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

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

ABBRévIATIONS
AYAs—adolescents and young adults
EoL—end-of-life
MTMWMV—My Thoughts, My Wishes, My Voice

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.

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 liked 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

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.
Each year, more than 11,000 adolescents and young adults (AYAs), ages 15 to 34, die of cancer and other life-threatening conditions and the number of youth with chronic and life-limiting conditions is increasing. 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. Although some provider and parent discomfort exists surrounding discussions of death and EoL care, AYAs have expressed a desire and the ability to share their values, beliefs, and preferences for treatment at the EoL. 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.

During normal adolescent development, individuals gain independence, formulate their self-identity, strengthen peer and romantic relationships, and define their future role in life. 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. 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. 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 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). 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 study10 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

<table>
<thead>
<tr>
<th>Five Wishes</th>
<th>MTMWMV</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Person I Want To Make Health Care Decisions For Me When I Can’t Make Them For Myself</td>
<td>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.</td>
</tr>
<tr>
<td>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.</td>
<td>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).</td>
</tr>
<tr>
<td>My Wish For How Comfortable I Want To Be</td>
<td>One page reformatted with check boxes for ease and space to include other wishes.</td>
</tr>
<tr>
<td>My Wish For How I Want People to Treat Me</td>
<td>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.</td>
</tr>
<tr>
<td>My Wish for What I Want My Loved Ones To Know</td>
<td>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.</td>
</tr>
<tr>
<td>Spiritual Wishes</td>
<td>A separate page to discuss spiritual preferences.</td>
</tr>
<tr>
<td>Formerly a portion of My Wish For What I Want My Loved Ones To Know.</td>
<td>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.</td>
</tr>
<tr>
<td>My Voice</td>
<td>Blank pages added for writing messages and/or letters to family, friends, and loved ones.</td>
</tr>
</tbody>
</table>
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 ($\chi^2 [1] = 2.8, P < .10$). 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 MWMTMV 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 3).

 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.

 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, 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 4 Which Version Is More Appropriate for Someone Your Age?

<table>
<thead>
<tr>
<th></th>
<th>Total n (%)</th>
<th>Diagnosis</th>
<th>Age Group</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HIV n (%)</td>
<td>Cancer n (%)</td>
<td>16–21 n (%)</td>
<td>22–28 n (%)</td>
</tr>
<tr>
<td>Wish 1: Who will make my medical care decisions if I cannot</td>
<td>25 (48.1)</td>
<td>10 (38.5)</td>
<td>11 (37.9)</td>
<td>11 (47.8)</td>
</tr>
<tr>
<td>Five Wishes</td>
<td>27 (51.9)</td>
<td>14 (61.5)</td>
<td>18 (62.1)</td>
<td>14 (58.3)</td>
</tr>
<tr>
<td>MTMWMV</td>
<td>26 (50.0)</td>
<td>17 (85.4)</td>
<td>14 (78.6)</td>
<td>7 (30.4)</td>
</tr>
<tr>
<td>Wish 2: Kind of medical treatment I want/do not want</td>
<td>26 (50.0)</td>
<td>15 (78.3)</td>
<td>17 (79.2)</td>
<td>7 (30.4)</td>
</tr>
<tr>
<td>Five Wishes</td>
<td>27 (51.9)</td>
<td>16 (72.2)</td>
<td>18 (62.1)</td>
<td>11 (46.2)</td>
</tr>
<tr>
<td>MTMWMV</td>
<td>26 (50.0)</td>
<td>17 (85.4)</td>
<td>18 (76.0)</td>
<td>8 (32.1)</td>
</tr>
<tr>
<td>Wish 3: How comfortable I want to be</td>
<td>26 (50.0)</td>
<td>16 (73.1)</td>
<td>17 (61.5)</td>
<td>6 (24.0)</td>
</tr>
<tr>
<td>Five Wishes</td>
<td>27 (51.9)</td>
<td>17 (85.4)</td>
<td>18 (76.0)</td>
<td>9 (36.0)</td>
</tr>
<tr>
<td>MTMWMV</td>
<td>26 (50.0)</td>
<td>17 (85.4)</td>
<td>18 (79.2)</td>
<td>7 (28.0)</td>
</tr>
<tr>
<td>Wish 4: How I would like to be treated</td>
<td>27 (51.9)</td>
<td>16 (75.0)</td>
<td>18 (76.0)</td>
<td>9 (36.0)</td>
</tr>
<tr>
<td>Five Wishes</td>
<td>28 (52.9)</td>
<td>17 (85.8)</td>
<td>18 (76.0)</td>
<td>8 (32.1)</td>
</tr>
<tr>
<td>MTMWMV</td>
<td>27 (51.9)</td>
<td>17 (85.4)</td>
<td>18 (76.0)</td>
<td>7 (28.0)</td>
</tr>
<tr>
<td>Wish 5: What I want family/friends to know</td>
<td>27 (51.9)</td>
<td>16 (75.0)</td>
<td>18 (76.0)</td>
<td>9 (36.0)</td>
</tr>
<tr>
<td>Five Wishes</td>
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</tr>
<tr>
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<td>18 (76.0)</td>
<td>7 (28.0)</td>
</tr>
</tbody>
</table>

* P < .05
* P < .10
* P < .01
* One respondent answered “both” and was excluded from these questions.

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

<table>
<thead>
<tr>
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<th>Total n (%)</th>
<th>Diagnosis</th>
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<tbody>
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<td>Cancer n (%)</td>
<td>16–21 n (%)</td>
</tr>
<tr>
<td>Wish 1: Who will make my medical care decisions if I cannot</td>
<td>35 (67.3)</td>
<td>19 (73.1)</td>
<td>16 (61.5)</td>
</tr>
<tr>
<td>Wish 2: Kind of medical treatment I want/do not want</td>
<td>42 (80.8)</td>
<td>20 (76.9)</td>
<td>22 (84.6)</td>
</tr>
<tr>
<td>Wish 3: How comfortable I want to be</td>
<td>25 (48.1)</td>
<td>14 (53.8)</td>
<td>11 (42.3)</td>
</tr>
<tr>
<td>Wish 4: How I would like to be treated</td>
<td>21 (40.4)</td>
<td>9 (34.6)</td>
<td>12 (46.2)</td>
</tr>
<tr>
<td>Wish 5: What I want family/friends to know</td>
<td>27 (51.9)</td>
<td>16 (61.5)</td>
<td>11 (42.3)</td>
</tr>
<tr>
<td>Wish 6: Spiritual wishes</td>
<td>16 (30.8)</td>
<td>9 (34.6)</td>
<td>7 (28.0)</td>
</tr>
<tr>
<td>Wish 7: How I want to be remembered</td>
<td>31 (59.6)</td>
<td>18 (69.2)</td>
<td>13 (52.0)</td>
</tr>
<tr>
<td>Wish 8: My voice</td>
<td>35 (67.3)</td>
<td>18 (69.2)</td>
<td>17 (73.8)</td>
</tr>
</tbody>
</table>
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, 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, 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
REFERENCES


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

<table>
<thead>
<tr>
<th>Who should introduce an advance care planning document</th>
<th>• 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.”</th>
</tr>
</thead>
<tbody>
<tr>
<td>When should an advance care planning document be introduced</td>
<td>• The ideal time is when the AYA’s 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.²⁶</td>
</tr>
</tbody>
</table>
| The process of completing an advance care planning document | • It is not recommended that documents such as Voicing My Choices be completed quickly.  
• Each topic within the document can be presented as separate “modules,” starting with the section addressing (comfort) or (support) tailored to the AYA’s concerns at the time. The document may be revised as health needs and support systems change over time.²²  
• 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. |
| Legal considerations | • For youth younger than 18, advance care planning documents hold no legal status in the United States and the document belongs to the family.  
• These documents, with permission from the AYA, can be shared with involved providers to provide insight into the AYA’s preferences. |
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