Published in final edited form as:

Support Care Cancer. 2020 March ; 28(3): 1109–1119. doi:10.1007/s00520-019-04910-1.

A mixed methods analysis of patients' advance care planning values in outpatient oncology: Person-Centered Oncologic Care and Choices (P-COCC)

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Abstract

Purpose—Person-Centered Oncologic Care and Choices (P-COCC) combines an advance care planning (ACP) value-focused patient interview with a care goal video decision aid. Our randomized study showed that P-COCC was acceptable but increased participant distress, compared with video-alone and usual care study arms. This mixed methods approach explores the ACP values in the P-COCC arm and their relationship to the distress phenomenon.

Methods—Qualitative thematic analysis of the 46 audio-recorded P-COCC interview transcripts with advanced gastrointestinal cancer patients was performed by multiple reviewers. Quantitative (Likert scale) changes in ACP values were compared across study arms. ACP themes and value change were analyzed in participants with increased distress.

Results—Transcript analysis resulted in thematic saturation and identified eight distinct themes on ACP values relating to end-of-life wishes, communication needs, and psychosocial supports. Of 98 participants (33 P-COCC, 43 videos, 22 usual care) who completed the change in value measure, there was no difference detected with P-COCC compared with either video ($p=0.052$) or usual care ($p=0.105$) arms alone, but P-COCC led to a frequency distribution of more change in personal values compared with the other study arms combined ($p=0.043$). Among the subset of P-COCC participants with increased distress, there was no statistical relationship with change in values.

Conclusions—The ACP paradigm P-COCC both informs and supports patients in individualized, value-based decision-making. Distress is not associated with changes in ACP

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Compliance with ethical standards The study was reviewed by the Institutional Review Board at MSK.

Conflict of interest Dr. Epstein receives royalties from Up-to-Date for reviewing GI Medical Oncology and Palliative Medicine topic reviews. All other authors declare that they have no conflict of interest.

Publisher's note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

values and may be a necessary, at least transient, byproduct of discussing sensitive but pertinent topics about end-of-life medical care.

Keywords

Advance care planning; Cancer; Communication; Goals; Patient participation

Introduction

Advance care planning (ACP) is crucial in caring for patients with cancer, as it allows patients to reflect on and communicate their personal values to make the most optimally informed decisions for their future care, particularly at the end of life [1–3]. Previous data have demonstrated the impact of ACP on end-of-life healthcare utilization and outcomes: ACP discussions are associated with less receipt of life-sustaining measures and cancer-directed therapy, fewer hospitalizations and healthcare costs, and greater use of hospice services in the last weeks of life [4–7]. Despite its potential to improve goal-concordant care, ACP still does not occur frequently, and therefore, there remains a pressing need for high-quality ACP communication in clinical practice [8, 9].

Currently, there are several ongoing initiatives attempting to enhance ACP in oncology, as no gold standard ACP process exists [10–14]. Along with presenting end-of-life care options to patients and their caregivers, effective ACP discussions must elicit patients' values and preferences to facilitate medical decision-making. Value-focused communication strategies have been proven useful for the psychosocial well-being of patients with advanced cancer [15, 16] and are now being utilized in ACP research endeavors [17]. To this end, we developed the Person-Centered Oncologic Care and Choices (P-COCC) outpatient ACP model, which combines a video decision aid on end-of-life care options and an interview eliciting patient values regarding their goals, concerns, and support systems [18].

Our 3-arm randomized study recently showed that P-COCC (compared with either an informational care goal video aid alone or usual care) was acceptable but may lead to increased levels of distress in patients with advanced gastrointestinal cancers. In particular, mean distress scores (measured on a 0–10 scale at baseline and 1 month post-intervention) increased by 43% in the P-COCC arm, but decreased by 4% in the video-alone arm ($p = 0.03$, P-COCC vs video alone) and decreased by 21% in the usual care arm ($p = 0.04$, P-COCC vs usual care) [19]. To explore potential reasons for distress and to better understand the effect of our intervention on patients' values pertaining to ACP (i.e., ACP values), we performed a mixed methods analysis. We herein report the qualitative thematic content analysis of patients' interviews and quantitative assessment of change in ACP values. We further describe the relationship between the evolution of values, patient distress, and associated underlying ACP themes. We hypothesized that patients who were randomized to the P-COCC intervention, compared with patients in the other study arms, would have a greater change in personal ACP values and that such change might contribute to higher levels of reported distress.

Methods

Participant selection

English-speaking patients, ages 21 years or older, with advanced gastrointestinal (GI) cancers from GI medical oncology clinics at Memorial Sloan Kettering (MSK) were eligible for participation. The recruitment approach, eligibility criteria, and patient selection have been reported [19]. All participants provided written informed consent before enrollment.

Study design

We have previously described the full details of this randomized controlled trial, along with primary quantitative analyses on the acceptability of the P-COCC intervention and secondarily its effect on patient well-being and decisional conflict [19]. The study was reviewed by the Institutional Review Board at MSK.

Participants were randomly assigned 2:2:1 to the P-COCC intervention (value-focused patient interview with informational care goal video aid), video only, or usual care (no video or interview). Participants in the P-COCC arm and the video arm watched the same 6-min informational care goal video, which depicted three different end-of-life care options for patients with advanced cancer: (1) life-prolonging care consisting of CPR and mechanical ventilation; (2) limited care including cancer-directed treatments such as chemotherapy, but not CPR or mechanical ventilation; and (3) comfort care prioritizing management of symptoms. Only participants in the P-COCC arm were interviewed about their personal values by a research team member (who received formal coursework training at MSK in cognitive interviewing and had prior clinical research experience in discussing patients' goals in the context of living with serious illness), using eleven previously validated P-COCC value questions [18]. Of note, our P-COCC intervention discussions did not involve clinicians. To minimize bias, treating oncologists were not informed of the results of randomization for their patients and did not participate in the value-focused interview in the P-COCC arm.

A trained research assistant conducted all testing procedures for each study participant in a quiet private clinic space. Validated questionnaires pertaining to patient well-being were administered to participants in all arms at baseline and at follow-up intervals (1 month or sooner), with details and quantitative results published separately [19]. This included baseline and 1-month follow-up patient distress scores, measured using the NCCN Distress Thermometer scale [20, 21].

Data collection and procedures

Interviews with P-COCC participants were open-ended, semi-structured, and conducted in person [22–24]. Each interview contained the eleven validated questions [18] about goals, concerns, and support systems, all pertaining to participants' experiences as patients with advanced cancer, impressions of the video they had watched, and the decision-making process for their end-of-life care [19]. Participant responses guided the course of the interview and the types of probing questions used to further explore responses. A range of question types were used to elicit participants' beliefs and experience. Participants were

given sufficient time to provide answers to each question; additional time was allowed for clarification of responses and discussion of information as necessary. Interviews were audio-recorded and transcribed verbatim for qualitative thematic content analysis.

At the 1-month follow-up visit following consent, participants from all arms were asked to rate “How much your values about your illness (specifically your goals, concerns, and support systems) have changed since we originally contacted you about a month ago.” Response choices were quantified on a Likert scale as follows: a lot (0), somewhat (1), a little (2), and not at all (3). Those participants who expressed a change in values were asked with an open-ended prompt to describe what had changed and why. P-COCC participants were also asked what (if anything) was helpful about the value-focused narrative process.

Data analysis

A mixed methods approach with concurrent triangulation was employed to combine qualitative and quantitative analyses [25].

Qualitative—Inductive thematic analysis was used to analyze the interview data [22, 24], incorporating the use of multiple coders to ensure reliability and analytic rigor [26, 27]. The qualitative data analysis process consisted of multiple steps. First, research team members (including oncologists with experience in ACP) identified and reached consensus on key conceptual domains to guide transcript coding. Second, a two-person coding team, consisting of a research assistant and a qualitative methods specialist, independently coded the interview transcripts line by line with ATLAS.ti software [28] to achieve triangulation [23, 24, 29–32] and held consensus meetings to reach agreement on the development of code names, meanings, and application of codes to the interviews verbatim. Through this process, a foundational codebook was developed, with codes confirmed by an oncologist. Each coded transcript was reviewed for quality assurance by a research study assistant. Categorical data generated from the coding process was then applied into a framework to encapsulate the main themes from the patient interviews. This inductive approach was used similarly in a qualitative analysis of dignity therapy in patients with advanced cancer [15, 23, 24, 33, 34].

Following completion of line-by-line coding, a secondary analysis was performed. Focused research questions served to deductively facilitate categorization of codes to create code families, utilizing themes from our prior study investigating ACP impressions following video education about CPR [35]. For each code family, we used ATLAS.ti to generate patient quote reports consisting of verbatim content, coded with codes from each code family. A secondary analysis team consisting of two researchers independently reviewed each quote report and synthesized the content, to examine for recurring patterns across the texts. Finally, three reviewers, which included a clinical oncologist, each analyzed and compiled the data from related code families, to independently generate key themes. Three final consensus meetings were held to finalize distinct themes from the study. Reviewers compared individual thematic coding to arrive at a consensus. When individual thematic coding results did not match exactly, minor differences were reconciled during the joint review process. Thematic saturation was achieved with agreement on the overlap of themes and without the emergence of new themes from the coding data. The themes were then

ordered to cohesively describe the data, regarding the value questions about goals, concerns, and support systems.

Quantitative—Fisher's exact test was used to compare the frequency distribution, or pattern of spread, of the change in values for participants in the P-COCC arm, versus the video-only and usual care arms. The distribution of participants in the P-COCC arm with increased or decreased distress, relative to values change, was characterized with descriptive statistics. For the subgroup of P-COCC participants whose distress scores increased from pre- to post-intervention, transcripts were reviewed to identify and quantify thematic content.

Results

Sample

A total of 151 patients consented and were randomized 2:2:1 to the study arms, with $n = 61$ participants in the P-COCC intervention, $n = 61$ in the video-alone arm, and $n = 29$ in the usual care arm. Study arms were well-balanced with respect to baseline demographics [19]. Of the 61 participants randomized to P-COCC, 46 ultimately watched the informational care goal video and completed the value-based narrative interview. Therefore, a total of 46 interview transcripts were available for coding and qualitative analysis. For the change in value study measure, answers were obtained from 98 participants (33 P-COCC, 43 video alone, 22 usual care). Of the 33 participants in the P-COCC arm who completed the change in value measure, 28 provided both baseline and 1-month follow-up distress scores. Reasons for study participants not completing study measures have been described and are largely attributed to death or disease progression [19].

ACP thematic content analysis

From the 46 P-COCC interview narratives, 109 codes were generated and categorized into 15 value code families. Our analysis resulted in 8 distinct themes on ACP values relating to medical treatment preferences, communication needs, and psychosocial supports. These themes are described in detail with contextual participant quotes in Table 1. The 8 themes were as follows: (1) Participants selected end-of-life treatment options that aligned with their personal values and preferences; (2) participants expressed negative emotions to life-prolonging care; (3) the video provided most participants with sufficient information to make informed end-of-life care decisions; (4) participants expressed trust in their oncology teams; (5) concerns about illness and prognosis drove a desire for open communication and being understood; (6) relationships with loved ones provided meaning to participants' lives; (7) religion and spirituality enhanced inner strength and well-being; and (8) participants valued maintaining an identity, keeping agency, and living life outside of having cancer.

Evolution of values

From the 98 participants who completed the change in value measure, Table 2 depicts the distribution of participant responses per Likert score in all three arms. The frequency distribution of responses was not statistically significant ($p = 0.052$) when comparing P-COCC with the video intervention alone, and no difference was detected when comparing P-

COCC with usual care ($p = 0.105$). However, as our study was small and effectively pilot in nature, we performed a post hoc exploratory analysis to compare P-COCC with any intervention which did not utilize all of P-COCC's active components. To boost the sample size of such a reference comparison, we combined the video-only and usual care study arms to explore the potential difference between P-COCC and non-P-COCC approaches to ACP on participants' change in values. In this exploratory analysis, the frequency distribution of survey responses regarding change in values was significantly different across arms ($p = 0.043$). The pattern of spread in the P-COCC arm indicated more change in values when compared with the spread of the other two arms combined. This was partly due to (a) the more extreme distribution observed in the video arm, with most participants reporting either no change in values (58%) or that their values had changed a lot (28%), and (b) most participants in the usual care arm reporting no change in values (73%). Fewer participants indicated responses that their values did not change at all with P-COCC (39%) when compared with non-P-COCC (63%, or 41 of 65 participants in the video-only and usual care arms combined).

Table 3 provides representative quotes from participants who indicated change or no change of their values from all three arms, as well as P-COCC participant impressions of the helpfulness of the narrative process. Overall, participants who reported a change in their values discussed how engaging in a value-based interview and/or watching a video on end-of-life care options added transparency and increased their awareness for what to expect. These participants also reflected on cherishing their time and what remaining goals they sought to accomplish in life. For those who reported no change, participants expressed acceptance about their prognosis and feeling informed of their end-of-life options, indicating no major changes from the intervention caused them to question their values. P-COCC participants specifically reported that the process of reviewing a transcribed narrative from their audio-recording provided relief, guidance, and additional clarity for planning their end of life.

Relationship between values, distress, and ACP themes

The distribution of P-COCC participants with increasing, decreasing, and no change in distress, relative to the presence of values change, is shown in Fig. 1. There was no significant difference in the proportions of P-COCC participants with increased distress ($n = 14$) based on whether they experienced change in their values. The previously reported statistical increase in distress [19] appeared to be independent of the potential change in values. From the narratives of the 14 P-COCC participants with increased distress, thematic analysis demonstrated that nearly all preferred limited or comfort care at the end of life had a negative emotional response and expressed fear of life-prolonging measures (CPR and mechanical ventilation) as depicted in the video and identified their familial relationships and religious faith as sources of support.

Discussion

After our pilot study showed that our ACP paradigm Person-Centered Oncologic Care and Choices (P-COCC) was acceptable but was associated with an increase in patient-reported

distress [19], we herein employed a mixed methods approach to evaluate the thematic underpinnings behind patients' ACP values and to explore the effect of our intervention on values and distress. Our analysis identified 8 distinct ACP themes from P-COCC narratives. In addition, compared with the other study arms (usual care or video only) combined, P-COCC led to a frequency distribution of more change in personal values, with fewer patients reporting that their personal values did not change at all. Though patients randomized to the P-COCC arm had higher reported levels of distress, our data suggest that increased distress is not directly associated with change in values during the ACP process.

Our qualitative analysis provides important findings on what cancer patients prefer and think about when asked about their end-of-life treatment options, communication needs, and psychosocial supports. To our knowledge, this is one of the largest qualitative analyses on ACP values in patients with advanced cancer. Other qualitative studies have identified thematic impressions on end-of-life care and patient wishes from interviews exclusively [36–38]. Conversely, our prior work investigated cancer patients' impressions after only watching a video about CPR [35]. Our P-COCC qualitative data is unique because it reflects how patients think about their values within the context of receiving video information, which thereby imparts knowledge and perspective to guide introspection. From 46 patient interviews, the 8 ACP themes generated from our P-COCC intervention span a variety of pertinent topics. The ACP themes not only confirm that the video provided sufficient information for patients to make informed decisions but also indicate that patients prefer limited or comfort care over life-prolonging care at the end of life (Themes 1–3). Furthermore, our themes highlight the complex and meaningful relationships (e.g., with oncologists, family members, spirituality, self-identity) that patients value in life and as they relate to ACP. For example, patients expressed trust and overall satisfaction with their oncology teams, but simultaneously called for greater communication to address their concerns about their illness and prognostic uncertainty (Themes 4–5). Patients cherished their relationships with loved ones and their religion, while also placing importance on having control and enjoying the non-cancer-related aspects of their lives (Themes 6–8). In summary, the 8 themes that emerged from P-COCC highlight key abstract and practical components of high-quality ACP. We consider this to be a direct result of our combined approach of interviewing patients about who they are and what matters in their lives, in the context of their advanced cancer, while also providing them with video education on their end-of-life care choices. In doing so, P-COCC dovetails patient values with concrete medical information, with the hope that this will lead to informed, value-concordant decision-making.

Along with these qualitative findings, our data did not show a difference in the distribution of responses when patients were asked if their values had changed, when comparing P-COCC with either the video or usual care arm alone. As our sample size may have been too small to precisely compare P-COCC with either non-P-COCC arm separately, we performed an exploratory analysis to detect the potential impact of P-COCC compared with non-P-COCC interventions on participants' values. Specifically, the spread of responses from P-COCC participants demonstrated a greater change in personal values when compared with the spread of responses from the other two study arms combined. This observation, while subtle, may be suggestive of a possible effect of P-COCC on change in personal values

relating to ACP and warrants further study for validation. P-COCC participants who expressed value change indicated that both the video and narrative process (i.e., reviewing a personalized interview transcript) increased awareness of end-of-life options, led to acceptance of one's illness and potential outcomes, and provided relief by way of empowerment and solidification of one's value-based decisions. P-COCC both informed and supported patients in their decision-making, possibly doing so by changing patients' values and perceptions of their future end-of-life care.

ACP discussions held in the setting of prognostic disclosure are important but challenging, due to concerns for negative impact on emotional well-being. Discussions that occur when patients have progressed on one or more lines of chemotherapy do not increase sadness or anxiety [39], whereas prognostic awareness within weeks of diagnosis is associated with worse quality of life and mood, mitigated by active coping [40]. Additionally, ACP decision aids (e.g., online planning tools) do not induce anxiety or diminish hope [41]. Within this framework, our data show no clear association between distress and change in personal values pertaining to ACP. Yet, our data reveal that screening for distress may be essential, particularly when patients are asked to reflect upon and plan for their future medical care [19, 42].

Consistent with our prior work which emphasizes the concept of "necessary discomfort" [35], we believe that distress from P-COCC may therefore be a byproduct of engaging in a value-based interview while coping with disease-related emotions and processing information from the video about end-of-life care options. Although participants in our study found P-COCC to be acceptable, the increase in distress from P-COCC may have been driven by discussing personal values and sensitive but pertinent topics on end-of-life care with non-clinicians, an element which is unique to our ACP model. As ACP is considered a clinical process with most conversations occurring between patients, caregivers, and clinicians (oncologists or oncology nurse providers), the observed distress phenomenon may be partly explained by a lack of comfort and therapeutic alliance between P-COCC participants and the study research interviewer. That said, our review of P-COCC transcripts did not uncover this potential concern, and we purposefully designed our study with a non-clinician researcher conducting the value-based interviews, instead of patients' primary oncology teams, to maximize objectivity. In addition, though most participants from the P-COCC arm found the informational care goal video to be helpful, few reported a negative emotional response to watching the video, stating that they were not ready to partake in discussions about their end-of-life care in relation to the video's content. Finally, distress from P-COCC may be further influenced by thinking deeply about what adds value and meaning to one's life during the narrative ACP review process.

Our study has limitations. Besides those described separately [19], this was a single-institution study which exclusively enrolled patients with advanced gastrointestinal cancer. Second, selection bias may have influenced the themes generated, as we do not know the impressions of those patients who were not referred or who chose not to participate. These groups may have had different values pertaining to their end-of-life care. Nonetheless, for those patients who did participate, we achieved thematic saturation and used robust qualitative methodology. Third, though we quantified change in values, we cannot comment

on whether participants changed from wanting life-prolonging care to less aggressive measures at the end of life (although most P-COCC participants expressed a preference for limited or comfort care). Fourth, our study was small and may not have been powered to precisely detect differences between P-COCC and either the video-only or usual care arm, with respect to change in values. For this reason, we performed an exploratory analysis of P-COCC vs non-P-COCC approaches (combining video and usual care arms) on value change, and we acknowledge the limitations in interpreting such post hoc results, which require validation in the future. Lastly, we did not investigate the sustainability of distress and longitudinal end-of-life outcomes after engaging in P-COCC, to determine if distress reduced (or intensified) over time and if patients ultimately received value-concordant care.

In conclusion, this secondary analysis of the Person-Centered Oncologic Care and Choices (P-COCC) model highlights key advance care planning themes for patients with advanced cancer and its capacity to bring about change in personal values. The results from our study have potential implications for clinical practice in oncology and supportive care, in that these themes can be leveraged to guide high-quality value-based discussions and enhance end-of-life communication. Awareness of such themes can help create a communication framework, which can be used iteratively, to discuss with patients about what matters most to them in their lives and how this may directly relate to the cancer care that they are receiving. This will ultimately help support patients as they make optimally informed decisions for their current and future care. Our ongoing research is aimed at honing our value-focused communication strategies, which are in part built on these thematic findings. Our current research and clinical practice now implements an early and scalable value-based ACP intervention for all cancer types [43]. Future studies should evaluate the durable impact of such ACP communication models on patient well-being, end-of-life healthcare utilization, and value-concordant care.

Acknowledgments

We thank the patients and families, as well as the colleagues who referred patients to the trial. The colleagues include Drs. Geoffrey Ku, Yelena Janjigian, Leonard Saltz, Anna Varghese, James Harding, Zsafia Stadler, Diane Reidy, David Ilson, Neil Segal, Armin Shahrokni, Rona Yaeger, Sree Chalasani, Monica Shcherba, and Kenneth Yu.

Funding This study was supported by the National Palliative Care Research Center (through a 2013 Career Development Award to Andrew S. Epstein, MD). The research was also funded in part through the NIH/NCI Cancer Center Support Grant P30 CA008748.

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Fig. 1.
P-COCC participants' change in distress relative to change in values

Table 1

Themes on advance care planning (ACP) values

1. Participants selected EoL treatment options that aligned with their personal values and preferences.

Most participants preferred comfort care ($n = 17$) and limited care ($n = 8$) at the EoL. Five participants expressed that limited care would be their first choice, and they would later transition to comfort care as their health declined. Participants expressed flexibility and fluidity toward comfort and limited care options. Two participants supported life-prolonging care (LPC) due to the possibility of new and more effective treatments, wanting more time and living longer, and concern that doctors were incorrect in predicting life expectancy. These participants felt that LPC was worth the discomfort if it meant living long enough to see a cure. Lastly, a number of participants were undecided ($n = 12$); they felt that this decision was complicated and difficult to make. Two participants did not provide responses to indicate their EoL treatment preferences.

"This is the first time I've heard about those three, so I do not know much about them. The first one, definitely, I do not want that, the resuscitation, no. That's a no. I have to think about the limited care versus the comfort care. At this time, as I said, because it's the first time I've heard about them, I think the limited care sounds good... Maybe after a while, I might change and go for comfort." (349; female, 60, pancreas)

"Well, I guess limited medical care if it would be helpful in terms of making things better. If not, then it's the hospice care because I do not want to be an invalid and confined to a bed and unable to do anything. That's not my style" (271; male, 78, colorectal).

2. Participants expressed negative emotions to life-prolonging care.

Participants' negative emotional response to LPC was due to the fear of suffering that was evoked by LPC and being kept alive by "artificial" means. The discourse around LPC was one of being "stuck" in a diseased and dying body, of being kept alive but not truly living. These participants prioritized quality of life over extension of life, as they realized that their prognosis was terminal, and therefore LPC went against their personal values.

"The first option (LPC), it's definitely, no, at that stage, at that stage, clinging to that hope, which you might not even know any more that you are — designated to be that way, would be unthinkable right now. I think that almost a fear that this would happen as bad as being buried alive, the thought about that, being kept alive as long as machinery allows. And the scary thing is machinery today can do amazing things." (254; male, 54, gastroesophageal).

"Well, I certainly do not want to be on a ventilator and living more dead than alive. They're keeping you alive. But once your mental capacity is gone, I'm pretty much of the feeling that you are no longer living, period... The real fear is being on a ventilator, and they give you CPR, and your brain is already flat-lined. That's not life." (309; male, 67, gastroesophageal).

"If my health gets to a point where there's nothing more that can be done for me, I do not see a need for prolonged care. To live long, not delay it or... you know just CPR without a hope of ever coming off the machine or getting to a point where you could enjoy life again, it's pointless." (314; male, 60, cholangiocarcinoma).

3. The video provided most participants with sufficient information to make informed EoL care decisions.

The video intervention was an acceptable mechanism of communicating ACP options. Participants referred back to the video as providing adequate information for EoL care. Participants expressed their dislike of LPC and its procedures, such as CPR, which were conveyed in the video as risks of engaging with more aggressive treatments. The video was also effective in educating participants on the benefits of limited and comfort care procedures. A large majority of participants reported no fears or concerns about the video's content.

"I watched the video and saw the three options, and to my understanding I feel the last one, which is the comfort care, but at the same time, the second, which is limited care. I would like to discuss with my family first and definitely discuss with a doctor, but the comfort care is the best approach for my future." (335; female, 62, neuroendocrine)

"The life prolonging care is completely out of the picture because in my opinion at that stage you are just a vessel for some remaining biological functions... I think it was expressed in the video. You're not an accident victim where you can say, oh well, with CPR once or twice and a bit of this and that, and a week on the breathing tube, he's going to recover. That's not the case with cancer." (254; male, 54, gastroesophageal)

Few participants ($n = 5$) had negative emotional reactions to the video; these participants questioned the video's appropriateness in relation to their state of illness and readiness to engage in ACP.

"At the stage with someone sitting in the treatment of, you know, going through treatment... I think it's rude. I think it's very untimely, because... you are already going through whatever thoughts and emotions to get through this... and to give it so early on, I feel it's um, it's almost very unfair, or it's like a slap in the face, you know. Here on the one hand you are saying again, you are going to get through this... But now [on] day two of treatment, you are telling me I have to pick three different life choices and my life expectancy... in all fairness right now, I do not want to decide which of the three I want to go... So, I do not feel that that's a fair video this early on" (293; female, 45, pancreas).

4. Participants expressed trust in their oncology teams.

Participants expressed overall satisfaction with their oncologic care. Needs were satisfied in part due to trust in the healthcare team and relationship with their provider.

"I do not have any fears or worries because looking at the past and what I'm through, I've been taken care of extremely well." (254; male, 54, gastroesophageal)

- “I trust the people around me and I’m very optimistic in the sense that I’ll get out of here.” (240: male, 48, gastroesophageal)
- “He’s (my oncologist) is extremely so good. He touches your feelings, [and] heart. He understands you, gives time, listens to you, [and] explains things really well.” (335: female, 62, neuroendocrine)
5. Concerns about illness and prognosis drove a desire for open communication and being understood. Participants expressed concerns about their medical treatments ($n = 28$), specifically in relation to uncertainties toward future outcomes (including death, possible pain, ineffective treatment, disease progression, and impact on family members). Fears were associated with a desire for improved communication and relationships with their oncologists. Participants wanted to express their fears honestly with their oncologists and feel validated and known on a personal level.
 - “Well, the big question always is when are you going to die and how are you going to die... Right now, that’s not next week or the week after, but it’s always the elephant in the room.” (309: male, 67, gastroesophageal)
 - “My fears are that there are things out there that could be a potential cure or a better treatment. That my timing is not right or maybe doctors are not able to apply [certain drugs] yet because of FDA approval or things like that. My biggest concern is that there’s a solution out there that I cannot get access to it.” (207: male, 70, gastroesophageal)
 - “I guess I have a vision, and my family and I have a vision of how we have lived our lives, and as long as that’s respected then I think we’ll be okay.” (331: male, 60, colorectal)
 - “I guess knowing what I want and how I’m feeling [would be helpful].” (284: female, 76, colorectal)
6. Relationships with loved ones provided meaning to participants’ lives. Participants reported that maintaining relationships with loved ones was important to enhance meaning in their lives. Loved ones also served as primary medical decision-makers in the event that participants were unable to make decisions on their own.
 - “Being with my family and friends. We are now... closer, and a lot of time is being spent with them, so it makes me feel so much better. I feel like I’m healthy because I’m with them.” (222: female, 48, colorectal)
 - “Well to me the meaningful thing is what I’m doing right now, spending as much time with them (my children) as possible. You know, helping them plan their future while I have the opportunity to give them any sort of insight I might have on it, answer their questions, and keeping them, I use the word calm, but I guess more focused.” (298: male, 55, gastroesophageal)
7. Religion and spirituality enhanced inner strength and well-being. Participants varied in their dependence on their religious or spiritual views for support. For some participants, preserving a relationship with their higher power and/or religion and engaging in the act of praying were sources of inner comfort and helped maintain well-being.
 - “That is why you see I am a happy person. I go through this. You know, I have experienced a lot of things from the chemotherapy, all the hardness and things like that. My Christian belief helped me to go through this.” (208: female, 56, colorectal)
 - “Whatever time God has given me, gifted me, I feel like it’s a gift to me that I knew that my life would be not as long, but now I see that God is very kind, that God has given me time to think what I have in my mind for the future for myself, for my family.” (335: female, 62, neuroendocrine)
8. Participants valued maintaining an identity, keeping agency, and living life outside of having cancer. Participants expressed a desire to regain control and live in the present, without feeling overwhelmed by their cancer. By focusing on the non-medical aspects of their lives, participants could promote a stronger sense of self.
 - “To live as close to a normal routine as possible, I guess. It’s really just about not wasting a, trying not to waste a single day. Not to have too much idle time or just have those sorts of throw-away days, but [to] just try to accomplish something every day for myself. It can be personal. It can be professional.” (262: male, 53, colorectal)
 - “Just day-to-day normal living basically, just come and go as I feel like and take care of things and stay in touch with people and so on. Just nice routine basically.” (345: male, 74, colorectal)
 - “I’m happy with my life the way it is and, you know, I really do not have anything pressing that I have to go to someplace or - maybe the only thing I think to maybe make my life meaningful for me is I want to finish the bench that I made... And it’s a little too cold outside. Maybe if it gets a little warmer, I’ll finish working on that bench.” (272: male, 71, pancreas)

Table 1 Description of key ACP themes and representative quotes. ACP, advance care planning; EoL, end of life; CPR, cardiopulmonary resuscitation; LPC, life-prolonging care. Quotes are followed parenthetically by participant study identification numbers, gender, age, and primary gastrointestinal malignancy.

Table 2

Evolution of ACP values

Values score ^a	P-COCC (1) N = 33	Video (2) N = 43	Usual care (3) N = 22	1 vs 2 <i>p</i> = 0.052	1 vs 3 <i>p</i> = 0.105	1 vs 2 vs 3 combined <i>p</i> = 0.043 ^b
0, changed a lot	6 (18%)	12 (28%)	1 (5%)			
1, changed somewhat	6 (18%)	3 (7%)	3 (14%)			
2, changed a little	8 (24%)	3 (7%)	2 (9%)			
3, not changed at all	13 (39%)	25 (58%)	16 (73%)			

^aParticipants were asked to rate how much their values about their illness (specifically their goals, concerns, and support sources) changed at 1 month following consent. Response choices were quantified using a Likert scale: 0 “My values have changed a lot,” 1 “My values have changed somewhat,” 2 “My values have changed a little,” and 3 “My values have not changed at all”

^b*P* values were calculated by Fisher’s exact test to compare the frequency distribution of change in values between pairs of intervention conditions

Table 3

Participant impressions on values and helpfulness of the narrative process

	P-COCC	Video	Usual care
Participants who reported a change in their values	<p>"The video gave me a sense of what to go through and what I should expect." (216)</p> <p>"Just coming to terms with my illness, [and] accepting the fact that although it is terminal, life can and will be enjoyable" (261)</p> <p>"[I have] more awareness concerning future planning" (289)</p> <p>"What's changed: My thinking that I have time to complete certain goals. Why? Disease makes me worry about dying and having to get things done sooner than later; I want to feel like I have completed some life goals before my time" (293)</p> <p>"After the intervention, I spoke with my family about advanced care planning and my outlook has changed" (311)</p> <p>"I am better informed regarding do not resuscitate" (317)</p> <p>"Weighing 'good days' and 'bad days.' I may not be so absolutely positive about what lies ahead. I think I sounded [too] optimistic" (327)</p> <p>"The thought of death bothers me more because I am not sure what to expect" (349)</p>	<p>"Seeing the video showed me things I did not want done. I do not see why I would want to be on a machine. If I cannot breathe on my own, might as well let me go. Do not hook me up with those tubes" (204)</p> <p>"I had not thought about it, so this was an introduction to undiscussed topic. Now it's in the back of my head" (214)</p> <p>"I am at the phase of making decisions, and it's important to think about what choices and options I'll have; like moving back to spend time with my family..." (223)</p> <p>"I have been doing more research on my own, for alternative treatments. I'm not so sure for chemo being the sole [treatment], I'm glad I started this conversation, and I've only had this conversation with you. It should be a part of the discussion with my doctor, definitely" (226)</p> <p>"My principles have changed. This process and illness has helped me to see what is more important in life. Life is precious, life is valuable" (276)</p> <p>"My faith has not changed, my love for my family has not changed. What has changed is my resignation to whatever happens to me" (301)</p> <p>"I am more focused about what is important and what is superficial" (316)</p>	<p>"Now I'm thinking about my future, thinking about my family, my boys. [I] gave my brother my medical, life insurance documents last month so he'd be able to manage everything in case anything ever happens" (228)</p> <p>"Some of my supports have changed. After being in ICU, I am more determined to live as long as I can" (291)</p> <p>"I'm focused more and more on the hard fact that my illness is most definitely terminal" (320)</p>
Participants who reported no change in values	<p>"Was well-informed already and knew what needed to do" (209)</p> <p>"I was already aware of choices. As a result, not much changed" (272)</p>	<p>"No change. Overall, I feel pretty good, good outlook, do not consider myself sick. I've been much better then when I first spoke to you" (210)</p> <p>"I'm doing okay. I have my views. It was the same before." (218)</p> <p>"Nothing has changed, but I am feeling better and that is encouraging. I am hopeful that one day they will find the process that will cure me" (319)</p>	<p>"I do not have any new information that changed anything. Not much has changed" (215)</p> <p>"When I was diagnosed I felt strongly that I did not want to put myself or my family through the expense, financially or emotionally, all that entails in prolonging the inevitable ending of my cancer and my life. And I am good with that" (260)</p>
Helpfulness of the narration process on values (audio recording followed by reviewing a transcribed personal narrative)	<p>"I did not realize I had some anger against cancer. But through the narration, I [am] relieved from the anger" (203)</p> <p>"It did not really help, but I can see how for other people it might. It depressed me, the way I interpreted it was 'hey, you are dying and these are your choices'" (209)</p> <p>"Yes, I read it again and thought about it. It gives me relief" (216)</p> <p>"It helped to confirm and solidify my thoughts and plans" (289)</p> <p>"The overall narration was helpful. It provided me with information and guided me to make important decisions" (311)</p> <p>"I was able to express my ideas to an audience specifically intent on the relationship of my condition and me" (321)</p> <p>"Yes, it was good to get a clear picture of options. Good to be confronted with 'basic' question regarding my life and death. My narrative sounded almost incoherent" (327)</p> <p>"It made me more aware of the end of life process" (349)</p>	<p>Participant quotes: P-COCC participants only</p>	

Participants' impressions on values and reasons for change (or no change) in all three study arms. P-COCC participants' reflections on the benefit of being audio-recorded when discussing end-of-life care options and then reviewing a transcribed personal narrative. Quotes are followed parenthetically by participant study identification numbers.