

How I Wish to be Remembered: The Use of an Advance Care Planning Document in Adolescent and Young Adult Populations

Lori Wiener, Ph.D.,¹ Elizabeth Ballard, B.A.,² Tara Brennan, Psy.D.,¹ Haven Battles, Ph.D.,¹
Pedro Martinez, M.D.,² and Maryland Pao, M.D.²

Abstract

Background: Discussing end-of-life (EOL) issues is difficult with any population. These conversations are even more challenging with adolescents and young adults due to the poignancy of the situation and the need for developmentally appropriate language.

Objective: To explore whether adolescents and young adults living with a life-limiting illness find it acceptable and helpful to have a planning document to share their wishes and thoughts regarding EOL care. If so, to learn about specific concerns adolescents and young adults feel are important to include in such a document.

Methods: Adolescents and young adults with metastatic cancer or pediatric human immunodeficiency virus (HIV)-1 infection were presented *Five Wishes*[®], an advance directive document for adults. Each participant was asked to critically evaluate each wish in terms of whether the concepts within were considered (1) appropriate to ask individuals the participant's age; (2) helpful for other people the participant's age to think about; (3) helpful to the participant to think about; (4) stressful to contemplate. Participants were also asked to suggest modifications and additions to the document.

Results: Twenty patients completed the survey. Ninety-five percent of the participants reported that an advance directive like *Five Wishes*[®] would be "helpful" or "very helpful" to themselves, 90% stated that the document would be helpful to others, and no patients found talking about the issues in *Five Wishes*[®] "stressful" or "very stressful." Participants were more interested in items concerning how they wanted to be treated and remembered than items concerning medical decision-making.

Conclusions: An advance care planning document may be appropriate and helpful for adolescents and young adults living with a serious illness. Future research should further validate the preferences identified by participants and explore whether an age-appropriate document can improve communication with family and staff in EOL care.

Introduction

DISCUSSIONS ABOUT END-OF-LIFE (EOL) care are a priority in providing comprehensive palliative care to all patients.¹⁻³ The American Academy of Pediatrics and the Institute of Medicine recommend that children, adolescents, and young adults with a life-limiting illness be involved in the palliative care and decision-making process as much as possible and in a developmentally appropriate manner.^{1,2} Previous interviews with adolescent chronically ill patients have shown that this population is able and willing to take

part in conversations about palliative care.⁴⁻⁶ While chronically ill adolescents and young adults express a strong desire to share in medical decision-making if they are very ill,⁵ nurses,⁷ doctors,^{8,9} and parents¹⁰ often report discomfort with initiating EOL discussions with this population. In addition, there is concern among adults that speaking about death and dying with seriously ill young patients would be too stressful and may counteract the "culture of hope" present in pediatric and adolescent medical settings.⁸

While the ability of advance directives to capture patient preferences has been debated,^{11,12} it is generally believed that

¹Pediatric Oncology Branch, National Cancer Institute/National Institutes of Health, Bethesda, Maryland.

²National Institute of Mental Health, National Institutes of Health, Bethesda, Maryland.

advance care planning documents may aid in initiating EOL discussions between patients, families, and clinicians.

Comprehensive and sensitive EOL documents exist for the adult population, yet no planning guides are currently available to aid in palliative care discussions with adolescents and young adults. Prior studies with seriously ill adolescent and young adult populations have provided valuable information on EOL preferences, but most of the literature has been primarily anecdotal in nature.¹³ Furthermore, a number of important areas have not yet been explored. It is not known how the personal wishes of adolescents and young adults can best be expressed to family and staff, or which specific topics should be addressed in EOL discussions. Additionally, while one recent study suggested that healthy adolescents felt it was important for someone their age to have a living will,⁶ it is not known if adolescents and young adults with a life-limiting illness would consider an advance care planning document to be appropriate or helpful.

We sought to determine whether an EOL document like *Five Wishes*®, and other relevant topics raised in clinical sessions prior to the current study would be considered appropriate and helpful for adolescents and young adults living with a serious illness. This study also attempts to explore which specific concerns adolescents and young adults feel are most important in planning EOL care.

Methods

Sample

Participants were enrolled in research protocols at the National Cancer Institute, Pediatric Oncology Branch (NCI, POB). All participants were outpatients at the time of study participation. In order to be eligible for participation, participants had to (1) have a diagnosis of HIV-1 acquired at birth or early in life, or a diagnosis of metastatic or recurrent cancer, (2) be English- or Spanish-speaking, and (3) be between the ages of 16 and 28. This age range was based on the NCI Institutional Review Board (IRB) stipulations and also reflects the age range of the majority of patients treated for pediatric malignancies or pediatric HIV infection within the POB. Further eligibility requirements included a score above a cutoff on scales of performance status and general well-being (40 or greater on Lansky/Karnofsky scale; 3 or less on the Eastern Cooperative Oncology Group Performance Status Scale), and primary physician approval of participation. This study was approved by the NCI IRB.

TABLE 1. ADVANCE CARE PLANNING READINESS QUESTIONS

- | |
|---|
| 1. It might be helpful for me to talk about what would happen if treatments were no longer effective. (Yes/No) |
| 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 treatments options available would upset me very much. (Yes/No) |
| 3. I feel comfortable writing down or discussing what I want to happen to me if treatments were no longer effective. (Yes/No) |

Measures

Readiness assessment. This questionnaire was developed for this study to assess patient comfort and preparedness to discuss EOL issues. The assessment consisted of three questions (Table 1) and took approximately 5 minutes to complete.

Five Wishes®. This is a document that appoints a legal health care decision-maker at the end of life and specifies desired medical and palliative care treatments (www.aging-withdignity.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 five “wishes” that concern different parts of the EOL care process:

- The Person I Want to Make Care Decisions for Me When I Can't
- The Kind of Medical Treatment I Want or Don't Want
- How Comfortable I Want to Be
- How I Want People to Treat Me
- What I Want My Loved Ones to Know

Within the document, each “wish” has a number of statements and respondents are asked to cross out the statements they do not agree with or would not want their designated health care agent to perform. The document also provides space for the individual to detail personal, emotional, and spiritual wishes. While over 6 million adults world wide use *Five Wishes*®, the demographics of those individuals are unknown.

Five Wishes® evaluation. In this in-person interview, participants were asked to assess each “wish” and the concepts within each of the *Five Wishes*® for appropriateness for themselves and other people their age with a serious illness. The participants were also asked which “wish” was the most and least helpful and which questions and statements should be removed and why.

Evaluation of clinically generated items. Prior to the described study, clinical sessions were conducted with 20 different adolescents and young adults with HIV or cancer, ages 16–25, to generate additional topics that would be useful in an EOL planning document. Items elicited that were not already included in *Five Wishes*® are listed in Table 2. Participants in the current study were asked to evaluate these items' helpfulness to themselves and others their age living with a serious illness.

Procedure

After primary physician approval, all eligible participants were informed of the study's purpose and were offered participation. If they expressed an interest in participating, an in-depth explanation of the study's purpose, risks, and benefits were described, and written informed consent obtained. In the case of individuals under the age of 18 years, parents were approached first and if they were interested in their child participating or their child learning more about the research, the study was explained to both the parent and child simultaneously. When parent and child agreed to partici-

TABLE 2. ADDITIONAL ITEMS ELICITED FROM PRIOR CLINICAL WORK ON EOL ISSUES

- If I get very ill and cannot communicate my wishes, these are the treatments and/or procedures I would prefer to never experience again
- This is where I want to be when the end of my life is near
- These are the people I would like to be with me when the end of my life is near
- Special ways I want to be remembered on my birthday by family and friends
- How I would like to be remembered on specific holidays
- The people who I would like to receive my belongings
- Final Arrangements
 - I would like to be buried
 - I would like to be cremated
 - I would like for there to be a funeral/celebration of my life
- Music/readings/schedule/decorations that I would like to be at my service
- How I want my family to treat each other when the end of my life is near
- The things I would like to accomplish/do or the places I would like to go

Note: The original *Five Wishes*® document can be viewed at www.agingwithdignity.org. EOL, end of life.

pate, parents provided consent while participants provided written assent.

Participants were aware that to be eligible for the study, they must be living with a serious illness, either recurrent or advanced cancer or HIV disease acquired early in life or at birth. To assess and assure readiness to discuss issues pertaining to end-of-life care, each participant completed the yes/no questions in Table 1. In the event that a participant expressed discomfort with any of the options (thus, did not meet the readiness criteria), they were asked if they would feel comfortable being contacted for follow-up in a month to determine if they were more willing at that time to discuss EOL issues. If they were not, their involvement in the study was completed.

Interviews evaluating *Five Wishes*® concepts were conducted by one of three members of the research team, all of whom received training in clinical interviewing techniques and the study documents. Participants who met readiness criteria read through *Five Wishes*® and were asked whether each question was: (1) appropriate to ask individuals the participant’s age; (2) helpful for other people the participant’s age to think about; (3) helpful for the participant to think about; and (4) stressful to contemplate. Responses were based on a Likert scale of 1 to 5. Participants were then asked if there were statements or questions they would remove from the document or if there were items they would add to it. Participants were not asked to answer the questions for themselves; rather, they were asked only to evaluate the concepts within the document for their appropriateness, helpfulness, and stressfulness. Participants then evaluated the items generated from prior clinical sessions, rating their appropriateness and helpfulness. Interviews were completed in one session and took between 30 and 45 minutes to complete.

Statistical analysis

This study was exploratory in nature. It was designed to gather qualitative information from a small sample of adolescents and young adults with HIV and cancer on the applicability of an advance directive like *Five Wishes*® to an adolescent and young adult population. All data are reported descriptively.

Results

Demographic information is provided in Table 3. Twenty-two patients were approached for inclusion in this study: one participant did not meet readiness criteria and therefore did not continue with the evaluation and one consented participant died before the scheduled study interview, resulting in a final sample size of 20. All primary physicians approved their patients’ participation. Ninety-five percent ($n = 19$) of participants reported that, overall, a document like *Five Wishes*® could be “helpful” or “very helpful” in their own EOL situation, and 90% ($n = 18$) reported the document could be helpful to others their age living with a serious illness. None of the participants reported that reviewing the concepts in *Five Wishes*® was “stressful” or “very stressful.” Thirty-five percent ($n = 7$) described reviewing the document as “somewhat stressful”, 20% ($n = 4$) reported that it was a little stressful, and 45% ($n = 9$) reported that it was not stressful at all. While none of the participants reported that overall review of *Five Wishes*® was “stressful” or “very stressful,” individual wishes did elicit some stress. The item associated with the greatest amount of stress was Wish 2 (My

TABLE 3. DEMOGRAPHICS CHARACTERISTICS OF STUDY PARTICIPANTS ($n = 20$)

	n (%)
Gender	
Male	10 (50)
Age range	
16–19 years	9 (45)
20–28 years	11 (55)
Race	
Caucasian	10 (50)
African American	8 (40)
Hispanic	2 (10)
Diagnosis	
Cancer	10 (50)
Mean age = 21.7	
HIV	10 (50)
Mean age = 19.1	

HIV, human immunodeficiency virus.

Wish for the Kind of Medical Treatment I Want or Don't Want), which asks respondents about preferences for life support treatments in four possible medical conditions/states (e.g., close to death, comatose, severe brain damage). Forty-percent ($n = 8$) of participants described reviewing this wish as "stressful" or "very stressful." Many participants were confused by the language (i.e., "end stage condition") and felt that there were too many medical conditions listed. There were several suggestions to make this section more open-ended (i.e., "Thoughts about what I would like my doctor to do or not do").

Forty percent ($n = 8$) of participants found Wish 5 (My Wish for What I Want My Loved Ones to Know) to be the most helpful. Many participants were particularly interested in the statements referring to the offer of love and forgiveness to family and friends, planning their memorial service, and indicating ways they could be remembered after their death.

When asked what changes they would make to the document, participants wanted to remove the phrase "health care agent," citing it to be unclear and impersonal. An alternative of "chosen responsible adult" was suggested. Furthermore, several participants reported discomfort with identifying only one individual to make health care decisions, preferring that additional family members be involved in any decision making. Concerns about assisted living, hospice, and nursing home care, and medical record release were not considered to be a high priority to this population. Several participants suggested that the questions addressing pain were limiting and there was a desire to be able to balance pain control with "being drowsy." Participants were particularly interested in issues of personal comfort and wanted to add questions about who and what they wanted around them at the end-of-life, including visitors, personal items, music, and food. Formatting changes included having more open-ended statements (e.g. "I wish for my family and friends to know that this is how I view death . . ." "The things most important to me before this illness were . . ." "The things most important to me now are . . .") and more space for elaborating on their wishes. Suggestions were made to create an open-ended section where a letter could be written to loved ones. Other format changes involved the religious/spiritual questions that are included throughout *Five Wishes*[®]. Some participants welcomed the opportunity to ask for supportive spiritual guidance while others were uncomfortable with these items. A suggestion was made to have a separate section on religious and spiritual questions that would be optional to complete.

The participants' responses to the clinically generated items provided further insight and feedback on the usefulness of an age-appropriate EOL document. All of the statements were endorsed as helpful to themselves and others their age living with life-limiting illness. These topics included where they would like to be at the end of their life, final arrangements, bequeathing their belongings, and how they would like to be remembered after their death.

Discussion

To the best of our knowledge, this is the first examination and critique of the usefulness of an advance care planning document by adolescents and young adults living with a life-

limiting illness. These results provide additional empirical support that adolescents and young adults are open and interested in discussing their EOL care. The nearly universal finding that such a document would be useful, appropriate, helpful, and minimally stressful is particularly important for future clinical care and research endeavors.

Advance directives like *Five Wishes*[®] often address a broad range of treatment options ranging from relatively non-invasive procedures to mechanical ventilation. Our participants appeared to be more interested in items regarding how they want to be treated and remembered, and having an opportunity to express concern for those they will leave behind, than they were about items related to legalities, medical decision-making, and life-support treatments. Adolescents may be less concerned with medical decision-making due to difficulties in understanding legal language and concepts, but it is also possible that participants treated in a pediatric facility would rely on their parents to make such decisions for them. Regardless, adolescents and young adults report that end-of-life topics are difficult to discuss with family and friends.^{14,15} While all participants endorsed the statement that talking about end-of-life care is important, only 45% reported that they had discussed these thoughts with their parents in the month prior to when the study interview was conducted. Having an advance care planning document could foster discussion with family and friends, and could facilitate communication between the primary health care provider and the adolescent or young adult regarding their personal goals, values, or beliefs. As such, EOL conversations in the context of completing a planning document might increase communication, reduce isolation, and have a positive therapeutic effect.

This study had several limitations. First, our sample size was small. Since we were unsure how adolescents and young adults would respond to questions about an EOL document, a sample size of 20 patients was believed to be adequate to gain qualitative data for this exploratory study. This did not afford adequate power to conduct statistical testing between age groups or disease type. In addition to the small sample size, the specific inclusion criteria may limit the generalization of our findings. Study participation included adolescents and young adults with cancer or HIV infection, who had good performance status and were enrolled in research protocols. Future investigations with advance care planning tools will benefit from larger cohorts, the addition of individuals with different chronic and serious illnesses, and individuals with lower performance status and/or those not enrolled in a research study. Also, in planning for this study, a Readiness Assessment was created to protect individuals who were not comfortable discussing issues associated with end-of-life care. Reliability or validity of the three questions was not assessed prior to the study onset. Since a screening measure that could assess a young person's readiness to complete an advanced care planning guide could be a very useful tool, future research would benefit from investigating the psychometrics of such an instrument. Last, a limitation and perhaps also an advantage of this investigation is that participants were not asked to complete *Five Wishes*[®], but rather to examine it as a "consultant," which may have led to a less stressful experience. This caveat may have also led to the ability to obtain such rich information. Despite these limitations, the excellent study participation rate, and the nearly universal report by the participants that an advance care planning document

would be useful and appropriate for someone their age is a particularly striking finding. The comments received from participants will lead to the creation of a developmentally appropriate document to be used in future validation studies. Future studies would benefit from evaluating how adolescents and young adults understand terms like cardiopulmonary resuscitation, mechanical ventilation, hospice and hospice care and how adolescents younger than age 16 would respond to reviewing an EOL planning document. Moreover, there has been no research on the willingness of adolescents or young adults to complete an advance care planning document or the impact of doing so on decision-making at the end of life. It is critical that future studies investigate whether having an advance care planning guide allows the individuals' preferences to be known and honored.

Conclusions

A developmentally appropriate advance care planning document may play an important role in the care of seriously ill adolescents and young adults. As we listen to the concerns and provide counsel to our adolescent and young adult patients throughout treatment, we need to do the same about their thoughts surrounding their death and how they would like to be remembered in the years to come. By providing an avenue to share such intimate views and wishes, communication is promoted, decision making is fostered and in the face of death, the experience of dignity and respect of self-autonomy and determination can be augmented.

Acknowledgements

We would like to thank Kristin Baird, M.D., Christine Grady, Ph.D., David Wendler, Ph.D., Alan Wayne, M.D., Crystal Mackall, M.D., Lee Helman, M.D., Rohan Hazra, M.D., and Rebecca Prengler, for their support in implementing this study and special thanks to the patients that so graciously shared their time and insights with us. We would also like to thank Aging with Dignity for providing the Five Wishes® document to be used in this research endeavor and for their ongoing enthusiasm for our study.

This research was supported by the Center for Cancer Research, National Cancer Institute and the National Institute of Mental Health.

The opinions expressed in the article are the views of the authors and do not necessarily reflect the views of the Department of Health and Human Services or the United States government.

Author Disclosure Statement

No competing financial interests exist.

References

1. American Academy of Pediatrics: Palliative care for children. *Pediatrics* 2000;106:351–357.
2. Committee on Palliative and End-of-Life Care for Children and Their Families, Board on Health Sciences Policy; Field MJ, Behrman RE (eds): *When Children Die: Improving Palliative and End-of-Life Care for Children and their Families*. Washington, D.C.: National Academies Press, 2002.
3. Sahler OJ: The child and death. *Pediatr Rev* 2000;21:350–353.
4. Hinds PS, Drew D, Oakes LL, Fouladi M, Spunt SL, Church C, Furman WL: End-of-life care preferences of pediatric patients with cancer. *J Clin Oncol* 2003;23:9146–9154.
5. Lyon ME, McCabe MA, Patel KM, D'Angelo LJ: What do adolescents want? An exploratory study regarding end-of-life decision-making. *J Adolesc Health* 2004;35:1–6.
6. McAliley LG, Hudson-Barr DC, Gunning RS, Rowbottom LA: The use of advance directives with adolescents. *Pediatr Nurs* 2000;26:471–480.
7. Feudtner C: Collaborative communication in pediatric palliative care: A foundation for problem-solving and decision-making. *Pediatr Clin North Am* 2007;54:583–607.
8. Morgan ER, Murphy SB: Care of children who are dying of cancer. *N Engl J Med* 2000;342:347–348.
9. Davies B, Serhing S, Partridge C, Cooper BA, Hughes A, Philp JC, Amidi-Nouri A, Kramer RF: Barriers to palliative care for children: Perceptions of Pediatric Health Care Providers. *Pediatrics* 2008;121:282–288.
10. Steele R, Davies B: Impact on parents when a child has a progressive, life-threatening illness. *Int J Palliat Nurs* 2006;12:576–585.
11. Tulsky JA: Beyond advance directives: Importance of communication skills at the end of life. *JAMA* 2005;294:359–365.
12. Perkins HS: Controlling death: The false promise of advance directives. *Ann Intern Med* 2007;147:51–57.
13. Kristjanson LJ, Hanson EJ, Balneaves L: Research in palliative care populations: Ethical issues. *J Palliat Care* 1994;10:10–15.
14. Kreicbergs U, Valdimarsdottir U, Onelov E, Henter JI, Steinck G: Talking about death with children who have severe malignant disease. *N Engl J Med* 2004;351:1175–1186.
15. Wiener LS, Hersh SP, Kazak AE: Psychiatric and psychosocial support for the child and family. In: Pizzo PA, Poplack D (eds): *Principles and Practice of Pediatric Oncology*, 5th ed. Philadelphia: Lippincott, 2006, pp. 1414–1445.

Address reprint requests to:
Lori Wiener, Ph.D.
Pediatric Oncology Branch
NCI/NIH
10 Center Drive
Room 1-6466
Bethesda, MD 20892

E-mail: wienerl@mail.nih.gov