A Pilot Randomized Trial of an Advance Care Planning Video Decision Support Tool for Adolescents and Young Adults With Advanced Cancer

Jennifer M. Snaman, MD, MS1,2; Deborah Feifer, BA1; Gabrielle Helton, BA3; Yuchiao Chang, PhD4; Areej El-Jawahri, MD4; Angelo E. Volandes, MD4,7; and Joanne Wolfe, MD, MPH4,*

ABSTRACT

Background: Adolescents and young adults (AYAs) with advanced cancer often receive intensive end-of-life care, yet it is unclear if this is goal-concordant. Advance care planning (ACP) video tools may promote identification and communication of AYA preferences.

Patients and Methods: We conducted a dual-site, 1:1 pilot randomized controlled trial of a novel video-based ACP tool in 50 dyads of AYA patients aged 18 to 39 years with advanced cancer and their caregivers. ACP readiness and knowledge, preferences for future care, and decisional conflict were obtained pre, post, and 3 months after the intervention and compared between groups. Results: Of the 50 AYA/caregiver dyads enrolled, 25 (50%) were randomized to the intervention. Participants primarily identified as female, white, and non-Hispanic. Most AYAs (76%) and caregivers (86%) identified their overall goal as life-prolonging preintervention; less identified this goal postintervention (42% AYAs; 52% caregivers). There was no significant difference in change in proportion of AYAs or caregivers choosing life-prolonging care, CPR, or ventilation between arms postintervention or at 3 months. The change in participant scores for ACP knowledge (AYAs and caregivers) and ACP readiness (AYAs) from preintervention to postintervention was greater in the video arm compared with the control arm; the difference in caregivers’ scores for decisional conflict from preintervention to postintervention in the video arm was statistically significant (15 vs 7; P = .005). Feedback from the video participants was overwhelmingly positive; of the 45 intervention participants who provided video feedback, 43 (96%) found the video helpful, 40 (89%) were comfortable viewing the video, and 42 (93%) indicated they would recommend the video to other patients facing similar decisions.

Conclusions: Most AYAs with advanced cancer and their caregivers preferred life-prolonging care in advanced illness, with fewer preferring this type of care postintervention. A brief video-based ACP tool was well-liked by participants and improved caregiver decision certainty. Videos may be a useful tool to inform AYAs and caregivers about end-of-life care options and promote ACP discussions.


Background

Adolescent and young adult (AYA) patients with cancer, defined by the National Cancer Institute as those aged 15 to 39 years,1 often receive intensive end-of-life (EoL) medical care.2–4 Inadequate knowledge and poor or absent communication between patients and their caregivers about preferences and goals of care may result in AYAs’ receipt of intensive treatment in advanced disease.5,6 Palliative care has been associated with receipt of less intensive EoL care in AYAs with cancer, possibly due to greater AYA involvement in communication and decision-making.2,7

Advance care planning (ACP) tools have been developed to facilitate conversations regarding EoL care preferences.3,6 Emerging evidence indicates that ACP tools may prompt discussions of AYA preferences with family members and promote preference concordance over time.8,9 AYA-specific ACP tools have been found to be feasible and acceptable10 and may result in decreased anxiety.11 Despite these promising data, ACP tools remain clinically underutilized in this population.

AYAs and caregivers alike require accurate information about EoL care options, presented in a standardized and accessible manner. However, the traditional clinical approach to ACP discussions relies on ad hoc verbal descriptions of hypothetical clinical situations, which may be inconsistent and limited by literacy, emotional, or language barriers.12–14 Video can enhance understanding and improve decision-making by providing realistic visual images.15 Prior work among adults with serious illness has shown that videos can educate patients and caregivers about care options more effectively than verbal-only explanations and can improve patient–caregiver preference concordance.16–30 ACP in AYAs is complicated by their shifting desired role in decision-making, emerging

See JNCCN.org for supplemental online content.
independence, and evolving sense of vulnerability and identity development, and AYA-specific video tools are needed. In response, our interprofessional team developed, iteratively modified, and pilot tested a brief (10-minute) video decision aid for AYAs with advanced cancer and their caregivers. The primary aim of this pilot randomized controlled trial was to assess the rate of concordance in treatment preference (overall goal of care) between members of an AYA/caregiver dyad randomized to view the ACP video compared with those receiving enhanced usual care. We also examined preference concordance for cardiopulmonary resuscitation (CPR) and mechanical ventilation, participant decisional conflict, and ACP knowledge and readiness before, immediately after, and 3 months following the intervention. To our knowledge, this is the first video ACP decision aid developed and tested in AYAs with advanced cancer.

Patients and Methods

Study Design and Participants

This was a pilot randomized controlled trial of 50 dyads of AYAs aged 18 to 39 years with advanced cancer and their identified caregiver, conducted at Dana-Farber Cancer Institute (DFCI) and Massachusetts General Hospital (MGH). The AYA cohort included patients whose cancer had progressed or recurred after initial treatment; those with low-grade glial brain tumors were excluded, as well as those who were non-English speaking, visually impaired, or unable to participate in ACP discussions due to mental incapacity as determined by the treating clinician. AYAs were asked to identify 1 caregiver for study inclusion; eligible caregivers included English-speaking individuals aged ≥18 years without visual impairment; only complete dyads were included.

This study was approved by the Institutional Review Board of DFCI and registered with ClinicalTrials.gov (NCT04149704).

ACP Video Development

The AYA ACP video development followed a systematic approach, using the International Patient Decision Aid Standards and including iterative review by interprofessional pediatric palliative care and oncology clinicians, AYAs with advanced cancer, and their caregivers. The video is narrated by an AYA who introduces the concept of ACP and the 3-goal framework commonly used in pediatric palliative care: life-prolonging care (ie, live as long as possible), selective care (ie, live as long and as well as possible), and comfort care (ie, live as comfortably as possible). For each option, visual images illustrate the interventions (eg, CPR, intubation, and hospice care) while discussing risks and benefits.

Recruitment and Enrollment Procedures

Potential DFCI participants were identified by patient census review. Study information and contact information was also shared in patient-facing materials (ie, young adult program newsletter, phone application, Twitter feed). An email to the primary oncologist of eligible patients offered 3 business days to opt out of their patient being approached. Eligible patients were then mailed a letter outlining the study, including a plan to approach them for enrollment at the next visit.

Enrollment strategies were modified in spring/summer 2020 to allow for virtual enrollment and study completion due to the COVID-19 pandemic. After the initial mailed letter, eligible participants were called to provide further study details and assess interest. Members of the dyads completed study components on separate electronic devices or via a HIPAA-compliant Zoom platform. MGH was added as a second study site in May 2021, after which study team members (A.E. Volandes, A. El-Jawahri) emailed oncologists to explain the study and request a list of possibly eligible patients; eligibility was confirmed by the DFCI team who conducted all study activities.

Enrolled participants met with a research assistant in person or over Zoom for the initial study visit. Participants were reminded of the elements of informed consent and provided verbal consent. They then completed a preintervention questionnaire, which included sociodemographic information and questions querying care preferences, ACP knowledge and readiness, and decisional conflict. Using a computer-generated simple randomization design, dyads randomized to the intervention viewed the ACP video using a tablet or the “share screen” option on Zoom. Participants then independently completed a postintervention questionnaire assessing care preferences, knowledge, readiness, and decisional conflict and asking about their experience with the video. They received a checklist on initiating ACP discussions that summarized topics discussed in the video (supplemental eAppendix 1, available with this article at JNCCN.org) and an access code allowing them to rewatch the video. Approximately 3 months later, participants were contacted to again to assess their care preferences.

Dyads randomized to usual care received scripted verbal descriptions of types of care in advanced cancer (life-prolonging, selective, and comfort care) and then immediately completed the postintervention questionnaire. Participants were contacted again at 3 months to assess their care preferences.

Measurements and Tools

The assessment tools (supplemental eAppendices 2 and 3) were similar to those used in previous studies of video decision aids. Participants were asked their overall care preference in the setting of advanced illness (life-prolonging, life-prolonging, selective, and comfort care) at each timepoint. ACP, advanced care planning; AYA, young adult; ACP Video Development, ACP Video Development; CPR, cardiopulmonary resuscitation; DFCI, Dana-Farber Cancer Institute; MGH, Massachusetts General Hospital; HIPAA, Health Insurance Portability and Accountability Act; eAppendix, electronic appendix.
were allocated to control (enhanced usual care) and 26 and completed the study materials virtually; 26 dyads randomized to either the control arm or the intervention (intervention) screening test was used to measure participant decision-making uncertainty, with a threshold of ≥3 indicating decisional conflict. ACP readiness was assessed using 4 validated questions, and scores ranged from 0 to 20, with higher scores indicating increased readiness. Video acceptability was measured using questions regarding usefulness, comfort, and recommendation to others.

Data Analysis
We summarized continuous variables using means with standard deviation and categorical variables using count with percentage. For comparisons of postintervention and 3-month follow-up versus preintervention within each study arm, we used paired t tests for continuous outcomes and symmetry tests for categorical outcomes. For comparisons between study arms, we used 2-sample t tests for continuous outcomes and Fisher exact tests for categorical outcomes. We added difference-in-differences analysis for outcomes with observed preintervention difference between arms to control for baseline differences. For the primary outcome of concordance between AYA and caregiver care preferences, our primary analysis assumed “Not answered” as a discordant goal for missing data due to loss to follow-up at 3 months. We performed 2 sensitivity analyses to assess the effect of missing data: (1) imputed missing data using response from postintervention (ie, the last value carried forward approach) and (2) excluded all dyads with at least 1 missing component. The original power analysis assumed that 50% of the control arm achieved dyadic preference concordance and was designed to detect a 41% difference (50% vs 89%) with 80% power. All statistical analyses were conducted using SAS 9.4 (SAS Institute Inc.), and a 2-sided P≤.05 was considered statistically significant.

Results
We assessed 444 participants for possible study inclusion, of which 392 were excluded. A total of 52 AYAs identified a caregiver to participate with and the dyads were randomized to either the control arm or the intervention arm (supplemental eFigure 1) from November 2019 to February 2022. All but 1 dyad was approached, enrolled, and completed the study materials virtually; 26 dyads were allocated to control (enhanced usual care) and 26 to the video intervention. One dyad in each arm was excluded from analyses because 1 member of the dyad did not participate despite multiple attempts, resulting in a total of 50 dyads analyzed. All 100 (100%) allocated participants completed the preintervention and postintervention assessments, and 83 participants (44 AYAs and 39 caregivers) completed the 3-month follow-up, resulting in 18 (72%) and 20 (80%) complete dyads in the control and video arms at the final timepoint, respectively.

Participant Characteristics
Among 50 AYAs, the average age was 33 years (range, 18–39 years) and most identified as female (60%), white (84%), and non-Hispanic (92%) (Table 1). Most AYAs had a solid tumor diagnosis (56%) and received care at DFIC (84%). Approximately half of AYAs rated their health as either very good/excellent (24%) or good (26%), whereas others reported their health as fair (34%) or poor (10%). Most (62%) caregivers identified as spouses/partners and reported similar demographics as the AYAs; average age of the caregivers was 42.6 years (range, 19–69 years).

Care Preferences
Table 2 outlines participant care preferences by study arm and group at each timepoint. At baseline, most AYAs and caregivers (76% and 86%, respectively) selected life-prolonging care. Only 42% of AYAs and 52% of caregivers immediately postintervention and 45% and 41%, respectively, at 3 months opted for life-prolonging care; however, the difference in proportion of participants identifying care preferences between study arms did not reach statistical significance.

Of the 38 AYAs who identified life-prolonging care preintervention, 17 changed care preferences postintervention, with most (n=12) opting for selective and 5 for comfort-focused care. Similarly, 17 (45%) caregivers changed care preferences from life-prolonging postintervention (n=15 selective, n=2 comfort).

At baseline, most AYAs (68%) and caregivers (56%) wanted CPR to be performed in very advanced disease; rates remained relatively unchanged postintervention (64% and 58%, respectively) and at 3 months (59% and 46%, respectively), with no significant difference by study arm (Table 2). The percentage of AYAs and caregivers who wanted mechanical ventilation in advanced disease changed from preintervention (54% and 34%, respectively) to postintervention (48% and 42%, respectively) and at 3 months (46% and 26%, respectively), but no difference in proportion of care preferences was noted between study arms.

Dyadic Congruence of Preferences for Future Care
Table 3 summarizes the dyadic concordance for goals for care. At baseline, 80% of video and 60% of control dyads

Video ACP Tools for AYAs With Cancer

ORiGINAL RESEARCH

JNCCN.org | Volume 21 Issue 7 | July 2023 717
were concordant on overall goals of care, 52% of video and 56% of control dyads were concordant on CPR, and 48% of video and 44% of control dyads were concordant on mechanical ventilation. Postintervention, there were only slight differences in concordance for overall goals of care (video, 52%; control, 60%), CPR (video, 48%; control, 44%), and mechanical ventilation (video, 48%; control, 40%). Concordance in both groups decreased at the 3-month timepoint for overall goals of care (video, 40%; control, 36%), CPR (video, 48%; control, 36%), and mechanical ventilation (video, 44%; control, 36%). There were no significant differences between the video and control groups’ concordance at any timepoint after adjusting for baseline difference (Table 3); sensitivity analysis to explore the impact of missing follow-up data results were similar. Cross-tabulation between AYA and caregiver responses by each type of care is presented in supplemental eTable 1.

Table 1. Participant Demographics

<table>
<thead>
<tr>
<th>Demographics</th>
<th>AYA Patients</th>
<th></th>
<th>Caregivers</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total n (%)</td>
<td>Video n (%)</td>
<td>Control n (%)</td>
<td>Total n (%)</td>
</tr>
<tr>
<td>All</td>
<td>50 (100)</td>
<td>25 (100)</td>
<td>25 (100)</td>
<td>50 (100)</td>
</tr>
<tr>
<td><strong>Demographics</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age, mean [SD], y</td>
<td>33 (6.1)</td>
<td>33 (6.1)</td>
<td>33 (6.1)</td>
<td>42.6 (14.0)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>30 (60)</td>
<td>16 (64)</td>
<td>14 (56)</td>
<td>28 (56)</td>
</tr>
<tr>
<td>Male</td>
<td>20 (40)</td>
<td>9 (36)</td>
<td>11 (44)</td>
<td>22 (44)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>42 (84)</td>
<td>21 (84)</td>
<td>21 (84)</td>
<td>42 (84)</td>
</tr>
<tr>
<td>Asian</td>
<td>3 (6)</td>
<td>2 (8)</td>
<td>1 (4)</td>
<td>3 (6)</td>
</tr>
<tr>
<td>Black or African American</td>
<td>1 (2)</td>
<td>1 (4)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>More than 1 race</td>
<td>2 (4)</td>
<td>0 (0)</td>
<td>2 (8)</td>
<td>2 (4)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (4)</td>
<td>1 (4)</td>
<td>1 (4)</td>
<td>3 (6)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>1 (2)</td>
<td>1 (4)</td>
<td>0 (0)</td>
<td>1 (2)</td>
</tr>
<tr>
<td>Not Hispanic or Latino</td>
<td>46 (92)</td>
<td>24 (96)</td>
<td>22 (88)</td>
<td>47 (94)</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>3 (6)</td>
<td>0 (0)</td>
<td>3 (12)</td>
<td>2 (4)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school, GED</td>
<td>3 (6)</td>
<td>3 (12)</td>
<td>0 (0)</td>
<td>3 (6)</td>
</tr>
<tr>
<td>Some college, college graduate</td>
<td>30 (60)</td>
<td>15 (60)</td>
<td>15 (60)</td>
<td>30 (60)</td>
</tr>
<tr>
<td>Postgraduate, Master’s, PhD</td>
<td>17 (34)</td>
<td>10 (40)</td>
<td>7 (28)</td>
<td>17 (34)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married or with partner</td>
<td>30 (60)</td>
<td>18 (72)</td>
<td>12 (48)</td>
<td>42 (84)</td>
</tr>
<tr>
<td>Divorced</td>
<td>3 (6)</td>
<td>1 (4)</td>
<td>2 (8)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Single, not widowed/divorced</td>
<td>17 (34)</td>
<td>6 (24)</td>
<td>11 (44)</td>
<td>8 (16)</td>
</tr>
<tr>
<td>Religion</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Catholic</td>
<td>10 (20)</td>
<td>5 (20)</td>
<td>5 (20)</td>
<td>14 (28)</td>
</tr>
<tr>
<td>Christian non-Catholic</td>
<td>7 (14)</td>
<td>3 (12)</td>
<td>4 (16)</td>
<td>9 (18)</td>
</tr>
<tr>
<td>Jewish</td>
<td>5 (10)</td>
<td>3 (12)</td>
<td>2 (8)</td>
<td>3 (6)</td>
</tr>
<tr>
<td>Hindu</td>
<td>1 (2)</td>
<td>1 (4)</td>
<td>0 (0)</td>
<td>1 (2)</td>
</tr>
<tr>
<td>Buddhist</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>2 (4)</td>
</tr>
<tr>
<td>None</td>
<td>21 (42)</td>
<td>11 (44)</td>
<td>10 (40)</td>
<td>13 (26)</td>
</tr>
<tr>
<td>Other/Prefer not to answer</td>
<td>6 (12)</td>
<td>2 (8)</td>
<td>4 (16)</td>
<td>8 (16)</td>
</tr>
</tbody>
</table>

(continued on next page)
Decisional Conflict, Knowledge, and ACP Readiness

Many AYA and caregiver participants expressed some degree of uncertainty in baseline care preferences. Moreover, 58% and 42% of AYAs and 64% and 48% of caregivers had decisional conflict preintervention and postintervention, respectively (Table 2). The proportion of AYAs with decisional conflict (SURE score ≥3) in the video arm decreased by 20% from preintervention to postintervention (60% vs 40%; P = .1) but was not significantly different from the change from preintervention to postintervention in the control arm (56% vs 44%; P = .77). However, the proportion of caregivers with decisional conflict in the video arm was significantly lower from preintervention to postintervention (60% vs 28%; P < .005) and between video and control arms at the postintervention timepoint (68% vs 28%; P = .005).

The AYA mean knowledge score increased by 0.6 points from preintervention to postintervention in the video arm compared with 0.3 in the control. The increase in mean knowledge score among caregivers was 0.4 in the video arm and 0.5 in the control arm. The mean AYA ACP readiness score also increased by 1.2 points in the video and 0.6 in the control arm. None of these changes were statistically significant.

Video Feedback

A total of 45 intervention participants provided video feedback (Figure 1). Of these, 43 (96%) found the video at least a little helpful, 40 (89%) felt comfortable viewing the video, and 42 (93%) would recommend the video to other patients with cancer.

Discussion

This dual-site, pilot randomized trial is the first study to examine the effect of a video ACP tool in AYAs with advanced cancer and their caregivers on EoL care preferences. Most AYAs and their caregivers preferred life-prolonging care and intensive interventions in very advanced illness, with many indicating a shift to less invasive care at follow-up. There was no statistically significant difference in care preferences by study arm or change in concordance between dyadic care preference after the intervention. Change in knowledge, ACP readiness, and decisional certainty all improved in the intervention arm, but only caregiver certainty was statistically significant. The video was well liked by participants, and almost all would recommend it to other patients with cancer.

Our findings suggest that participation in an ACP study may itself serve as an intervention to inform AYAs and caregivers about EoL care options and lead to shifts in care preferences. All participants were introduced to a framework for contemplating goals of care in advanced illness. Dyads randomized to the control arm received a...
Table 2. Responses Related to Goals of Care, Decisional Conflict, Advance Care Planning Knowledge, and Readiness

<table>
<thead>
<tr>
<th></th>
<th>AYA Patients</th>
<th>Caregivers</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Video Control</td>
<td>Total</td>
<td>Video Control</td>
</tr>
<tr>
<td></td>
<td>Pre n (%)</td>
<td>Post n (%)</td>
<td>3 mo n (%)</td>
</tr>
<tr>
<td><strong>How would you describe your overall goal of medical care at this time?</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Life prolonging</td>
<td>22 (88)</td>
<td>11 (44)</td>
<td>12 (50)</td>
</tr>
<tr>
<td>Selective</td>
<td>2 (8)</td>
<td>0 (0)</td>
<td>2 (8)</td>
</tr>
<tr>
<td>Comfort</td>
<td>1 (4)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Not sure</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Decisional conflict (SURE score #3)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>15 (60)</td>
<td>12 (48)</td>
<td>11 (45)</td>
</tr>
<tr>
<td>No</td>
<td>6 (24)</td>
<td>11 (44)</td>
<td>12 (50)*</td>
</tr>
<tr>
<td>Not sure</td>
<td>4 (16)</td>
<td>2 (8)</td>
<td>1 (4)</td>
</tr>
<tr>
<td><strong>Knowledge score, out of 6, mean (SD)</strong></td>
<td>3.6 [1.7]</td>
<td>4.2 [1.7]*</td>
<td>3.4 [1.3]</td>
</tr>
</tbody>
</table>

Abbreviations: ACP, advance care planning; AYA, adolescent and young adult; Post, postintervention; Pre, preintervention; SURE, Sure of myself, Understand information, Risk-benefit ratio, Encouragement) screening test.

*A*: P < .05 when compared with preintervention of the same arm.

*B*: P < .05 when compared with control arm at the same timepoint.
verbal description, which, although not thorough or nuanced, may be the first time this concept was introduced.

In one of the only prior randomized studies of an ACP tool in the AYA population, the intervention included 3 60-minute sessions led by a trained research team member.5,9 The intervention resulted in increased congruence in dyadic responses to most hypothetical scenarios,5 and this congruence was sustained over a year.9 Other recent studies indicated that completion of the Voicing My CHOiCES ACP guide resulted in enhanced ACP communication8 and decreased AYA anxiety about EoL care planning.11 In contrast to these time- and resource-intensive interventions, we used a 10-minute video to educate AYAs about models of care and encourage them to begin having these discussions with their caregivers and oncologists.

Ten AYAs chose not to participate in the study because they were concerned about causing caregiver distress, consistent with other ACP studies in this population.9 Others chose an alternate caregiver (grandfather, friend) to participate. Meanwhile, several caregivers opted out on behalf of their AYA, citing fears that the study may be overwhelming or upsetting. In this mutual pretense, both patients and family members sought to avoid open discussions about prognosis and future care with each other in order to shield them from harm.36,37 Still other AYAs chose not to participate because they did not want to engage with ACP or EoL care, and some oncologists denied permission to approach because of worries about AYAs’ readiness to discuss ACP. However, of those who participated, nearly all felt comfortable viewing the tool and would recommend it to others, and many obtained increased decisional certainty and readiness to engage in ACP. Despite concerns over readiness, many AYAs and caregivers are prepared to engage in ACP and are comfortable entering such discussions, consistent with prior interventions.10,38,39

Inadequate or poorly timed ACP discussions may result in anxiety and fear at EoL, more intensive care, and lingering regret in bereaved caregivers. A video-based ACP tool may be one component of a primary palliative care intervention aimed at normalizing and initiating conversations about care preferences between AYAs, their caregivers, and the medical team. Importantly, decreased-intensity care should not be the standard, and the focus should remain on providing care consistent with patients’ wishes and values. ACP tools can facilitate the provision of goal-concordant care after ensuring good understanding of prognosis and care options by creating space for further conversations regarding a patient’s wishes.

Although this study contributes important knowledge on the value of a video ACP tool in AYAs, it has limitations. The study population consisted mostly of individuals identifying as white and non-Hispanic, limiting generalizability. Further research can explore how ACP tools can best support underrepresented groups. Additionally, many AYAs

---

<p>| Table 3. Summary of Concordance Between AYA Patients and Caregiver Responses Over Time by Randomization Group |
|---------------------------------------------------------------|---------------------------------------------------------------|</p>
<table>
<thead>
<tr>
<th><strong>Preintervention</strong></th>
<th><strong>Postintervention</strong></th>
<th><strong>Missing</strong></th>
<th><strong>Missing Imputed From</strong></th>
<th><strong>Missing Excluded</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Overall goals of care</strong></td>
<td>20 (80)</td>
<td>15 (60)</td>
<td>.22</td>
<td>13 (52)</td>
</tr>
<tr>
<td><strong>CPR</strong></td>
<td>13 (52)</td>
<td>14 (56)</td>
<td>1.00</td>
<td>12 (48)</td>
</tr>
<tr>
<td><strong>Mechanical ventilation</strong></td>
<td>12 (48)</td>
<td>11 (44)</td>
<td>.90</td>
<td>12 (48)</td>
</tr>
<tr>
<td><strong>Abbreviation:</strong> CPR, cardiopulmonary resuscitation.</td>
<td><strong>P value</strong>: from testing difference from baseline between the 2 arms.</td>
<td><strong>P value</strong>: from testing difference between the 2 arms.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

---

a P value from testing difference between the 2 arms.  

b P value from testing difference in changes from baseline between the 2 arms.
chose not to participate or were unreachable, and future research should address the ACP experience of these groups. Moreover, several participants were unable to be contacted at the 3-month timepoint, limiting our ability to assess preference change and concordance for these dyads. We chose to focus on preference concordance as the primary outcome as an objective measure of communication of care preference. Furthermore, because many caregivers directly support AYA decision-making and/or serve as proxy decision-makers, the assessment of preference concordance is clinically relevant. Although assessment tools have been used in many other studies, they have not been validated in AYAs with cancer. Study team members were not blinded to the study arm randomization. Importantly, the potential benefit from the control procedures alone, as noted in the shift in care preferences at follow-up for both arms, likely limited our ability to detect differences among outcomes between study arms. Finally, we chose proximate outcomes with short follow-ups because of the pilot nature of the study and because there was no provider-specific communication training component to this intervention. Future larger studies would benefit from the addition of provider communication training and examination of longer-term outcomes, such as documentation of discussions with oncologists and EoL care delivery.

Conclusions
Among AYA patients with advanced cancer, poor ACP and communication about AYA preferences for EoL care contribute to the receipt of intensive medical care and possibly increased suffering at EoL. A standardized ACP video decision aid can inform AYAs and their caregivers about treatment choices and allow them to consider and discuss preferences, leading to better shared decision-making and ultimately, the delivery of AYA-centered care. Further research should focus on enhancing the video approach to standardize and normalize these conversations throughout the advanced illness course.

Submitted January 25, 2023; final revision received March 12, 2023; accepted for publication March 13, 2023.


Disclosures: Dr. Volandes has disclosed having a financial interest in ACP Decisions. Dr. El-Jawahri has disclosed serving as a consultant for Novartis, Incyte, and GlaxoSmithKline. The remaining authors have disclosed that they have not received any financial consideration from any person or organization to support the preparation, analysis, results, or discussion of this article.

Funding: Research reported in this publication was supported by the National Cancer Institute of the National Institutes of Health under award number 1R21CA234708-01A1 (A.E. Volandes).

Disclaimer: The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Correspondence: Jennifer M. Snaman, MD, MS, Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute, 450 Brookline Avenue, Boston, MA 02215. Email: jennifer_snaman@dfci.harvard.edu

References
Available at: https://deainfo.nci.nih.gov/advisory/ncab/archive/139_0906/presentations/AYA.pdf


Supplemental online content for:

A Pilot Randomized Trial of an Advance Care Planning Video Decision Support Tool for Adolescents and Young Adults With Advanced Cancer

Jennifer M. Snaman, MD, MS; Deborah Feifer, BA; Gabrielle Helton, BA; Yuchiao Chang, PhD; Areej El-Jawahri, MD; Angelo E. Volandes, MD; and Joanne Wolfe, MD, MPH

J Natl Compr Canc Netw 2023;21(7):715–723.e17

eFigure 1: CONSORT Diagram
eTable 1: Cross-Tabulation Between AYA Patients and Caregiver Responses for Care Preferences
eAppendix 1: ACP Decisions: Checklist for Young Adults With Cancer
eAppendix 2: Advance Care Planning in Young Adults Study: Preintervention Questionnaire
eAppendix 3: Advance Care Planning in Young Adults Study: Postintervention Questionnaire
eFigure 1. CONSORT diagram for pilot randomized controlled trial of video advance care planning tool compared with enhanced usual care. Abbreviation: AYA, adolescent and young adult.
**eTable 1. Cross-Tabulation Between AYA Patients and Caregiver Responses for Care Preferences**

<table>
<thead>
<tr>
<th>Patient Goal</th>
<th>Caregiver Goal</th>
<th>Video</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Preintervention n (%)</td>
<td>Postintervention n (%)</td>
<td>3 mo n (%)</td>
</tr>
<tr>
<td>Overall goal of care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Life-prolonging</td>
<td>Life-prolonging</td>
<td>19 (76)</td>
<td>7 (28)</td>
</tr>
<tr>
<td></td>
<td>Selective</td>
<td>2 (8)</td>
<td>4 (16)</td>
</tr>
<tr>
<td></td>
<td>Comfort</td>
<td>1 (4)</td>
<td>0 (0)</td>
</tr>
<tr>
<td></td>
<td>Not sure</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td></td>
<td>Not answered</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Selective</td>
<td>Life-prolonging</td>
<td>1 (4)</td>
<td>1 (4)</td>
</tr>
<tr>
<td></td>
<td>Selective</td>
<td>1 (4)</td>
<td>6 (24)</td>
</tr>
<tr>
<td></td>
<td>Comfort</td>
<td>0 (0)</td>
<td>1 (4)</td>
</tr>
<tr>
<td></td>
<td>Not answered</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Comfort</td>
<td>Life-prolonging</td>
<td>1 (4)</td>
<td>4 (16)</td>
</tr>
<tr>
<td></td>
<td>Selective</td>
<td>0 (0)</td>
<td>2 (8)</td>
</tr>
<tr>
<td></td>
<td>Comfort</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td></td>
<td>Not sure</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Not sure</td>
<td>Life-prolonging</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td></td>
<td>Selective</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td></td>
<td>Not sure</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Not answered</td>
<td>Comfort</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td></td>
<td>Not answered</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Cardiopulmonary resuscitation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>Yes</td>
<td>11 (44)</td>
<td>10 (40)</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>2 (8)</td>
<td>2 (8)</td>
</tr>
<tr>
<td></td>
<td>Not sure</td>
<td>4 (16)</td>
<td>3 (12)</td>
</tr>
<tr>
<td></td>
<td>Not answered</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>No</td>
<td>Yes</td>
<td>1 (4)</td>
<td>3 (12)</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>1 (4)</td>
<td>2 (8)</td>
</tr>
<tr>
<td></td>
<td>Not sure</td>
<td>2 (8)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Not sure</td>
<td>Yes</td>
<td>3 (12)</td>
<td>4 (16)</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>0 (0)</td>
<td>1 (4)</td>
</tr>
<tr>
<td></td>
<td>Not sure</td>
<td>1 (4)</td>
<td>0 (0)</td>
</tr>
<tr>
<td></td>
<td>Not answered</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Not answered</td>
<td>No</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td></td>
<td>Not answered</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

(continued on next page)
### eTable 1. Cross-Tabulation Between AYA Patients and Caregiver Responses for Care Preferences (cont.)

<table>
<thead>
<tr>
<th>Patient Goal</th>
<th>Caregiver Goal</th>
<th>Video</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Preintervention</td>
<td>Postintervention</td>
<td>3 mon</td>
<td>Preintervention</td>
<td>Postintervention</td>
<td>3 mon</td>
</tr>
<tr>
<td></td>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>Mechanical ventilation</td>
<td>Yes</td>
<td>7 (28)</td>
<td>8 (32)</td>
<td>3 (12)</td>
<td>5 (20)</td>
<td>5 (20)</td>
<td>2 (8)</td>
</tr>
<tr>
<td>Yes</td>
<td>No</td>
<td>3 (12)</td>
<td>4 (16)</td>
<td>1 (4)</td>
<td>2 (8)</td>
<td>4 (16)</td>
<td>2 (8)</td>
</tr>
<tr>
<td>No</td>
<td>Not sure</td>
<td>5 (20)</td>
<td>0 (0)</td>
<td>4 (16)</td>
<td>5 (20)</td>
<td>3 (12)</td>
<td>4 (16)</td>
</tr>
<tr>
<td>Not answered</td>
<td>Not answered</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>3 (12)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (4)</td>
</tr>
<tr>
<td>No</td>
<td>Yes</td>
<td>1 (4)</td>
<td>3 (12)</td>
<td>3 (12)</td>
<td>0 (0)</td>
<td>1 (4)</td>
<td>1 (4)</td>
</tr>
<tr>
<td>Yes</td>
<td>No</td>
<td>3 (12)</td>
<td>4 (16)</td>
<td>8 (32)</td>
<td>4 (16)</td>
<td>4 (16)</td>
<td>6 (24)</td>
</tr>
<tr>
<td>No</td>
<td>Not sure</td>
<td>2 (8)</td>
<td>4 (16)</td>
<td>0 (0)</td>
<td>2 (8)</td>
<td>1 (4)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Not answered</td>
<td>Not answered</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (4)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Not sure</td>
<td>Yes</td>
<td>1 (4)</td>
<td>0 (0)</td>
<td>1 (4)</td>
<td>3 (12)</td>
<td>4 (16)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>No</td>
<td>No</td>
<td>1 (4)</td>
<td>2 (8)</td>
<td>0 (0)</td>
<td>2 (8)</td>
<td>2 (8)</td>
<td>2 (8)</td>
</tr>
<tr>
<td>Not sure</td>
<td>Not sure</td>
<td>2 (8)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>2 (8)</td>
<td>1 (4)</td>
<td>1 (4)</td>
</tr>
<tr>
<td>Not answered</td>
<td>Not answered</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (4)</td>
</tr>
<tr>
<td>Not answered</td>
<td>No</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (4)</td>
</tr>
<tr>
<td>Not answered</td>
<td>Not answered</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (4)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>4 (16)</td>
</tr>
</tbody>
</table>
eAppendix 1. Checklist: Advance Care Planning for Young Adults With Cancer

ACP DECISIONS

Checklist: Advance Care Planning for Young Adults with Cancer

If you or a friend or loved one is a young adult with cancer, there can be important medical choices to make. These choices are often about the type of treatment and care you want if you get very sick.

It can be hard to think or talk about these choices. But doing so is one of the most important ways to help control what happens in your medical care. Part of being prepared includes talking with your family, friends, and health care team about the type of medical care you want if you get really sick.

Advance Care Planning

This checklist is designed to help prepare you for making some of those choices. It includes important facts, issues to think about, and questions to ask yourself or others. You can put a check mark by those boxes you feel are most important. You can also write notes or comments about topics you want to discuss or learn more about.

Start this process early.

In some ways, health is like the weather. Sometimes, you do not know that a big storm is coming. Or if you know there will be a storm, then not when it will start or what it will be like. Once this storm starts — like getting much sicker — it is often too late to prepare. It helps to start thinking now about your choices you may need to make.

Allow time for Advance Care Planning.

This process takes time. Start by asking your health care team to explain your choices for treatment and care. Next, think of your feelings about each of these choices. Then discuss this with your family and friends. Do not worry or feel scared about making a “wrong” choice. Know that you do not need to make any choices right now. And that you can change your mind later on.

(continued)
eAppendix 1. Checklist: Advance Care Planning for Young Adults With Cancer (cont.)

ACP DECISIONS

Think about what matters to you.
Here are some questions to get started:

☐ What is important? What makes you happy or brings you joy?
   Is it important to you to play sports or be active? Would you rather be in
   the hospital with hopes of getting better or spend as much time as you
   can at home with family and friends? Are there certain things you do that
   makes you feel like life is worthwhile?

☐ What are your fears about getting sicker? Some people fear not
   being in control. Others fear being in a lot of pain. Many people
   say they don’t want to suffer. What symptoms most concern you?
   Are there any symptoms that you feel would make life not worth
   living? What do you want your health care team to do if there are
   hard choices that need to be made? For instance, maybe they need
   to decide how much medicine to give you. One choice might be
   giving you enough medicine to keep you comfortable, even if this
   amount of medicine may make you very sleepy or feel “out of it.”
   The other choice is to give you less medicine. You would be more
   awake and able to think clearly. But you also might have pain or be
   less comfortable. What choice do you want them to make?

☐ Are there any medications or treatments you think could be too
   much? Is there a point when you would rather have care that mostly
   provides comfort? If so, what is that point? How would others know when
   you are at that point? How would your family, friends, and your health
   care team react to this choice?

☐ Do you have spiritual, religious, cultural, and philosophical
   beliefs that affect your choices for medical care? For many people,
   these beliefs bring richness, order, and meaning to their lives. These
   beliefs may also guide choices about medical care. Do you have any such
   beliefs? If so, how do these beliefs help you decide what to do? What
   helps you feel supported when you are sick or face difficult times?

☐ How do you want to communicate with the health care team?
   Some people want to know everything about their medical care and like
   to ask lots of questions. Others prefer that the health care team speak
   not to them but instead talk with their family. And many people want
   something in-between. Who do you want to speak for you if you are too
   sick to do so yourself?

(continued)
eAppendix 1. Checklist: Advance Care Planning for Young Adults With Cancer (cont.)

ACP DECISIONS

Learn about 3 types of medical care for people who are very sick.
Here are goals for each type of care:

**Life-Prolonging Care**
With **Life-Prolonging Medical Care**, the goal is to live as long as possible, wanting doctors to do everything that makes sense to keep you alive. Life-prolonging care may include interventions such as CPR (cardiopulmonary resuscitation), defibrillators (electric shocks to restart the heart), ventilators (breathing machines) or other care that may be provided in the intensive care unit (ICU), regardless if these procedures cause pain or suffering. Sometimes you can choose just certain treatments or change your mind if some cause problems or do not help. Talk with your health care team about how long you would be willing to continue to receive this type of care to see if these treatments work. It is important to know that CPR, breathing machines, and other such treatments are sometimes not helpful for young adults with advanced cancer.

**Selective Medical Care**
With **Selective Medical Care**, the goal is to balance living as long as possible with being as comfortable as possible. With selective medical care, you can choose specific types of care that allow you to live longer with a particular quality of life. This type of care may include going to the hospital or clinic for treatable problems like an infection and possibly receiving blood transfusions and chemotherapy, but it would not likely include CPR, defibrillators, or breathing machines in the intensive care unit.

**Comfort Care**
With **Comfort Care**, the goal is to focus on your comfort and relieve your symptoms. This would usually include medications for pain and shortness of breath but would not include CPR and breathing machines. Comfort care usually would not include coming to the hospital, unless being there would make you more comfortable.

(continued)
eAppendix 1. Checklist: Advance Care Planning for Young Adults With Cancer (cont.)

ACP DECISIONS

Tell your family and health care team about your choices for treatment and care.

Here are some ways:

• Talk in person, over the phone, or with an online service like Skype or FaceTime. These discussions may be hard to have and may be a series of conversations that happens over time, not just once.

• Make a video. You can make a video (using your phone or tablet) about the type of medical care you want, what is important to you, and who should speak for you if you are unable to talk for yourself. Then share this video with your friends, family, and your health care team. This will help them to honor and respect your wishes if you cannot speak for yourself.

• Find out about important forms and other paperwork. Your health care team can tell you about important forms that will make your treatment choices clear. There even is a form where you can say who should make medical choices for you if you are too sick to do so yourself.

When it comes to advance care planning, there is no right or wrong choice. What matters are those choices that are important to you.

Please take time now to start thinking about what is important to you, including the type of care you would want to receive if you become sicker. Know that it is okay to later change your mind. Always keep your family and health care team up-to-date. Also, talk to your health care team who may suggest a certain type of medical care to you based on your disease and what you tell them is important to you. They can help protect your rights and wishes when they know what you want for treatment and care. This is one of the best ways to prepare for any storm in the setting of serious illness.

Notes, comments, and questions:
eAppendix 2. Advance Care Planning in Young Adults Study: Preintervention Questionnaire

AYA ACP Video Forms ver 1.0

Study ID ___ ___ ___

Demographic Questions

1. Age ____ years

2. What is you Gender?
   1 ☐ Female
   2 ☐ Male
   3 ☐ Prefer not to answer

3. Which of the following ethnic groups do you consider yourself?
   1 ☐ Hispanic or Latino
   2 ☐ Not Hispanic or Latino
   3 ☐ Prefer not to answer

4. What race do you consider yourself?
   1 ☐ American Indian / Alaskan Native
   2 ☐ Asian
   3 ☐ Native Hawaiian or other Pacific Islander
   4 ☐ Black or African American
   5 ☐ White
   6 ☐ More than one race
   7 ☐ Prefer not to answer
   8 ☐ Other, specify ____________________________

5. Are you currently:
   1 ☐ Married or with partner
   2 ☐ Widowed
   3 ☐ Divorced
   4 ☐ Single, not widowed or divorced

6. What is the highest grade or year of school you completed?
   1 ☐ Never attended school or kindergarten only
   2 ☐ Elementary, Grades 1-8
   3 ☐ Some high school, Grades 9-11
   4 ☐ High school graduate, grade 12 or GED
   5 ☐ Some college or technical school
   6 ☐ College graduate
   7 ☐ Post graduate, masters, PhD
   8 ☐ Prefer not to answer

(continued)
7. What is your current religious affiliation?
   1 ☐ Catholic
   2 ☐ Protestant
   3 ☐ Christian non-Catholic, denomination__________________________
   4 ☐ Jewish, denomination________________________________________
   5 ☐ Muslim
   6 ☐ Hindu
   7 ☐ Buddhist
   8 ☐ None
   9 ☐ Other, specify________________________________________________
   10 ☐ Prefer not to answer

8. How often, if ever, do you attend spiritual or religious services?
   1 ☐ Never
   2 ☐ Several times a year or less
   3 ☐ Once a month
   4 ☐ Two or three times a month
   5 ☐ Once a week
   6 ☐ More than once a week

(continued)


**eAppendix 2. Advance Care Planning in Young Adults Study: Preintervention Questionnaire (cont.)**

AYA ACP Video Forms ver 1.0

**Study ID ____ ____ ____**

**Health and Advance Care Planning**

1. In general, would you say your health is excellent, very good, good, fair, or poor?
   1. ☐ Excellent
   2. ☐ Very Good
   3. ☐ Good
   4. ☐ Fair
   5. ☐ Poor
   6. ☐ Not sure (Not offered as a choice, but if subject does not choose one of the above)

2. Have you ever had a conversation about your wishes if you were to get sicker?
   1. ☐ Yes
   2. ☐ No
   3. ☐ Not sure

   **(If yes) 2a. With whom did you talk to about your wishes?**
   1. ☐ Health care worker
   2. ☐ Family and/or friends
   3. ☐ Both
   4. ☐ Other, please specify who ______________________

3. Do you have an advance directive, for example a living will which documents your wishes at the end of life or a health-care proxy who will represent your wishes?
   1. ☐ Yes, living will
   2. ☐ Yes, health-care proxy
   3. ☐ Yes, both
   4. ☐ No
   5. ☐ Not sure

(continued)
eAppendix 2. Advance Care Planning in Young Adults Study: Preintervention Questionnaire (cont.)

AYA ACP Video Forms ver 1.0

Study ID ___ ___ ___

Preferences for Medical Care
The next several questions are about your desires for medical care if your cancer were to get worse. The choices provided are life prolonging care, limited care, and comfort care.

1. How would you describe your overall goal of medical care at this time from these three options?
   1. ☐ Life-prolonging medical care
   2. ☐ Selective medical care
   3. ☐ Comfort medical care

2. If your cancer were very advanced and you were to get so sick that your heart stopped beating, would you want doctors to do chest compressions and CPR to try to make your heart start again?
   1. ☐ Yes
   2. ☐ No
   3. ☐ Not sure

3. If your cancer were very advanced and you were to get so sick that you could not breathe on your own, would you want doctors to place you on a breathing machine to help you breathe?
   1. ☐ Yes
   2. ☐ No
   3. ☐ Not sure

Decision-Making
Please think about your answers to the above questions and your decisions around treatment if your cancer were to get worse as you answer the following questions.

1. Do you feel sure about the best choice for you?
   1. ☐ Yes
   2. ☐ No

2. Do you know the benefits and risks of each option?
   1. ☐ Yes
   2. ☐ No

3. Are you clear about which benefits and risks matter most to you?
   1. ☐ Yes
   2. ☐ No

4. Do you have enough support and advice to make a choice?
   1. ☐ Yes
   2. ☐ No

(continued)
eAppendix 2. Advance Care Planning in Young Adults Study: Preintervention Questionnaire (cont.)

AYA ACP Video Forms ver 1.0

Study ID ___ ___ ___

Readiness to Discuss Advance Care Planning

1. How ready are you to talk to your decision-maker/healthcare proxy about the kind of medical care you would want if you were very sick or near the end of life?
   1. □ I have never thought about it
   2. □ I have thought about it, but I am not ready to do it
   3. □ I am thinking about doing it in the next 6 months
   4. □ I am definitely planning to do it in the next 30 days
   5. □ I have already done it

2. How ready are you to talk to your doctor about the kind of medical care you would want if you were very sick or near the end of life?
   1. □ I have never thought about it
   2. □ I have thought about it, but I am not ready to do it
   3. □ I am thinking about doing it in the next 6 months
   4. □ I am definitely planning to do it in the next 30 days
   5. □ I have already done it

3. How ready are you to sign official papers putting your wishes in writing about the kind of medical care you would want if you were very sick or near the end of life?
   1. □ I have never thought about it
   2. □ I have thought about it, but I am not ready to do it
   3. □ I am thinking about doing it in the next 6 months
   4. □ I am definitely planning to do it in the next 30 days
   5. □ I have already done it

4. How ready are you to sign official papers naming a person or group of people to make medical decisions for you?
   1. □ I have never thought about it
   2. □ I have thought about it, but I am not ready to do it
   3. □ I am thinking about doing it in the next 6 months
   4. □ I am definitely planning to do it in the next 30 days
   5. □ I have already done it

(continued)
eAppendix 2. Advance Care Planning in Young Adults Study: Preintervention Questionnaire (cont.)

AYA ACP Video Forms ver 1.0

Study ID _____ _____ _____

Information and Knowledge
Please select one answer only.

1. Cardiopulmonary resuscitation or CPR is a medical procedure that is done on patients whose heart stops beating in an attempt to restart their heart.
   1 ☐ True
   2 ☐ False
   3 ☐ Not sure

2. Most patients with advanced cancer that get CPR in the hospital survive and get to leave the hospital.
   1 ☐ True
   2 ☐ False
   3 ☐ Not sure

3. Most people with advanced cancer who survive CPR and being placed on a breathing machine have very few complications from these procedures.
   1 ☐ True
   2 ☐ False
   3 ☐ Not sure

4. Comfort care is a type of medical care that can only be provided for patients living in a hospice home.
   1 ☐ True
   2 ☐ False
   3 ☐ Not sure

5. Once you talk with your doctor about the kind of medical care you want if your cancer advances and your health worsens, you cannot change your wishes in the future.
   1 ☐ True
   2 ☐ False
   3 ☐ Not sure

6. How many patients with advanced cancer that get CPR in the hospital survive and get to leave the hospital?
   1 ☐ Almost all (more than 90%)
   2 ☐ About half (more than 50%)
   3 ☐ Few (less than 10%)
   4 ☐ Not sure
eAppendix 3. Advance Care Planning in Young Adults Study: Postintervention Questionnaire

AYA ACP Video Forms ver 1.0

Study ID ___ ___ ___

Randomization?

Preferences for Medical Care

The next several questions are about your desires for medical care if your cancer were to get worse. The choices provided are life prolonging care, limited care, and comfort care.

1. How would you describe your overall goal of medical care at this time from these three options?
   1. □ Life-prolonging medical care
   2. □ Selective medical care
   3. □ Comfort medical care

2. If your cancer were very advanced and you were to get so sick that your heart stopped beating, would you want doctors to do chest compressions and CPR to try to make your heart start again?
   1. □ Yes
   2. □ No
   3. □ Not sure

3. If your cancer were very advanced and you were to get so sick that you could not breathe on your own, would you want doctors to place you on a breathing machine to help you breathe?
   1. □ Yes
   2. □ No
   3. □ Not sure

Decision-Making

Please think about your answers to the above questions and your decisions around treatment if your cancer were to get worse as you answer the following questions

1. Do you feel sure about the best choice for you?
   1. □ Yes
   2. □ No

2. Do you know the benefits and risks of each option?
   1. □ Yes
   2. □ No

3. Are you clear about which benefits and risks matter most to you?
   1. □ Yes
   2. □ No

4. Do you have enough support and advice to make a choice?
   1. □ Yes
   2. □ No

(continued)
eAppendix 3. Advance Care Planning in Young Adults Study: Postintervention Questionnaire (cont.)

AYA ACP Video Forms ver 1.0

Study ID ___ ___ ___

Readiness to Discuss Advance Care Planning

1. How ready are you to talk to your decision-maker/healthcare proxy about the kind of medical care you would want if you were very sick or near the end of life?
   1. I have never thought about it
   2. I have thought about it, but I am not ready to do it
   3. I am thinking about doing it in the next 6 months
   4. I am definitely planning to do it in the next 30 days
   5. I have already done it

2. How ready are you to talk to your doctor about the kind of medical care you would want if you were very sick or near the end of life?
   1. I have never thought about it
   2. I have thought about it, but I am not ready to do it
   3. I am thinking about doing it in the next 6 months
   4. I am definitely planning to do it in the next 30 days
   5. I have already done it

3. How ready are you to sign official papers putting your wishes in writing about the kind of medical care you would want if you were very sick or near the end of life?
   1. I have never thought about it
   2. I have thought about it, but I am not ready to do it
   3. I am thinking about doing it in the next 6 months
   4. I am definitely planning to do it in the next 30 days
   5. I have already done it

4. How ready are you to sign official papers naming a person or group of people to make medical decisions for you?
   1. I have never thought about it
   2. I have thought about it, but I am not ready to do it
   3. I am thinking about doing it in the next 6 months
   4. I am definitely planning to do it in the next 30 days
   5. I have already done it

(continued)
eAppendix 3. Advance Care Planning in Young Adults Study: Postintervention Questionnaire (cont.)

AYA ACP Video Forms ver 1.0

Study ID ___ ___ ___

Information and Knowledge
Please select one answer only.

1. Cardiopulmonary resuscitation or CPR is a medical procedure that is done on patients whose heart stops beating in an attempt to restart their heart.
   1. True
   2. False
   3. Not sure

2. Most patients with advanced cancer that get CPR in the hospital survive and get to leave the hospital.
   1. True
   2. False
   3. Not sure

3. Most people with advanced cancer who survive CPR and being placed on a breathing machine have very few complications from these procedures.
   1. True
   2. False
   3. Not sure

4. Comfort care is a type of medical care that can only be provided for patients living in a hospice home.
   1. True
   2. False
   3. Not sure

5. Once you talk with your doctor about the kind of medical care you want if your cancer advances and your health worsens, you cannot change your wishes in the future.
   1. True
   2. False
   3. Not sure

6. How many patients with advanced cancer that get CPR in the hospital survive and get to leave the hospital?
   1. Almost all (more than 90%)
   2. About half (more than 50%)
   3. Few (less than 10%)
   4. Not sure

(continued)
eAppendix 3. Advance Care Planning in Young Adults Study: Postintervention Questionnaire (cont.)

AYA ACP Video Forms ver 1.0

Study ID ____ ____ ____

Feedback on Video (only for participants randomized to video)

1. Was the video helpful in making a decision about medical care? Your choices are very helpful, somewhat helpful, or not helpful.
   1 □ Very helpful
   2 □ Somewhat helpful
   3 □ A little helpful
   4 □ Not helpful

2. How and in what way?

3. Did you feel comfortable seeing the video in order to help you answer the questions regarding medical care? Your choices are very comfortable, somewhat comfortable, or not comfortable.
   1 □ Very comfortable
   2 □ Somewhat comfortable
   3 □ Not comfortable
   4 □ Don’t know

4. Would you recommend the video to other patients with cancer who are facing a similar decision?
   1 □ I would definitely recommend it
   2 □ I would probably recommend it
   3 □ I would probably not recommend it
   4 □ I would definitely not recommend it