Published in final edited form as:

Psychooncology. 2015 December ; 24(12): 1767–1773. doi:10.1002/pon.3786.

‘We have to discuss it’: cancer patients’ advance care planning impressions following educational information about cardiopulmonary resuscitation†

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Abstract

Objective—Most cancer patients desire information about care options at the end of life, including cardiopulmonary resuscitation (CPR). Communicating such care options can be challenging and is part of advance care planning (ACP). Our prior studies with video educational media produced data on patients’ categoric preferences (yes/no/unsure) for CPR; however, the thematic underpinnings of these educated preferences in patients treated for advanced cancer aren’t well known.

Methods—Qualitative thematic content analysis of participants’ responses in a randomized trial of an educational video (V) or narrative (N) about CPR in patients with advanced gastrointestinal cancers. Responses were independently coded and categorized for thematic content by two reviewers.

Results—Of 54 study participants, 26 total (41% of V arm, 56% of N arm) articulated questions, comments, or both. Reviewer analyses demonstrated thematic consensus and resulted in seven distinct themes listed in decreasing order of prevalence: (a) ACP should be started early; (b) educational information about CPR affirmed participants’ existing beliefs/knowledge/values about advanced illness; (c) participants were apprehensive about ACP but wanted to discuss it; (d) gaps in knowledge about ACP emerged; (e) CPR information was helpful/acceptable; (f) physicians should be involved in ACP; and (g) medical questions about critical illness arose.

Conclusions—Findings identified that while sometimes difficult to discuss, advance care planning is desired, deemed helpful, and ideally begun early by clinicians, and that video education is an appropriate and affirming initiator of discussions. These themes are incorporated into our ongoing research on cancer patient-specific values and education about care options.

†The study data were presented at the 2013 Annual Meeting of the American Society of Clinical Oncology, Chicago, IL, USA.

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Conflict of interest

The authors have declared no conflicts of interest.

Background

Most cancer patients desire information about care options at the end of life, including cardiopulmonary resuscitation (CPR) [1], but the processes by which health care clinicians communicate such information to patients is challenging. Such communication is part of advance care planning, the process by which patients, families, and clinicians plan for future medical care [2].

Early end-of-life discussions are associated with care more in line with patient wishes, as well as less aggressive care (e.g. acute care hospitalization, chemotherapy, ICU admission, and associated ICU procedures and treatments), and greater hospice utilization [3,4]. Furthermore, barriers for effective communication by clinicians with cancer patients and their families at the end of life have been well documented and include time constraints, limitations in advance directive documents [5,6], patient health illiteracy [7], clinician communication shortcomings [8,9], and the inaccuracies of lifespan prognostication [10]. A recent study [11] assessed oncologists' opinions on end-of-life communication strategies, identifying open, honest, early, and ongoing communication as important. Among others, cited barriers to such communication included lack of processes and training for clinicians to conduct such discussions [11].

Patient preferences for life-sustaining interventions such as CPR and mechanical ventilation ('code status') is a particularly important advance care planning topic in many areas of medicine, and particularly in oncology settings. Discussions specifically about code status, when undertaken upon admission to the hospital in the setting of acute medical care needs, are often inadequate [12], supporting the notion that earlier conversations about code status might be better. Semi-structured interviews with advanced cancer patients and their families about Do-Not-Resuscitate (DNR) orders have been performed [1,13] and reveal that most patients and family members view DNR orders as a means to a natural death, and want to discuss these matters at an early time period, when appropriate. However, these impressions were queried in patients expected to die within weeks [1], or those who had already been involved in a discussion about resuscitation with their clinicians [13]. The perceptions of cancer patients and families specifically regarding CPR have not been investigated in an earlier timeframe (e.g. patients regularly receiving cancer treatment), including wherein they have been formally educated first about the process and typical outcomes of CPR. Furthermore, while recent literature documents perceived benefit (care more in line with patient preferences) from earlier end-of-life discussions [3,4] there is variation [11,14] in oncologist participation in such discussions, and the relative optimal timing for outpatient code status discussions is not known.

Video is a medium, which in our research [15–19] and clinical experience, is palatable, educational, and can therefore address some of the communication barriers described above. Our prior studies with such media have produced data on cancer patients' categorical preferences (yes/no/unsure) for CPR [15–17,19]; however, the thematic underpinnings of these preferences in patients being treated for advanced cancer are not known. Patient values (specifically goals, concerns, and sources of support), especially for individuals with serious illnesses like advanced cancer, rest at the crux of a recent onus on person-centered care and

the need for assessing patient preference about various care options [20,21]. Providing such individualized care depends on the exploration of patient values regarding key health care choices surrounding cancer treatment, side effect profiles, and end-of-life priorities.

Because little is known regarding the reasons why advanced cancer patients may or may not prefer CPR at the end of life, we used an exploratory qualitative data analysis approach in this study in order to understand, in detail, patients' rationale for their CPR preferences, and their thoughts about the advance care planning process in general. Qualitative research is an appropriate methodology to use when there is little understanding of central concepts and domains underlying the research question under examination, and when the goal is to attain a nuanced understanding of the issues explored [22].

We therefore performed this qualitative assessment of patient responses to study instruments at the conclusion of participation in a randomized controlled trial [16] of video versus narrative (scripted) education about CPR in advanced cancer patients actively being followed in a medical oncology cancer center clinic in order to assess thematic underpinnings of impressions about CPR. In the randomized controlled trial [16], we investigated if rates of medical record documentation of advance care planning (either with a formal advance directive or a documented discussion about future health care wishes and/or priorities) would be higher in participants randomized to the video arm compared to those randomized to the narrative arm, in the 1-month post-intervention period. The increase in advance care planning documentation in the video arm participants was not statistically significant [16], but the educational information about CPR was perceived favorably by the majority of all study participants, many of whom had additional impressions to share at the conclusion of the study interview. We herein report on the qualitative thematic content analysis of those impressions, having hypothesized pre-analysis that patients would collectively share preferences for early education led by outpatient oncologists about end-of-life options in the face of advancing cancer. Broadly, we believed that the results of this analysis of impressions about CPR education for cancer patients could aid in better understanding the more general problem, and potential solutions to, barriers to communication about end-of-life care.

Methods

As above, the data analyzed for this study came from patients with advanced hepatopancreaticobiliary cancers who participated in a randomized, pre-post intervention trial of a one-time educational video (video arm) or narrative (narrative arm) about CPR. While the full details of this trial are available elsewhere [16], participants had advanced liver, biliary, or pancreas cancers and no prior advance directives. The majority was receiving chemotherapy, and all were being followed at least monthly by their outpatient medical oncologist. This was a representative sample of patients at this institution (and likely beyond) as there is no accepted advance care planning paradigm that exists for patients with advanced cancers, especially while they are still actively receiving chemotherapy. The short (3 minutes long) video was previously comprehensively vetted [23–25] and depicted chest compressions, oxygenation, and tracheal intubation, as well as continued mechanical ventilation of a sedated patient in an ICU. The video also contained

verbal information describing the images and the likely outcomes in patients with advanced cancer. Study staff read aloud verbatim this same information to the narrative arm participants [16]. The study was approved by the Institutional Review Board at Memorial Sloan Kettering Cancer Center.

Testing was performed in a quiet, private space with study participants (and any interested family/friends) by one member of the research team (A.S.E.), lasting approximately 30 min. After answering the post-intervention study questions (which focused on knowledge about and preferences for CPR and mechanical ventilation, as well as their impressions about the palatability of the study information), all participants were asked ‘Do you have any questions or concerns?’ Study participants who chose to answer this voluntary open-ended question had their responses written down by study staff verbatim.

Qualitative inductive analyses, a process of participant narrative review, interpretation, and consensus discussions [22,26–29] were subsequently performed on participants’ verbatim responses to the above question. Similar to a recent qualitative analysis of Dignity Therapy in patients with advanced cancer [30], the Framework analytic induction approach was used. This is appropriate for analyses such as this, which begin deductively and aim to develop a thematic codebook and identification of key themes [22,31,32]. Participant responses were independently coded and categorized for thematic content by two reviewers (A.S.E. and E.S.). Also according to standard qualitative methodology, reviewers subsequently met in consensus meetings to jointly compare and reconcile differences in order to maximize internal validity.

Results

Sample

Of 54 total study participants, 29 (53%) were randomized to and participated in the video arm, and 25 (47%) were randomized to and participated in the narrative arm. From the overall pool of 54 participants, 26 (48%) participants articulated questions, comments, or both; these 26 participants included 12 participants from the video arm (41%), and 14 participants from the narrative arm (56%). Participants in each arm were well-balanced with respect to demographics [16]. Approximately half of all 54 participants outlived the 6-month pre-planned follow-up duration of the study period [16].

Coding for thematic impressions

Of the 26 participants who articulated questions and/or comments, joint analysis between reviewers A.S.E and E.S. resulted in 1–4 (median =1) themes generated from each participant (see Table 1). There were no appreciable differences in the content or number of themes between the narrative and video arms.

Joint analysis between reviewers demonstrated thematic consensus and resulted in seven distinct themes as displayed in Table 1. These themes were identified after reviewers jointly reviewed individual thematic coding results. While the individual themes did not always match exactly between reviewers (e.g. one reviewer deemed the subject comment of ‘people sometimes think DNR means DNT (do-not-treat)’ as a concern, whereas the other reviewer

coded it as a question), there was overlap on all of the seven higher order themes. Reconciliation of the few and minor coding differences occurred on the first joint review of all the responses. Additionally, the overlap on themes was also agreed upon (thematic saturation achieved) during the first joint review. Herein, we list the themes in decreasing order of prevalence and describe them in detail including their categorizations and relationships to other identified themes:

1. Advance care planning (ACP) should be started early: This most common theme emerged in comments including ‘We have to discuss it. We have not discussed it’ and ‘It’s better to deal with these things when you’re reasonably healthy.’ It often was present with theme #3 below, the apprehension to discuss ACP, elucidating the realization that these are difficult but important conversations to have, and that they should occur sooner rather than later.
2. Information about the process of cardiopulmonary resuscitation (CPR) affirmed existing personal beliefs/knowledge/values: ‘The video reinforced what we felt inside,’ ‘I am guided by my [religious] laws,’ and ‘I don’t want my family to suffer’ were examples of the various ways in which the themes of affirmation emerged. On the surface, such expressions might seem useless to future medical care delivered (e.g. patients and families may have already made up their minds), but the complexity and uniqueness of individual patient values and medical situations calls for exactly these types of personal details to come to the fore in healthcare communication between clinical teams and patients/families such that medical decisions can be made, and be in line with patient wishes. As one patient and her son remarked, ‘we have to tailor a directive to the situation (son) ... but of course I don’t want to prolong this at this age if it’s hopeless (patient).’
3. Participants were apprehensive about ACP but wanted to discuss it: As above, participants were often apprehensive to discuss inherently difficult topics, but expressed the concomitant desire, nonetheless, to plan for the future through such discussions. This ‘paradox’ of ACP illustrated itself in different ways. Sometimes it arose within the family unit itself, such as with a spouse labeling the CPR information as ‘scary’ and the patient responding, ‘it’s reality.’ When a patient, themselves, expressed both components of the paradox (e.g. that ACP is difficult yet important), it came through in analysis either directly (‘Very hard to see, but I like to be educated.’) or more subtly, such as one patient indicating that ‘It’s important to know the facts’ after implying that the tendency to not discuss difficult of ACP topics ‘delays the mourning process [and] keeps you in denial.’
4. Gaps in medical knowledge emerged: Critical to education and ultimate decisions about medical treatment, gaps in knowledge emerged, as evinced by such comments as ‘I guess I didn’t realize that the heart is not the issue when you get really sick from cancer’ and ‘It’s something I knew absolutely nothing about.’
5. CPR information was helpful/acceptable: While less common than the ‘paradox’ theme, impressions also arose regarding the palatability of the educational material on CPR, including the notion that such information was helpful. One

participant indicated that the video was ‘Very informative, not only for the patient, but for family also.’

6. Physicians should be involved in ACP: Some responses spoke directly to this theme ‘You don’t know doctors care about you if you don’t talk about it,’ and ‘There was a time when doctors did not level with their patients, and that was a terrible time.’ Other responses more indirectly referenced the role of the physician, or at least the healthcare team, such as ‘Prolonging life: are you doing that for yourself or the patient?’ and ‘People sometimes think DNR [do-not-resuscitate] means DNT [do-not-treat].’ This theme relates to a slightly different paradox that others have described [33]: a minority of admitted cancer patients have discussed advance directives with their oncologist (or want to with their oncologist) although half would want their oncologist to be the doctor (as opposed to a previously unknown, admitting physician) with whom they discuss such issues should these conversations be deemed as ‘necessary’ to have. Therefore, despite an understandable degree of apprehension to discuss topics as difficult as death and dying, if presented as imperative, advance care planning is generally recognized by the patient, and sometimes the family caregiver, as important to discuss with the oncologist in order to best plan practically, realize life goals, and fulfill relationship duties.
7. Medical questions arose: Not only did gaps in knowledge emerge, but so did medical questions about CPR and other treatments (‘What about pacemakers?’), illustrating the utility of these educational media to act as a vehicle through which modifications can be made to medical treatment decisions, and shed light on common and often complex aspects about end-of-life care.

Conclusions

In these patients with poor prognosis hepatopancreaticobiliary cancers receiving education about cardiopulmonary resuscitation and mechanical ventilation, we found that while sometimes difficult to discuss, advance care planning (of which CPR is a critical component in progressive illness) is deemed a helpful and desired process. Furthermore, they and their families generally believe that the process ideally should be begun early, involve clinicians, and that video education is an appropriate and affirming conversation starter. The themes we hypothesized pre-study to be present were all verbalized, although the notion that advance care planning discussions should be initiated by clinicians was slightly different: comments on clinicians (specifically, physicians), both directly and indirectly, more spoke to the importance of involvement by clinicians instead of an imperative that clinicians initiate such discussions. Nonetheless, these findings are in general consistent with recent efforts by the Institute of Medicine, including their support of patient-centered cancer treatment planning [34] and shared decision making [35], as well as several of their reports (including recently) that recognize deficits in, and the need to improve, health literacy [36].

This study adds to the existing advance care planning literature. Whereas prior perceptions about code status have been queried in patients within weeks of death [1], those who have already had a discussion about resuscitation with their clinicians [13], or those asked to

make choices about a theoretical patient [37], our trial generated data in patients more upstream in their illness trajectory (most lived months after study enrollment and the majority was receiving ongoing chemotherapy), and the vocalized opinions were about them personally, or their family. Our study also used established qualitative methodology in content analysis, theme creation, and reconciliation of reviewer differences. Such qualitative methodology is increasingly used and accepted [22], including in a recent study by Granek et al. on oncologist perceptions of strategies and barriers to sound communication with patients and families at the end of life [11]. Several of the themes generated in our study suggest that video education about code status may address some of the barriers noted by Granek et al., [11] namely the multifaceted (physician, patient, and family) reluctance to start these conversations. Larger scale studies of video education led by our group are underway, which we believe will further inform clinical practice for these and other patient populations.

Our study findings are also consistent with the existing advance care planning literature, as well as behavioral economics. Rhondali et al. [37] showed no difference in preference for code status conversation strategy between a question approach (e.g. ‘Would you like to have a DNR order established?’) compared with a recommendation approach (e.g. ‘As your physician, I recommend we implement a DNR order’) in patients in a supportive care setting [37]. Our video might suffice for patients who prefer either of these approaches in that it has been designed [25] to present, in a neutral fashion, the components of CPR and mechanical ventilation, effectively serving as a springboard for patients, families, and health care providers to discuss and tailor end-of-life care to individual patient values. Furthermore, misperceptions about CPR fuel some of the reluctance (by clinician, patient, and/or family) to discuss code status early [1]. Recognizing that the participants voicing perceptions in our trial were generally a select population (e.g. agreeable to participate in a research protocol on advance care planning), the themes we illustrated of acceptability of CPR education, and gaps in knowledge about CPR, bolster the notion that misperceptions about these sensitive issues exist, and should be addressed. Furthermore, the negative emotions that can result from a surrogate’s authorization of a DNR for a patient [38] are reflected in some of the verbalized difficulty of our participants’ family members, and therefore call for such discussions to occur early such that patient values can be known and choices can be made directly by the patient. This call for earlier discussions is supported by a 2007 multi-center French study of a proactive intervention of an educational end-of-life brochure and meeting for families of patients dying in an ICU; compared to usual, reactive, meetings with such families, families randomized to the intervention had significantly better bereavement coping post-death [39].

Finally, some of the themes generated likely reflect patient and family human behavioral biases, including those recently well-described [40] in medical decision making processes about potentially low value health care options (a category in which end-of-life CPR in cancer patients is included). For instance, confirmation bias (the tendency to favorably accept information that confirms existing values) seems related to our observation about how prior beliefs are often affirmed with the CPR education; and notably, the apprehension of many patients and families likely involves other human psychological tendencies, such as loss aversion and the affect heuristic [40]. Clinicians should be aware of the myriad

psychological factors at play in medicine in order to best individualize communication with and care of their patients.

Our study has limitations. First, this sample was limited in size and disease type, and all from one treating institution. However, we did reach thematic saturation during the process of analysis and theme generation, and a patient population with progressive gastrointestinal cancers does share many similarities with other advanced cancer settings. Second, bias may exist in not knowing the impressions of the study participants who did not verbalize comments and/or questions, as well as those patients who chose not to participate in the trial, although the latter was the minority [16]. Both of these groups may have had different impressions about the topics of CPR and advance care planning compared to the participants who did articulate their thoughts. Nonetheless, via the written study questionnaires, the majority of the entire cohort reported positive impressions of the CPR information presented to them [16]. Therefore, it is possible that participants who both did and not offer comments had similar impressions of the CPR information, although further investigation would be needed to study this hypothesis. Third, we did not generate data correlating or comparing the verbalized comments to the other results of these participants, including care ultimately received. Finally, the results of the qualitative analyses may have been biased by having only two study authors analyze the subject responses. However, independent review and the subsequent reconciliation of existing analytical differences are standard processes in behavioral science qualitative methodology, and therefore suggest that our findings have qualitative content validity [22,31,32]. Additionally, the broad overlap in themes independently generated by each reviewer further bolsters the findings of the study.

In conclusion, advance care planning must be individualized to the specific medical situations and values of each patient, but these and other data suggest that the process is welcomed by the majority of patients and their families. The themes generated herein are being incorporated into our ongoing studies on the relationships between cancer patient values and education about care options.

Acknowledgments

This work was supported by the American Society of Clinical Oncology 2010 Young Investigator Award to Andrew S. Epstein, MD

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Table 1

Thematic coding of study participant responses

Video arm				Verbatim response
Coding				
Educational				It's something I knew absolutely nothing about.
Qs/concerns				Don't we have an advance directive in our medical record already? [explored with patient that there is a proxy, but no other directive]
Affirming				I am guided by my orthodox Jewish religious laws.
Affirming	Necessary early	Paradox		I don't want to live like that. It's worse to believe in a last ditch effort than to find out sooner that CPR doesn't work.
Paradox				[Re: female narrator in video] She looks sad (patient); she's being sincere (patient wife).
Helpful/acceptable				Why did I have all that apprehension? These questions are OK. This is nothing.
Educational	Necessary early	Paradox	MDs	I think everybody should have to watch that. I didn't realize that. Very hard to see, but I like to be educated. Prolonging life: are you doing that for yourself or the patient?
Paradox				It's scary (wife); it's reality, this is common sense (patient).
Affirming				Life comes to an end at a certain point. The video reinforced what we felt inside.
Helpful/acceptable				That was easy.
Helpful/acceptable	Educational			Very informative, not only for the patient, but for family also.
Affirming	Necessary early	Paradox		Common sense: anyone would not want CPR in that state. Sometimes I don't like to think that far in advance. Makes me feel worse about it: when it happens, it happens.
				But, best to be prepared with the information.
Narrative arm				Verbatim response
Coding				
Necessary early				Would make sure to catch people on a good day and better do it early on, rather than when they are down and out.
Educational	Necessary early			We have to discuss it. We have not discussed it. I didn't realize that that many people don't leave the hospital [pediatrician's wife].
Qs/concerns				What about pacemakers?
MDs				There was a time when doctors did not level with their patients, and that was a terrible time.
Affirming				Not offended—it's reality.
Helpful/acceptable	Necessary early	MDs		Good to talk about it for the future. If you don't talk about it, you'll never know. You don't know doctors care about you if you don't talk about it.
Affirming	Paradox			It's difficult for my family to accept my decision, but I want quality of life. It's a tough decision, but we got through it.
Affirming				I don't want my family to suffer.
Affirming	Necessary early	Paradox		You never know what the situation is (patient); we have to tailor a directive to the situation (son); but of course I don't want to prolong this at this age if it's hopeless (patient).
Qs/concerns	MDs			People sometimes think DNR means DNT (do-not-treat) [retired chemotherapy nurse].
Educational				I guess I didn't realize that the heart is not the issue when you get really sick from cancer.
Affirming	Necessary early	Paradox		In my opinion, life support delays the mourning process. It's not being realistic. It keeps you in denial. It's important to know the facts. You have to talk about it.

Educational	Necessary early	It's better to deal with these things when you're reasonably healthy. You are less clouded—the fear is different. And like you said, you can always change your mind.
Necessary early	Paradox	Hard to make decisions until you're there. Very good to talk about this, though.
Code key		
Theme		Theme explanation
Necessary early		ACP should be started early
Affirming		Information about cardiopulmonary resuscitation (CPR) affirmed existing personal beliefs/knowledge/values
Paradox		Participants were apprehensive about advance care planning (ACP) but wanted to discuss it
Educational		Gaps in knowledge emerged
Helpful/acceptable		CPR information was helpful/acceptable
MDs		Physicians should be involved in ACP
Qs/Concerns		Medical questions arose

Each row represents individual study subjects who articulated comments and/or questions, and their articulations are listed here verbatim. Coding columns represent themes ultimately coded from the verbal responses.