

# Allowing Adolescents and Young Adults to Plan Their End-of-Life Care

**AUTHORS:** Lori Wiener, PhD,<sup>a</sup> Sima Zadeh, MA,<sup>a</sup> Haven Battles, PhD,<sup>a</sup> Kristin Baird, MD,<sup>a</sup> Elizabeth Ballard, MA,<sup>b,c</sup> Janet Osherow, LICSW,<sup>d</sup> and Maryland Pao, MD<sup>c</sup>

<sup>a</sup>Pediatric Oncology Branch, National Cancer Institute, Center for Cancer Research, National Institutes of Health, Bethesda, Maryland; <sup>b</sup>Department of Psychology, Catholic University of America, Washington, District of Columbia; <sup>c</sup>Office of the Clinical Director, National Institute of Mental Health, Department of Health and Human Services, Bethesda, Maryland; and <sup>d</sup>Pediatric Infectious Disease Department, Georgetown University, Washington, District of Columbia

## KEY WORDS

adolescents, end-of-life, advance care planning, decision-making, young adults, cancer, HIV

## ABBREVIATIONS

AYAs—adolescents and young adults

EoL—end-of-life

MTMWMV—My Thoughts, My Wishes, My Voice

[www.pediatrics.org/cgi/doi/10.1542/peds.2012-0663](http://www.pediatrics.org/cgi/doi/10.1542/peds.2012-0663)

doi:10.1542/peds.2012-0663

Accepted for publication Jun 20, 2012

Address correspondence to Lori Wiener, PhD, Behavioral Science Core, Psychosocial Support and Research Program, Pediatric Oncology Branch, Center for Cancer Research, National Cancer Institute, 10 Center Drive, Bethesda, MD 20892. E-mail: [wienerl@mail.nih.gov](mailto:wienerl@mail.nih.gov)

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

Copyright © 2012 by the American Academy of Pediatrics

**FINANCIAL DISCLOSURE:** *The authors have indicated they have no financial relationships relevant to this article to disclose.*

**FUNDING:** Supported in part by the Intramural Research Programs of the National Institutes of Health, National Cancer Institute, Center for Cancer Research, and the National Institute of Mental Health. Funded by the National Institutes of Health (NIH).



**WHAT'S KNOWN ON THIS SUBJECT:** Discussing end-of-life (EoL) care with adolescents and young adults (AYAs) is difficult. Often, such conversations are delayed or avoided, but AYAs contemplate EoL issues and want to make decisions about their care. Few established resources exist to help this process.



**WHAT THIS STUDY ADDS:** Results support the use of a developmentally appropriate document that allows AYAs an opportunity to share their choices about EoL care and how they would like to be remembered in the future.

## abstract



**OBJECTIVE:** The objective of this study was to assess and compare the usefulness, helpfulness, and stress associated with reviewing a previously adapted advance care planning guide, My Thoughts, My Wishes, My Voice, in comparison with the widely used adult document Five Wishes by adolescents and young adults (AYAs) living with a serious illness.

**METHODS:** Fifty-two participants (age 16–28) living with metastatic or recurrent cancer or HIV infection (acquired at birth or early in life) were presented pages randomly from My Thoughts, My Wishes, My Voice and, Five Wishes, and asked to rank 25 items on several factors, including how likely they would be to complete each statement. Participant opinion on suggested changes in content, design, format, and style was obtained and resulted in development of a new document.

**RESULTS:** AYAs living with a life-threatening illness want to be able to choose and record (1) the kind of medical treatment they want and do not want, (2) how they would like to be cared for, (3) information for their family and friends to know, and (4) how they would like to be remembered.

**CONCLUSIONS:** AYA views of what should be included in an advance care planning guide were incorporated into a new document, Voicing My Choices, that provides youth, families and providers an opportunity to reduce the silence around the dying process by allowing an opportunity to share one's voice. We provide guidance on how to incorporate this tool into care. *Pediatrics* 2012;130:1–9

Each year, more than 11 000 adolescents and young adults (AYAs), ages 15 to 34, die of cancer and other life-threatening conditions<sup>1</sup> and the number of youth with chronic and life-limiting conditions is increasing.<sup>2</sup> Determining appropriate care for a young individual at the end-of-life (EoL) can be challenging. To facilitate the transition from curative treatments to EoL care, it is recommended that EoL discussions be routine, begin close to the time of diagnosis, and continue throughout the course of illness.<sup>3–5</sup> Although some provider and parent discomfort exists surrounding discussions of death and EoL care,<sup>6–9</sup> AYAs have expressed a desire and the ability to share their values, beliefs, and preferences for treatment at the EoL.<sup>10–17</sup> Moreover, the American Academy of Pediatrics, the Institute of Medicine, and the World Health Organization recommend involving AYAs in care decisions as much as possible, as they are developmentally and emotionally ready.<sup>5,18,19</sup>

During normal adolescent development, individuals gain independence, formulate their self-identity, strengthen peer and romantic relationships, and define their future role in life.<sup>20</sup> Having a life-threatening illness challenges healthy adolescent development by compromising independence from parents or guardians, interfering with school and social interactions, and potentially causing physical and emotional changes, arresting further development.<sup>16,21</sup> Allowing adolescents to be more involved in their health care decision-making processes, especially at EoL, can help reestablish their burgeoning autonomy and sense of purpose.

Advance care planning documents and advance directives provide patients with the opportunity to express their preferences for how they want to be treated if they cannot speak for themselves. Allowing AYA involvement in

advance care planning can help parents and health care agents make informed decisions, alleviate distress, avoid decisional regret, and perhaps improve the patient's quality of life by respecting their religious, cultural, and familial values and beliefs.<sup>22,23</sup> Yet, few resources exist to aid AYAs in addressing their changing physical, emotional and social needs and wishes around EoL.

In 2008, Wiener et al<sup>10</sup> published a study evaluating Five Wishes, an advance directive document that has shown success in facilitating AYA EoL conversations. Five Wishes was the only advance care planning guide found at the time that included issues of comfort, future planning, and spirituality along with choosing a durable power of attorney and specific life support options. Most participants reported that an advance directive like Five Wishes would be “helpful” or “very helpful” to themselves (95%) and to others (90%). Interestingly, they identified items concerning how they wanted to be treated and remembered as more important than items concerning specific medical decision-making. Using the feedback and recommendations obtained, the study team designed an AYA-specific advance care planning guide, My Thoughts, My Wishes, My Voice (MTMWMV).

This study was designed to compare MTMWMV to Five Wishes for further refinement of AYA preferences. The study also evaluated the feasibility and clinical benefits of providing a developmentally appropriate advance care document for seriously ill AYAs.

## METHODS

### Inclusion and Exclusion Criteria

Eligibility for enrollment included (1) a diagnosis of HIV-1 acquired at birth or early in life, or a diagnosis of metastatic

or recurrent cancer; (2) being English- or Spanish-speaking; (3) and being between the ages of 16 and 28 years. Further eligibility requirements included a >40 Lansky/Karnofsky Performance Score, <3 Eastern Cooperative Oncology Group (ECOG) Performance Status Score, and primary physician approval of participation.

### Procedure

Eligible participants were informed of the study's purpose and offered participation. If they expressed an interest, a detailed explanation of the study's purpose, risks, and benefits were described. For individuals <18 years, parents were approached first and if they were interested in their child participating, the study was explained to both the parent and child simultaneously. When parent and child agreed to participate, all patients >18 gave consent; for those <18, parent consent and adolescent assent was obtained. After assent/consent, the participants were interviewed individually.

### Design

To reduce bias, each wish within Five Wishes and MTMWMV was presented in random order to the participants who were not informed as to which document each wish was from.

### Measures and Documents

#### Readiness Assessment

To assess preparedness to discuss EoL issues, participants were asked to respond Yes or No to the following statements: (1) It might be helpful for me to talk about what would happen if treatments were no longer effective; (2) Talking about medical care plans ahead of time to make sure my wishes are followed in the case that treatment options are limited or there are no more treatment options available would

upset me very much; and (3) I feel comfortable writing down or discussing what I want to happen to me if treatments were no longer effective. All participants were found to be eligible based on the readiness assessment (by responding Yes, No, Yes, respectively).

Five Wishes is a document that legally appoints a health care agent at the EoL and specifies desired medical and palliative care treatments ([www.agingwithdignity.org](http://www.agingwithdignity.org)). It was created in association with doctors, nurses, and lawyers, and is recognized as a legal document in 40 states and the District of Columbia. The document is organized into 5 “wishes” that concern different aspects of the EoL care process (Table 1). Within the Five Wishes

document, each wish lists several statements and respondents are asked to cross out statements they do not agree with or would not want their designated health care agent to perform.

MTMWMV was an intermediate document created after careful analysis of data obtained during the first phase of this study<sup>10</sup> and is titled as such, as participants stated the document needed to reflect their voice and thoughts. Although the adapted document maintained a similar format as Five Wishes, some content was modified (Tables 1 and 2) to include more developmentally appropriate language, clarify difficult medical concepts, and add friends to several

sections. Requests around pain control were expanded. Items related to assisted living, hospice, and nursing home care, which participants felt were less important, were removed. The layout of MTMWMV includes more open-ended statements with space for elaborating on their wishes. Additionally, a place to provide details pertaining to how to bequeath their belongings and how they would like to be remembered after their death was added in a new section, “How I Would Like to be Remembered.” Last, some participants indicated a desire to describe preferred spiritual guidance. In response, we included an optional section on religious and spiritual preferences.

**TABLE 1** Differences Between Five Wishes and MTMWMV

Five Wishes	MTMWMV
<b>The Person I Want To Make Health Care Decisions For Me When I Can't Make Them For Myself</b>	
A health care agent and 2 alternates are identified. Options for types of decisions the health care agent can make are presented; person filling it out can cross out any he or she does not agree with. Section is 2 pages of text.	Two health care agents and up to 2 alternates can be named. Options for types of decisions the health care agent can make remain, with check marks replacing the crossing out option. Section is condensed to 1 page.
<b>My Wish for the Kind of Medical Treatment I Want or Don't Want</b>	
Four scenarios provided to present options for life-support treatment: (1) close to death, (2) in a coma and not expected to recover, (3) permanent and severe brain damage and not expected to recover, and (4) another condition under which I do not wish to be kept alive. Section is 2 pages of text.	Scenarios not offered. To the comment, “if my doctors think that I am likely to die within a short period of time, and life support treatment will only delay the moment of my death,” participants endorse whether they would want to have life-support treatment (defined). Section is condensed to 1 page.
<b>My Wish For How Comfortable I Want To Be</b>	
A half page of options, which can be crossed out.	One page reformatted with check boxes for ease and space to include other wishes.
<b>My Wish for How I Want People to Treat Me</b>	
A half page of options, which can be crossed out.	One page reformatted with check boxes for ease and space to include other wishes. Developmentally appropriate items including preference for favorite foods, music, and visitation options are added.
<b>My Wish for What I Want My Loved Ones to Know</b>	
One page of cross off options and 3 open-ended questions: how they wish to be remembered, preferences for services, and organ donation.	Check boxes and open-ended format that address personal concerns (“family can help me by getting along with each other”) and if they wish to receive or give forgiveness.
<b>Spiritual Wishes</b>	
Not available.	A separate page to discuss spiritual preferences.
<b>How I Want To Be Remembered</b>	
Formerly a portion of My Wish For What I Want My Loved Ones To Know.	Two pages where individuals can indicate preferences for memorial services, bequeath belongings, and indicate how they want to be remembered by family/friends in the future.
<b>My Voice</b>	
Not available.	Blank pages added for writing messages and/or letters to family, friends, and loved ones.

**TABLE 2** Developmental Considerations in Adaptation of Five Wishes and MTMWMV

Developmental Task	Participant Feedback	Changes Made
Gain independence and formulate self-identity	Having a say in who visits; making specific decisions	Being able to choose where they want to be and who they would like with them when the end of life is near
	Having spiritual thoughts and wishes respected	Specify who goes through their belongings
	Deciding what happens to their body after death	Provides an optional spiritual section  Opportunity to document whether they would want a postmortem autopsy or to donate their body to science in addition to choices around burial/cremation
Age-appropriate interests	Items should be more age-appropriate	Inclusion of items related to music/food preferences Removal of items related to assisted living and nursing home
Strengthening peer and romantic relationships	Five Wishes focuses only on family	Integrated “friends” where references made to family and/or loved ones Includes designating visits from friends, classmates, co-workers Provides space for letters to be written to those they care about
Defining future role in life and feeling understood	No place to document a positive outcome out of their death	Place to share how they would like to be remembered on certain days or holidays (e.g., award in my name at graduation, money given to favorite charity on Christmas, donations in lieu of flowers at funeral)
	Being able to share regrets	Section on forgiveness expanded
	No place to designate distribution of belongings	Section to bequeath belongings
Dealing with immortality	Being remembered	Added section allowing them to describe how they want to be remembered
Establish a sense of control over diagnosis/treatment, including relinquishing control when ready	Some medical terms/concepts are difficult to understand	Written using developmentally appropriate language
	A place to document preferred types of emotional and physical comfort	Provided a narrative explaining the purpose of each section of the document  Provided a glossary for more advanced terminology More specific options on pain control How they would like their appearance to be when visitors come to see them Specify degree of alertness balanced with level of comfort care
		More open-ended questions and room to elaborate
Other	Format	
	Title needs to be changed: my wish is not to die	Title changed to emphasize that their choices are being respected and their voice is being heard

**Outcome Measure**

The outcome evaluation measure consisted of a 5-point Likert-type scale evaluating degree of helpfulness and stressfulness of each wish and the document as a whole. A score of 3, somewhat helpful; 4, helpful; or 5, very helpful, was used to determine a positive response, and a score of 1, not at all helpful; or 2, a little helpful, was scored as a negative outcome. Likewise, a score of 3, somewhat stressful; 4, stressful; or 5, very stressful, was used to determine a negative response, and a score of 1, not at all stressful, or 2, a little stressful, was scored as a positive outcome. For each wish, the participant was asked to critically evaluate his or her perception of the appropriateness and helpfulness of the overall page for themselves and for others their age living with a serious

illness. Specifically, participants were told, “These are 2 similar wishes written in different formats. Please look at each version. Which version do you think is more appropriate for someone your age?” The same question was asked about how helpful the items would be for others their age living with a serious illness. Participants were also asked to evaluate how stressful each question would be to complete, how important the legality of such a document would be, and which document they would be more likely to complete. Additionally, qualitative information was gathered regarding document preferences pertaining to specific wording, layout, color, design, and additional content.

Analyses were conducted by using SPSS 12.0.1 (SPSS, Inc, Chicago, IL).

Descriptive data are described with frequency distributions;  $\chi^2$  analyses are used to compare demographic and diagnosis variables to appropriateness of wish topic, helpfulness, stress, and preference for document, document title, and legality of the document.

**Participants**

Between March 2008 and August 2011, 52 participants living with recurrent or metastatic cancer (26) or HIV disease (26) were recruited from the Pediatric Oncology Branch of the National Cancer Institute and from Georgetown University Hospital. One patient living with both HIV and cancer was placed into the HIV group, as that diagnosis preceded the cancer diagnosis. Patients ranged from 16 to 28 years (mean 20.3). Forty-four percent were African American,

35% were White, 14% were Hispanic/Latino, 2% were Asian/Pacific Islander, 4% were biracial, and 2% indicated “other.” Fifty-four percent of respondents were female.

## RESULTS

### Helpfulness

All wishes were rated by at least 94% of respondents as being helpful, except Wish 6 (spiritual wishes) and Wish 8 (open letter), which were still highly rated, at 87%. Females were marginally more likely to find Wish 2 (kind of medical treatment I want) to be helpful ( $\chi^2 = 2.8$  (1),  $P < .10$ ). There were no significant differences in helpfulness ratings by diagnosis, race/ethnicity, or age group (Table 3).

### Appropriateness

For wishes addressing medical care (Wishes 1 and 2), respondents were split about whether Five Wishes or MTMWMV was more appropriate for someone their age. There was a preference for Five Wishes for Wish 3 (comfort) and for MTMWMV for Wishes 4 and 5 (how they would like to be treated and information for family and friends to know) (Table 4). Individuals living with HIV were more likely to

prefer Five Wishes for Wishes 2 and 4 ( $\chi^2$  [1] = 4.9,  $P < .05$ ,  $\chi^2$  [2] = 10.1,  $P < .001$ , respectively; Table 3). Males preferred MTMWMV for Wish 2 ( $\chi^2$  [1] = 7.4,  $P < .01$ ) and preferred MTMWMV for Wish 4 ( $\chi^2$  [2] = 5.4,  $P < .01$ ). There were no significant differences by race/ethnicity (Table 4).

### Stress

Responses reported here are for those who endorsed the items as somewhat stressful/stressful/very stressful (Table 5). In descending order of stress were Wish 2 (type of medical treatment, 81%), Wishes 1 and 8 (who will make medical decisions and my voice, open ended, 67%), Wish 7 (how I want to be remembered, 60%), Wish 5 (what I want family/friends to know, 52%), Wish 3 (how comfortable I want to be, 48%), Wish 4 (how I would like to be treated, 40%), and Wish 6 (spiritual wishes, 31%). There were no significant differences by diagnosis, race/ethnicity, gender, or age group.

### Format

Most participants preferred formatting that included both closed choices and open-ended questions that would reflect their voice. They also felt the document would be more effective with

color, easy-to-read print, simplified wording, and explanations of difficult concepts or terms used, such as “life support.”

### Legality

Participants were asked to rate the importance that an advance care planning document be a legal document. Responses were collapsed into “not at all/a little/somewhat important” and “pretty/very important.” Most participants (83%) thought that it was pretty/very important that Five Wishes or MTMWMV be a legal document. There were no significant differences by diagnosis, race/ethnicity, age group, or gender.

### Document Preference

Fifty-four percent of respondents indicated a preference to complete MTMWMV, 37% preferred Five Wishes, and 9% did not express a preference. Males were more likely to prefer Five Wishes than females ( $\chi^2$  [1] = 4.4,  $P < .05$ ). There were no significant differences by diagnosis, race/ethnicity, or age group (Table 6). MTMWMV has additional sections that were found in the first phase of the study to be the most important components of an advance care planning guide for AYAs, namely, How I Would Like to be Remembered (including bequeathing their belongings, being able to donate one’s body, and how they would like to be remembered in the future by family and friends), a separate page where AYAs can document their specific spiritual wishes, as well as open pages to write letters. In Phase 2, these additions were consistently endorsed as very helpful by each group (Table 3).

### Title

Sixty-seven percent of respondents believed MTMWMV was generally an appropriate title for an advanced care planning document. Females were

**TABLE 3** Helpfulness of Wish Topics (Somewhat Helpful, Helpful, or Very Helpful)

	Total n (%)	Diagnosis		Age Group	
		HIV n (%)	Cancer n (%)	16–21 n (%)	22–28 n (%)
Wish 1: Who will make my medical care decisions if I cannot	50 (96.2)	24 (92.3)	26 (100.0)	28 (96.6)	22 (95.7)
Wish 2: Kind of medical treatment I want/do not want	50 (96.2)	25 (96.2)	25 (96.2)	29 (100.0)	21 (91.3)
Wish 3: How comfortable I want to be	49 (94.2)	23 (88.5) <sup>a</sup>	26 (100.0)	28 (96.6)	21 (91.3)
Wish 4: How I would like to be treated	52 (100.0)	26 (100.0)	26 (100.0)	29 (100.0)	23 (100.0)
Wish 5: What I want family/friends to know	51 (98.1)	25 (96.2)	26 (100.0)	29 (100.0)	22 (95.7)
Wish 6: Spiritual wishes	45 (86.5)	24 (92.3)	21 (84.0)	25 (89.3)	20 (87.0)
Wish 7: How I want to be remembered	50 (96.2)	25 (96.2) <sup>b</sup>	25 (100.0)	27 (96.4)	23 (100.0)
Wish 8: My voice	45 (86.5)	22 (84.6)	23 (95.8)	25 (92.6)	20 (90.0)

<sup>a</sup>  $P < .10$ , trending toward significance.

<sup>b</sup> One respondent answered “both” and was excluded from these questions.

**TABLE 4** Which Version Is More Appropriate for Someone Your Age?

	Total <i>n</i> (%)	Diagnosis		Age Group		Gender	
		HIV <i>n</i> (%)	Cancer <i>n</i> (%)	16–21 <i>n</i> (%)	22–28 <i>n</i> (%)	Male <i>n</i> (%)	Female <i>n</i> (%)
Wish 1: Who will make my medical care decisions if I cannot							
Five Wishes	25 (48.1)	15 (57.7)	10 (38.5)	11 (37.9)	14 (60.9)	10 (41.7)	15 (53.6)
MTMWMV	27 (51.9)	11 (42.3)	16 (61.5)	18 (62.1)	9 (39.1)	14 (58.3)	13 (46.4)
Wish 2: Kind of medical treatment I want/do not want							
Five Wishes	26 (50.0)	17 (65.4) <sup>a</sup>	9 (34.6)	16 (55.2)	10 (43.5)	7 (29.2) <sup>a</sup>	19 (67.9)
MTMWMV	26 (50.0)	9 (34.6)	17 (65.4)	13 (44.8)	26 (50.0)	17 (70.8)	9 (32.1)
Wish 3: How comfortable I want to be							
Five Wishes	18 (34.6)	11 (42.3)	7 (26.9)	13 (44.8)	5 (21.7)	6 (25.0)	12 (42.9)
MTMWMV	34 (65.4)	15 (57.7)	19 (73.1)	16 (55.2)	18 (78.3) <sup>b</sup>	18 (75.0)	16 (57.1)
Wish 4: How I would like to be treated							
Five Wishes	8 (15.4)	8 (30.8) <sup>c,d</sup>	18 (69.2)	6 (20.7) <sup>d</sup>	2 (8.7)	1 (4.2) <sup>b,d</sup>	7 (25.0)
MTMWMV	43 (82.7) <sup>d</sup>	0 (0.0)	25 (96.2)	22 (75.9)	21 (91.3)	23 (95.8)	20 (71.4)
Wish 5: What I want family/friends to know							
Five Wishes	18 (34.6)	9 (34.6) <sup>d</sup>	9 (34.6)	11 (37.9) <sup>d</sup>	7 (30.4)	5 (20.8) <sup>d</sup>	13 (46.4)
MTMWMV	33 (63.5) <sup>d</sup>	17 (65.4)	16 (61.5)	18 (62.1)	33 (63.5)	18 (75.0)	15 (53.6)

<sup>a</sup>  $P < .05$ .<sup>b</sup>  $P < .10$  (trending toward significance).<sup>c</sup>  $P < .01$ .<sup>d</sup> One respondent answered “both” and was excluded from these questions.

more likely to agree that it was an appropriate title ( $\chi^2 [1] = 6.0, P < .05$ ). There were no significant differences by diagnosis, race/ethnicity, or age group. Ten percent commented “the word wishes is awkward,” because “our wish is not to be sick and/or dying.”

## DISCUSSION

Terminal illness presents AYAs with an exceedingly difficult and contradictory challenge: they are dying yet it is their nature and developmental need to want

to live. They are concerned about their lack of achievements and although they believe they should be immortal, they wonder if they will be remembered.<sup>10,24</sup> The avoidance or lack of conversation about impending death by adults around them creates a sense of isolation, fear, and anxiety.<sup>25,26</sup> AYAs are unclear on how to say goodbye or how to communicate how they wish to be remembered.<sup>27</sup> Ultimately, it places AYAs at risk for dying in emotional isolation.<sup>28</sup> The endorsement of the wishes presented in both Five Wishes

and MTMWMV as both appropriate and helpful confirms that AYAs living with a serious illness contemplate specific EoL issues and want to take part in decisions pertaining to their care.

Participants identified items pertaining to making medical treatment decisions as the most stressful activity, perhaps indicating uncertainty about how to make those types of decisions. Health professionals may worry that discussing EoL plans or presenting an EoL planning document may send the message that the medical team wishes to withdraw care, that death is imminent, or will “destroy hope.” However, evidence suggests youth and parents appreciate open and honest discussion, and parents may feel resentful or fearful later when talk is avoided.<sup>29</sup> Reviewing the document can also provide an opportunity to address misconceptions and unrealistic expectations before major medical events occur while ensuring that the best interests and the wishes of the youth are met. Knowing what the youth wants can be a great relief to parents. Communicating one’s concerns and wishes can also be a great relief to AYAs.

Comparing the 2 documents provided less valuable information than what was derived from the critical and detailed comments offered on individual items reviewed. For example, for Wish 2, participants described a need for more specific information and clarity pertaining to life support and possible choices in the case of an acute event. This may reflect ambiguity in the information the AYA has been given, but may also reflect a developmental lack of understanding of abstract concepts or an inability to reconcile assumed immortality with the harsh reality of human frailty. For Wishes 3, 4, and 5, participants wanted to add information about the importance of staying connected to peers while maintaining their

**TABLE 5** Stress Associated With Answering Questions on Wish Topics (Somewhat Stressful, Stressful, or Very Stressful)

	Total <i>n</i> (%)	Diagnosis		Age Group	
		HIV <i>n</i> (%)	Cancer <i>n</i> (%)	16–21 <i>n</i> (%)	22–28 <i>n</i> (%)
Wish 1: Who will make my medical care decisions if I cannot	35 (67.3)	19 (73.1)	16 (61.5)	19 (65.5)	16 (69.6)
Wish 2: Kind of medical treatment I want/do not want	42 (80.8)	20 (76.9)	22 (84.6)	24 (82.8)	18 (78.3)
Wish 3: How comfortable I want to be	25 (48.1)	14 (53.8)	11 (42.3)	13 (44.8)	12 (52.2)
Wish 4: How I would like to be treated	21 (40.4)	9 (34.6)	12 (46.2)	12 (41.4)	9 (39.1)
Wish 5: What I want family/friends to know	27 (51.9)	16 (61.5)	11 (42.3)	16 (55.2)	11 (47.8)
Wish 6: Spiritual wishes	16 (30.8)	9 (34.6)	7 (28.0)	9 (32.1)	7 (30.4)
Wish 7: How I want to be remembered	31 (59.6)	18 (69.2)	13 (52.0)	18 (64.3)	13 (56.5)
Wish 8: My voice	35 (67.3)	18 (69.2)	17 (73.9)	19 (73.1)	16 (69.6)

**TABLE 6** Format Preferences

	Total <i>n</i> (%)	Diagnosis		Age Group		Gender	
		HIV <i>n</i> (%)	Cancer <i>n</i> (%)	16–21 <i>n</i> (%)	22–28 <i>n</i> (%)	Male <i>n</i> (%)	Female <i>n</i> (%)
Legality							
Pretty Important/Very Important	43 (82.7)	23 (88.5)	20 (80.0)	25 (89.3)	18 (78.3)	18 (78.3)	25 (89.3)
Document Preference							
Five Wishes	19 <sup>a</sup> (36.5)	12 (48.0)	7 (31.8)	11 (42.3)	8 (38.1)	5 (23.8) <sup>b</sup>	14 (53.8)
MTMWMV	28 (53.8)	13 (52.0)	15 (68.2)	15 (57.7)	13 (61.9)	16 (76.2)	12 (46.2)
Title							
MTMWMV appropriate	35 (67.3)	18 (75.0)	17 (73.9)	18 (72.0)	17 (77.3)	12 (57.1) <sup>b</sup>	23 (88.5)

<sup>a</sup> Five respondents missing because of nonresponse or indecision.

<sup>b</sup>  $P < .05$ .

dignity (physical appearance). This too reflects normal developmental absorption with self and the prominence of how peers view them. For Wish 7, How I Want to be Remembered, participants wanted additional options, such as an autopsy or donating their body to a medical school. Although altruism has been found to be a motivator for participation in cancer clinical trials and a recent study found 41% of parents whose child underwent autopsy felt that it helped them live with their loss,<sup>30</sup> little is known about how youth living with a life-threatening illness perceive the benefits or burdens associated with postmortem examinations. Similar to all educational materials, the style and level of information desired may vary. The findings suggest that mixed formats should be included within an advance care planning document to ease completion.

There are some potential limitations to this study. First, only patients aged 16 to 28 years were enrolled to limit concerns of safety, stress, and cognitive ability to discuss EoL planning. Although psychosocial issues vary greatly within this age group,<sup>31</sup> no differences were found in terms of appropriate content to include within an advance care planning guide for AYAs. Yet considering the range of ages within this study, differences in psychological responses to this tool should be of consideration in

future research. There is also a concern that patients treated at the National Institutes of Health are often self-referred and highly motivated to participate in medical research and therefore may not represent how all AYAs feel about EoL care planning. However, the participants included in the clinical interviews from both phases of the study (92 total participants) were from 2 hospital centers and diverse geographic locations, and had varying levels of education. High proportions of ethnic minorities were also represented. Therefore, we feel that the study population had good representation from the population being targeted.

### Future Directions: Voicing My Choices

Incorporating the findings and comments from this study, the research team further adapted MTMWMV to include the elements reported to be critically important from both documents. Although only 10% of the cohort specifically requested that the term, wishes, be deleted from the title, participants spoke passionately about being able to document their particular choices and being a valued voice in the process. A title change was made to reflect the sentiments of AYAs to have the opportunity to be heard and have their choices documented. The final document, titled Voicing My Choices,

uses developmentally appropriate wording, more detailed information (including a glossary of terms), and a format that allows both closed choice and open-ended responses. It addresses how one would like to be treated, cared for, and supported during their illness and how they wish to be remembered after death. Documents such as Voicing My Choices can ensure that when an AYA dies, there is not an escalation of medical care when the youth has specifically requested to have a natural death (Appendix, Supplemental Information).

### CONCLUSIONS

Seriously ill AYAs benefit from being involved in their EoL treatment and care plans. Involvement creates a sense of trust with the medical team and their family while providing some measure of control and independence as his or her wants and needs are incorporated into the treatment plan. An age-appropriate advance care planning guide provides this and helps staff to start difficult conversations. This study identified items that are important in a specific document that allows compassionate and self-directed care, support, and comfort both before and after death. Voicing My Choices allows AYAs to reflect on their life and to make choices about what nurtures, protects, and affirms their remaining life and how they wish to be remembered into the future.

### ACKNOWLEDGMENTS

The authors acknowledge the support of several individuals who helped make this work possible. We thank Crystal Mackall, MD, Alan Wayne, MD, and Brigitte Widemann, MD, for their support in implementing this study. We also thank Aging with Dignity for providing the Five Wishes document used in this research endeavor and for their ongoing enthusiasm for our study. We acknowledge Matthew Biel, MD, and

Mary Lane, LICSW-C, for their administrative support at Georgetown University and Pedro Martinez, MD, Brienne Kohrt, MA, and Tara Brennan, PsyD for their substantial efforts in the earlier phase of this study. For the work that

went into Voicing My Choices, we thank Kathleen Samiy for her exceptional graphic design and Melinda Merchant, MD, PhD, Erica Ludi, BS, and Sarah Westen, BA, for their repeated reviews of the document. Mostly, we thank the

adolescents and young adults who so openly shared their thoughts, their voices, and their desire to make this process easier for those who will unfortunately find themselves making end-of-life decisions in the future.

## REFERENCES

- National Vital Statistics System, National Center for Health Statistics, CDC. 10 Leading Causes of Death by Age Group, United States. 2011. Available at: [www.cdc.gov/injury/wisqars/leadingcauses.html](http://www.cdc.gov/injury/wisqars/leadingcauses.html). Accessed February 21, 2012
- Halfon N, Newacheck PW. Evolving notions of childhood chronic illness. *JAMA*. 2010;303(7):665–666
- Larson DG, Tobin DR. End-of-life conversations: evolving practice and theory. *JAMA*. 2000;284(12):1573–1578
- Mack JW, Wolfe J. Early integration of pediatric palliative care: for some children, palliative care starts at diagnosis. *Curr Opin Pediatr*. 2006;18(1):10–14
- Field M, Behrman R, eds. *When Children Die: Improving Palliative Care and End of Life Care for Children and Their Families*. Washington, DC: National Academy Press; 2002
- Feudtner C. Collaborative communication in pediatric palliative care: a foundation for problem-solving and decision-making. *Pediatr Clin North Am*. 2007;54(5):583–607, ix
- Morgan ER, Murphy SB. Care of children who are dying of cancer. *N Engl J Med*. 2000;342(5):347–348
- Davies B, Sehring SA, Partridge JC, et al. Barriers to palliative care for children: perceptions of pediatric health care providers. *Pediatrics*. 2008;121(2):282–288
- Steele R, Davies B. Impact on parents when a child has a progressive, life-threatening illness. *Int J Palliat Nurs*. 2006;12(12):576–585
- Wiener L, Ballard E, Brennan T, Battles H, Martinez P, Pao M. How I wish to be remembered: the use of an advance care planning document in adolescent and young adult populations. *J Palliat Med*. 2008;11(10):1309–1313
- Lyon ME, McCabe MA, Patel K, D'Angelo LJ. What do adolescents want? An exploratory study regarding end-of-life decision-making. *J Adolesc Health*. 2004;35(6):529.e1–529.e6
- Lyon ME, Garvie PA, McCarter R, Briggs L, He J, D'Angelo LJ. Who will speak for me? Improving end-of-life decision-making for adolescents with HIV and their families. *Pediatrics*. 2009;123(2). Available at: [www.pediatrics.org/cgi/content/full/123/2/e199](http://www.pediatrics.org/cgi/content/full/123/2/e199)
- Hammes BJ, Klevan J, Kempf M, Williams MS. Pediatric advance care planning. *J Palliat Med*. 2005;8(4):766–773
- McAliley LG, Hudson-Barr DC, Gunning RS, Rowbottom LA. The use of advance directives with adolescents. *Pediatr Nurs*. 2000;26(5):471–480
- Hinds PS, Drew D, Oakes LL, et al. End-of-life care preferences of pediatric patients with cancer. *J Clin Oncol*. 2005;23(36):9146–9154
- Stevens MM, Dunsmore JC, Bennett DL, Young AJ. Adolescents living with life-threatening illnesses. In: Balk DE, Corr CA, eds. *Adolescent Encounters with Death, Bereavement and Coping*. New York, NY: Springer Publishing Company; 2009:115–140
- Read K, Fernandez CV, Gao J, et al. Decision-making by adolescents and parents of children with cancer regarding health research participation. *Pediatrics*. 2009;124(3):959–965
- American Academy of Pediatrics; Committee on Bioethics and Committee on Hospital Care. Palliative care for children. *Pediatrics*. 2000;106(2 pt 1):351–357
- McGrath PA. Development of the World Health Organization Guidelines on cancer pain relief and palliative care in children. *J Pain Symptom Manage*. 1996;12(2):87–92
- American Academy of Child and Adolescent Psychiatry. Facts for families (No. 58): Normal adolescent development. 2011. Available at: [www.aacap.org/galleries/FactsForFamilies/58\\_normal\\_adolescent\\_development.pdf](http://www.aacap.org/galleries/FactsForFamilies/58_normal_adolescent_development.pdf)
- Pao M, Ballard ED, Rosenstein DL. Growing up in the hospital. *JAMA*. 2007;297(24):2752–2755
- Kane JR, Joselow M, Duncan J. Understanding the illness experience and providing anticipatory guidance. In: Wolfe J, Hinds PS, Sourkes BM, eds. *Textbook of Interdisciplinary Pediatric Palliative Care*. Philadelphia, PA: Elsevier Incorporated; 2011:30–40
- Barfield RC, Brandon D, Thompson J, Harris N, Schmidt M, Docherty S. Mind the child: using interactive technology to improve child involvement in decision making about life-limiting illness. *Am J Bioeth*. 2010;10(4):28–30
- Oppenheim D. The child's subjective experience of cancer and the relationship with parents and caregivers. In: Kreitler S, Weyl Ben Arush M, eds. *Psychosocial Aspects of Pediatric Oncology*. West Sussex, England: John Wiley & Sons Inc; 2004:111–138
- Bluebond-Langner M. Worlds of dying children and their well siblings. *Death Stud*. 1989;13:1–16
- Hilden JM, Watterson J, Chrustek J. Tell the children. *J Clin Oncol*. 2000;18(17):3195–3195
- Sourkes BM. *Armful of Time. The Psychological Experience of the Child with a Life Threatening Disease*. Pittsburgh, PA: University of Pittsburgh Press; 1995
- Wiener L, Hersh SP, Alderfer MA. Psychiatric and psychosocial support for the child and family. In: Pizzo PA, Poplack DG, eds. *Principles and Practices of Pediatric Oncology*. 6th ed. Philadelphia, PA: Wolters Kluwer/Lippincott Williams & Wilkins; 2011:1322–1346
- Himelstein BP, Hilden JM, Boldt AM, Weissman D. Pediatric palliative care. *N Engl J Med*. 2004;350(17):1752–1762
- Sullivan J, Monagle P. Bereaved parents' perceptions of the autopsy examination of their child. *Pediatrics*. 2011;127(4). Available at: [www.pediatrics.org/cgi/content/full/127/4/e1013](http://www.pediatrics.org/cgi/content/full/127/4/e1013)
- Gledhill J, Rangel L, Garraalda E. Surviving chronic physical illness: psychosocial outcome in adult life. *Arch Dis Child*. 2000;83(2):104–110
- Fraser J, Harris N, Berringer AJ, Prescott H, Finlay F. Advanced care planning in children with life-limiting conditions—the Wishes Document. *Arch Dis Child*. 2010;95(2):79–82

**APPENDIX** Introducing Advance Care Planning Guides to Adolescents and Young Adults

---

Who should introduce an advance care planning document	<ul style="list-style-type: none"> <li>• Can be introduced by a member of the health care team who has developed a trusting relationship with the AYA and family; has familiarity with the physical, psychosocial, cultural, and spiritual needs of the youth and family; and has the confidence and trust of the family to talk frankly about potentially upsetting issues without it being perceived as the health care team “giving up on them.”</li> </ul>
When should an advance care planning document be introduced	<ul style="list-style-type: none"> <li>• The ideal time is when the AYAs health is relatively stable. Considering the frequency of predictable and unpredictable crises of acute illness, this period may be brief and it is important that youth and their families are given encouragement to take the opportunity to address these issues when they are not in a state of crisis.<sup>26</sup></li> </ul>
The process of completing an advance care planning document	<ul style="list-style-type: none"> <li>• It is not recommended that documents such as Voicing My Choices be completed quickly.</li> <li>• Each topic within the document can be presented as separate “modules,” starting with the section addressing (comfort) or (support) tailored to the AYAs concerns at the time. The document may be revised as health needs and support systems change over time.<sup>32</sup></li> <li>• Some AYAs wish to complete planning documents on their own. Decisions about life support treatment are best completed with a health care provider. Even with the glossary of terms provided in documents such as Voicing My Choices, understanding resuscitation and supportive measures can be confusing.</li> </ul>
Legal considerations	<ul style="list-style-type: none"> <li>• For youth younger than 18, advance care planning documents holds no legal status in the United States and the document belongs to the family.</li> <li>• These documents, with permission from the AYA, can be shared with involved providers to provide insight into the AYA's preferences.</li> </ul>

---

**Allowing Adolescents and Young Adults to Plan Their End-of-Life Care**  
Lori Wiener, Sima Zadeh, Haven Battles, Kristin Baird, Elizabeth Ballard, Janet  
Osherow and Maryland Pao  
*Pediatrics*; originally published online October 8, 2012;  
DOI: 10.1542/peds.2012-0663

<b>Updated Information &amp; Services</b>	including high resolution figures, can be found at: <a href="/content/early/2012/10/02/peds.2012-0663">/content/early/2012/10/02/peds.2012-0663</a>
<b>Supplementary Material</b>	Supplementary material can be found at: <a href="/content/suppl/2012/10/02/peds.2012-0663.DCSupplemental.html">/content/suppl/2012/10/02/peds.2012-0663.DCSupplemental.html</a>
<b>Citations</b>	This article has been cited by 12 HighWire-hosted articles: <a href="/content/early/2012/10/02/peds.2012-0663#related-urls">/content/early/2012/10/02/peds.2012-0663#related-urls</a>
<b>Permissions &amp; Licensing</b>	Information about reproducing this article in parts (figures, tables) or in its entirety can be found online at: <a href="/site/misc/Permissions.xhtml">/site/misc/Permissions.xhtml</a>
<b>Reprints</b>	Information about ordering reprints can be found online: <a href="/site/misc/reprints.xhtml">/site/misc/reprints.xhtml</a>

PEDIATRICS is the official journal of the American Academy of Pediatrics. A monthly publication, it has been published continuously since 1948. PEDIATRICS is owned, published, and trademarked by the American Academy of Pediatrics, 141 Northwest Point Boulevard, Elk Grove Village, Illinois, 60007. Copyright © 2012 by the American Academy of Pediatrics. All rights reserved. Print ISSN: 0031-4005. Online ISSN: 1098-4275.

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™



# PEDIATRICS®

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

**Allowing Adolescents and Young Adults to Plan Their End-of-Life Care**  
Lori Wiener, Sima Zadeh, Haven Battles, Kristin Baird, Elizabeth Ballard, Janet  
Osherow and Maryland Pao  
*Pediatrics*; originally published online October 8, 2012;  
DOI: 10.1542/peds.2012-0663

The online version of this article, along with updated information and services, is  
located on the World Wide Web at:  
[/content/early/2012/10/02/peds.2012-0663](http://content.early/2012/10/02/peds.2012-0663)

PEDIATRICS is the official journal of the American Academy of Pediatrics. A monthly publication, it has been published continuously since 1948. PEDIATRICS is owned, published, and trademarked by the American Academy of Pediatrics, 141 Northwest Point Boulevard, Elk Grove Village, Illinois, 60007. Copyright © 2012 by the American Academy of Pediatrics. All rights reserved. Print ISSN: 0031-4005. Online ISSN: 1098-4275.

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™

