Published in final edited form as:

Psychooncology. 2017 June ; 26(6): 866–869. doi:10.1002/pon.4167.

Development of an advance care planning paradigm for advanced cancer: person-centered oncologic care and choices (P-COCC)

Andrew S. Epstein^{1,*}, Eileen M. O'Reilly¹, Elyse Shuk¹, William Breitbart¹, Maheen A. Shah¹, Michele Ly¹, Rachel Tayler¹, and Angelo E. Volandes²

¹Memorial Sloan Kettering Cancer Center, New York, NY, USA

²Massachusetts General Hospital, Boston, MA, USA

Dear Editor,

Background

It is plausible that inquiring about individual values is appropriate and ultimately helpful to patients receiving treatments for advanced cancers. But, the values of these cancer patients upstream of end-of-life are not widely known [1]. Furthermore, no specific person-centered advance care planning (ACP) paradigm yet exists for standard use by the medical oncology community. With the development of a whole-patient-centered ACP initiative Person-Centered Oncologic Care and Choices (P-COCC), we therefore seek to address patient perspectives in addition to specific choices about disease-modifying and medically intensive treatments such as cardiopulmonary resuscitation. In this study, we report on the development and initial testing of the values questions that comprise the P-COCC paradigm, having hypothesized pre-study that these questions would be appropriate to patients with advanced cancer.

Methods

Study design

The overall study was planned in two successive parts, Part 1 and Part 2; both of which were approved by the Memorial Sloan Kettering Cancer Center (MSKCC) Institutional Review Board. Part 1 involved cognitive interviewing of 25 patients, and those results are presented in this report. Part 2 was designed to serve as a proof-of-concept, small-scale, single-blind randomized trial to measure acceptability, and other quantitative and qualitative effects, of P-COCC. As of the time of this manuscript submission, 75 participants in Part 2 are in the

*Correspondence to: Memorial Sloan Kettering Cancer Center, 300 East 66th Street, Room 1013, 10065 New York, NY, USA. epsteina@mskcc.org.

Prior presentations of this work

None.

Conflict of interest

The authors have declared no conflict of interest.

process of being randomized to Usual Care, Video, or Video and Interview (the P-COCC intervention arm).

Our P-COCC model (Figure 1) is a novel construct, proposing that each person with cancer is a unique, multifaceted being whose care is influenced by key internal person factors and external person factors. The P-COCC intervention itself is two-pronged: the introspective narrative targets the internal person factors and is generated from a semi-structured interview on questions being assessed in this study, resulting in a personal values narrative which is transcribed and reviewed with the patient, ultimately for their keeping. The goals-of-care video is a decision aid pertinent to the external person factors, and can also impact a patient's preferences for care.

Participants

Eligibility criteria included: advanced gastrointestinal (GI) cancer, English fluency, 18 years of age or older, a plan to be seen at least monthly at an MSKCC GI medical oncology clinic, and a physician-estimated patient life expectancy between 1 and 12 months. Exclusion criteria included psychiatric or cognitive disturbance which, in the physician's judgment, would preclude informed consent or adequate participation in the interventions.

Given that age (below or above 60 years) and performance status (high [Eastern Cooperative Oncology Group (ECOG) 0–1] or low [ECOG 2–3]) [2] might potentially influence illness experience and values, we aimed to recruit six patients in each of the four possible categories made up by these two variables (target sample size of 24 total participants). Six patients per group have been postulated [3] to be sufficient in reaching saturation in cognitive interviewing of homogeneous subjects about overarching themes.

Materials

Consented study participants were asked to assess the P-COCC questions for content, clarity, comfort, and tone. In total, the questions were assembled and grouped to address broad ACP themes of advanced cancer patients who regularly attend medical oncology clinics for visits with their oncologist and chemotherapy. The questions were also designed in order to be used in Part 2 of the study as a modified Dignity Therapy [4] program.

Of our ten questions, six were from a previously-honed [5] version of an ACP interview prototype, the Living Well Interview, to which we added additional interview questions: [1] one question about desired health care proxies, [2] two questions about our goals-of-care video, and [3] the Patient Dignity Question, which elicits what is essential for a health care team to know about a person [6].

The goals-of-care video that subjects viewed has known benefits [7,8], is 6 minutes long, and depicts the components of three broad health care categories, life-prolonging care, limited care, and comfort care. Figure 2 shows where the video fit into the interview.

Testing and analysis

Study staff conducted brief (approximately 20 minutes) audio-recorded one-on-one cognitive interviews in person with study participants in a private, quiet clinic space.

The study principal investigator (A.S.E.) and a co-investigator from the MSKCC Department of Psychiatry independently listened to and took notes on the audio records of subject responses. They then met with an additional co-investigator (E.S.) to discuss and revise the prompts for further use in Part 2 of the study. Changes were made according to cognitive interviewing standards [9] regarding questionnaire creation, including revision, omission and/or addition of new questions depending on participant responses.

Results

From October 23, 2013 to August 15, 2014, 25 patients with advanced gastrointestinal cancers were recruited and interviewed to assess the appropriateness of the P-COCC interview questions. The final set of questions generated, after data analysis, is shown in Figure 2.

The mean age of participants was 62 years, and 50% were female. Figure 3 illustrates the pool from which these 25 participants were drawn. The most common cancers represented in the final sample were pancreatic (50%) and colorectal (19%). Of the four planned groups of six participants each, only one participant was recruited into the group defined by being younger than 60 years old and with ECOG performance status 2 (this being an uncommon patient group in this usually chemotherapy-eligible adult GI medical oncology clinic). The other three groups had at least six participants each. Patients ultimately died within the predicted time interval from the time of consent (mean 9 months).

Ten participants (40%) indicated that some of the ten questions were uncomfortable to consider (median 3.5, range 1–6, no specific questions more than others), but that they were all nonetheless relevant and necessary for patients in their situation to be asked. Overall, to half the interview questions, participants suggested minor modifications, such as removing short segments of limited clarity, separating a question regarding concerns about illness and medical care into two questions, and keeping terminology consistent between that used in the video and in the questions about the video. There were no disagreements between members of the study team regarding these P-COCC question revisions.

Discussion

Through cognitive interviews with 25 patients with advanced GI cancers, we validated the appropriateness of questions about the values of people receiving treatment for these serious illnesses. These questions are part of our newly-created ACP paradigm P-COCC.

We adhered to standards of piloting behavioral intervention research [10]. Our study therefore serves as a methodologic building block towards the creation of an ACP program for patients being treated with chemotherapy for advanced GI cancers, which is a diverse and highly prevalent population in oncology. As an ACP program, P-COCC targets both the internal (person values) and external (care choices) patient realms; and, it strengthens the foundation laid by the previously-honed [5] version of an ACP interview prototype, the Living Well Interview.

Our study also has limitations: It was conducted at a single tertiary cancer center solely in patients with GI cancers; there was an underrepresentation of debilitated patients younger than 60 years old; and themes of pertinence to ACP in this population may have been missing.

The discomfort reported by several participants in this study reflects the delicate nature of having advanced cancer and discussing values regarding ACP in that context. Nonetheless, all these participants indicated that such questions were necessary and relevant. Additionally, approximately one third of patients who were eligible declined to participate in the study, which reflects known challenges in accruing patients with advanced cancer to behavioral research.

This initial (Part 1) testing has validated the ACP questions about patient values, which we believe are crucial for patients to reflect on and discuss with their healthcare teams, in order for the best care to be delivered to each person.

Acknowledgments

Harvey M. Chochinov, MD, for his thoughtful insights into the design of the trial and for his assistance with manuscript review. This research was supported by the National Palliative Care Research Center (2013 Career Development Award, Epstein) and also funded in part through the NIH/NCI Cancer Center Support Grant P30 CA008748 (MSKCC).

References

1. Matsuyama R, Reddy S, Smith TJ. Why Do patients choose chemotherapy near the end of life? A review of the perspective of those facing death from cancer. *J Clin Oncol*. 2006; 24(21):3490–3496. [PubMed: 16849766]
2. Oken MM, Creech RH, Tormey DC, et al. Toxicity and response criteria of the Eastern Cooperative Oncology Group. *Am J Clin Oncol*. 1982; 5(6):649–655. [PubMed: 7165009]
3. Guest G, Bunce A, Johnson L. How many interviews are enough? : an experiment with data saturation and variability. *Field Methods*. 2006; 18(1):59–82.
4. Chochinov HM, Kristjanson LJ, Breitbart W, et al. Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial. *Lancet Oncol*. 2011; 12(8):753–762. [PubMed: 21741309]
5. Schwartz C, Lennes I, Hammes B, Lapham C, Bottner W, Ma Y. Honing an advance care planning intervention using qualitative analysis: the Living Well interview. *J Palliat Med*. 2003; 6(4):593–603. [PubMed: 14516501]
6. Chochinov HM, McClement S, Hack T, Thompson G, Dufault B, Harlos M. Eliciting personhood within clinical practice: effects on patients, families, and health care providers. *J Pain Symptom Manage*. 2015; 49(6):974–980. e972. [PubMed: 25527441]
7. Epstein AS, Volandes AE, Chen LY, et al. A randomized controlled trial of a cardiopulmonary resuscitation video in advance care planning for progressive pancreas and hepatobiliary cancer patients. *J Palliat Med*. 2013; 16(6):623–631. [PubMed: 23725233]
8. Volandes AE, Paasche-Orlow MK, Mitchell SL, et al. Randomized controlled trial of a video decision support tool for cardiopulmonary resuscitation decision making in advanced cancer. *J Clin Oncol*. 2013; 31(3):380–386. [PubMed: 23233708]
9. Willis, GB. *Cognitive Interviewing: A Tool for Improving Questionnaire Design*. SAGE Publications, Inc; Thousand Oaks, CA: 2005.
10. Rounsaville BJ, Carroll KM, Onken LS. A stage model of behavioral therapies research: getting started and moving on from stage I. *Clin Psychol Sci Pract*. 2001; 8(2):133–142.

Key points

- No person-centered advance care planning (ACP) standard exists for use by the oncology community.
- We conducted cognitive interviewing with advanced cancer patients to validate questions to be used in future patient interviews that are part of testing of a novel ACP program.
- The ten questions address major biopsychosocial ACP themes for patients with advanced cancer. Two of the questions query impressions about a video decision aid pertaining to goals of care, which subjects also viewed.
- 40% of the 25 participants were uncomfortable responding to some of the questions but voiced that the questions were nonetheless all relevant and necessary for similar patients to be asked. Participants suggested minor wording modifications to half the questions.
- These questions about individual values are being studied in a randomized controlled trial of acceptability and other effects of our program, which addresses both these patient values, as well as specific medical choices.

Figure 1.
Person-Centered Oncologic Care and Choices Conceptual Framework

Goals

- 1) What experiences are most important for you to live well at this time in your life?
1b) In what way do you feel you could make this time in your life especially meaningful to you?

Concerns

- 2) What fears or worries do you have about your illness, if any?
2b) What fears or worries do you have about your medical care, if any?
2c) What needs or services do you need to discuss, if any?

Supports

- 3) Who or what supports you when you face serious challenges in life?
3b) What religious or spiritual beliefs, if any, help you deal with difficult times?
3c) If you were unable to communicate or make medical decisions on your own, which person or people close to you to you would you want to do that on your behalf?

[Goals-of-Care Video shown now]

Goals (relating to video)

Of the 3 broad health care options you saw in the video (life-prolonging versus limited medical care versus comfort care), which do you think would best fit with your current values about living well and why?

Concerns (relating to video)

What fears or worries about what you saw in the video do you have, if any?

Final Question: What does your healthcare team need to know about you in order to take the best care of you during this time?

Figure 2.
Person-Centered Oncologic Care and Choices Narrative Questions

Figure 3.

Study Flow Diagram. ECOG; Eastern Cooperative Oncology Group. *Was one of the eligibility criteria for the study but due to slow accrual due to this criteria, it was removed through an IRB-approved protocol amendment. **Not English proficient (N=17), patient not expected to be followed monthly at MSKCC (N=13), oncologist-estimated patient life expectancy not within 1–12 months (N=13), no MSKCC pathology confirmation of patient's disease (N=2), ineligible based on results of SPMSQ cognitive testing (N=1) or deemed by oncologist to be too cognitively impaired for study measures (N=1). ***Did not want to discuss topic ("too soon" and/or "want to stay positive") (N=21), did not want to watch video (N=6), were not interested in participating in research (N=2), did not have time to complete intervention (N=1), felt participation would upset family members (N=1).