COPD population, which was evident by their use of various forms of technology, high education level, and active roles they assume in their health care. Despite these limitations, the study used a novel communication format to educate patients on an important health care topic, end-of-life care planning.

Implications for Future Research

Our presentation focused on tools and documents to facilitate end-of-life planning such as advanced directives and medical durable power of attorney forms. The postwebinar survey revealed that in addition to these tools, the majority of respondents had a desire to discuss the experience of dying from COPD. Creating a safe forum and approaches to discuss this issue, including in-person and technology-mediated communication, are important areas for future research. In addition, the time-intensive participant training and technical troubleshooting required with currently available Web conferencing technologies deserves further consideration. The availability of newer and easier to use communication tools and increased data bandwidth in the coming years will no doubt facilitate richer virtual interactions on sensitive topics such as end of life among and between patients and health providers who are geographically distributed.

Conclusion

We were able to demonstrate that a novel approach of using Web conferencing for patient education on end-of-life communication is an acceptable and feasible option for patients with COPD. Despite the technical challenges, study participants were excited to explore the technology and appeared to enjoy the process. Further, they demonstrated a willingness to use technology to interact about an important, and very personal, health care issue. Additional research is needed to examine emerging communication tools to facilitate and extend the reach of patient coaching on end-of-life communications and other related patient self-management topics.

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Table 1

Sample Characteristics (n = 7)

Variables	n = 7
Demographics	
Age, years	68 ± 4
Female, %	3 (43%)
Race	
Caucasian	6 (86%)
African American	1 (14%)
Education	
College or more	4 (57%)
Body mass index (BMI)	27.3 ± 8.7
Disease severity	
FEV ₁ /FVC	0.42 ± 0.10
FEV ₁ % predicted	33 ± 15
Supplement oxygen	4 (57%)
Previous pulmonary rehabilitation	6 (86%)
Computer/Internet skills	
Comfortable W/Internet browsing	7 (100%)
>1 year Internet use	7 (100%)

Abbreviations: FEV₁, forced expiratory volume in 1 second; FVC, forced vital capacity.

Table 2

Pre-Post Webinar Results

	Prewebinar	Postwebinar
	N (%) or Mean (SD)	N (%) or Mean (SD)
How important is it to you to have discussions about your end-of-life preferences with the following people? ^a		
Your family/friends	9.3 (1.9)	9.6 (0.79)
Your health care providers	9.3 (1.9)	9.7 (0.49)
Designated spokesperson	7.8 (4.0)	8.6 (3.4)
How confident are you about discussing end-of-life preferences with the following people? ^a		
Your family/friends	9.9 (0.38)	9.6 (1.13)
Your health care providers	9.9 (0.38)	8.0 (3.8)
Designated spokesperson	8.1 (4.0)	8.7 (3.4)
Please rate your level of agreement with the following statements: I have a lot of fear and anxiety about my end of life		
Agree	0	2 (28.6%)
Neutral	6 (86%)	1 (14.3%)
Disagree	0	3 (42.9%)
Strongly disagree	1 (14%)	1 (14.3%)
I feel in control of my health care related to my end of life treatment		
Strongly agree	2 (28.6%)	1 (14.3%)
Agree	3 (42.9%)	4 (57.1%)
Neutral	2 (28.6%)	1 (14.3%)
Disagree	0	0
Strongly disagree	0	1 (14.3%)
I believe I can effectively communicate my wishes to my health care provider re: my end-of-life treatment		
Strongly agree	3 (42.9%)	2 (28.6%)
Agree	4 (57.1%)	4 (57.1%)
Neutral	0	0
Disagree	0	0
Strongly disagree	0	1 (14.3%)
I am confident that my end-of-life treatment will be consistent with my wishes		
Strongly agree	3 (42.9%)	2 (28.6%)
Agree	3 (42.9%)	4 (57.1%)
Neutral	1 (14.2%)	0
Disagree	0	0
Strongly disagree	0	1 (14.3%)
Were there topics you would like to discuss during the Webinar?		
End-of-life symptoms	3 (42.9%)	4 (57.1%)
Legal forms (AD, living will, POLST, MPOA)	2 (28.6%)	1 (14.3%)
Treatment Options	3 (42.9%)	4 (57.1%)
Care options (palliative care, hospice, hospital)	2 (28.6%)	4 (57.1%)

	Prewebinar	Postwebinar
	N (%) or Mean (SD)	N (%) or Mean (SD)
Financial information	3 (42.9%)	2 (28.6%)
If you were not able to participate in a face-to-face discussion on EOL planning, would a webinar be an acceptable format?		
Very acceptable option	NA	5 (83.3%)
Not an acceptable option	NA	1 (16.7%)

Abbreviation: EOL, end of life; NA, not applicable.

^aBased on 1- to 10-point scale.