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

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eTable 1. Cross-Tabulation Between AYA Patients and Caregiver Responses for Care Preferences

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

AYA ACP Video Forms ver 1.0

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

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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
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 ___ ___ ___

Ready 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