

Family-Centered Advance Care Planning for Teens With Cancer

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Importance: Advance care planning (ACP) prepares patients and their families for future health care decisions; however, the needs of adolescent oncology patients for participation in ACP have not been well studied.

Objective: To examine the efficacy of family-centered ACP.

Design and Setting: Two-group randomized controlled trial in a pediatric oncology program.

Participants: Sixty adolescents aged 14 to 21 years with cancer and their surrogates or families were enrolled in the study between January 17, 2011, and March 29, 2012.

Intervention: Thirty dyads received 3- to 60-minute sessions 1 week apart. Intervention dyads completed (1) the Lyon Family-Centered ACP Survey, (2) the Respecting Choices interview, and (3) Five Wishes. Control subjects received standard care plus information.

Main Outcome Measures: Statement of treatment preferences and Decisional Conflict Scale score.

Results: The mean age of the adolescents was 16 years; 36 (60%) were male, 30 (50%) white, 26 (43%) black, and 4 (7%) Asian. Diagnoses were as follows: leukemia

(14 patients [47%]), brain tumor (8 [27%]), solid tumor (6 [20%]), and lymphoma (2 [7%]). Significantly increased congruence was observed for intervention dyads compared with controls for 4 of the 6 disease-specific scenarios; for example, for situation 2 ("treatment would extend my life by not more than 2 to 3 months"), intervention dyads demonstrated higher congruence ($\kappa = 0.660$; $P < .001$) vs control dyads ($\kappa = -0.0636$; $P = .70$). Intervention adolescents (100%) wanted their families to do what is best at the time, whereas fewer control adolescents (62%) gave families this leeway. Intervention adolescents were significantly better informed about end-of-life decisions ($t = 2.93$; effect size, 0.961; 95% CI, 0.742-1.180; $P = .007$). Intervention families were more likely to concur on limiting treatments than controls. An ethnic difference was found in only one situation.

Conclusions: Advance care planning enabled families to understand and honor their adolescents' wishes. Intervention dyads were more likely than controls to limit treatments. Underserved African American families were willing to participate.

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THE BENEFITS OF INVOLVING the surrogate decision maker in advance care planning (ACP) have recently been demonstrated empirically through increased congruence in treatment preferences, decreased decisional conflict for the patient,¹⁻⁴ and congruent care actually received before death,⁵ overcoming obstacles in initial ACP efforts.⁶⁻⁸ These

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benefits have not yet been translated to adolescents with cancer, although preliminary studies^{4,9-15} of adolescent patients with human immunodeficiency virus and AIDS demonstrated similar benefits. Many physicians continue to report that one barrier to conducting ACP discussions with children with a life-threatening condition is that they do not know the right thing to say.¹⁶

Despite advances, cancer remains the leading cause of death in teenagers.¹⁷ The quality of their palliative care is a health care priority.^{18,19} Approximately one-quarter die of their primary cancer, and a subset develop serious health problems and die prematurely as a result of late effects of treatment.²⁰⁻²² Left unprepared for end-of-life (EOL) decisions, families can be torn apart by miscommunication and disagreements and in extreme situations can even get involved in court battles and legislative intervention.²³ Advance care planning prepares patients and their loved ones for future health care decisions, including EOL care.^{24,25} Yet, the needs of adolescent oncology patients for participation in ACP, despite its priority,²⁶⁻²⁸ have not been well studied.^{29,30}

Our goal was to test a model of ACP that anticipates these issues, fully empowers the family and adolescent, and keeps the key

role of health care professionals central, building on our earlier work.^{4,9-15,31} We hypothesized that family-centered ACP would (1) increase congruence in treatment preferences between adolescents and surrogates, (2) decrease decisional conflict for adolescents, and (3) increase quality of communication compared with controls.

METHODS

PARTICIPANTS

Between January 17, 2011, and March 29, 2012, adolescents aged 14 to 21 years with cancer and an available legal guardian (if the patient was younger than 18 years) or surrogate decision maker who was at least 21 years old were enrolled. Eligibility criteria were able to speak and understand English; knew the diagnosis; were not in foster care; were not developmentally delayed; were not severely depressed, suicidal, or homicidal; and did not have impaired mental status.³²⁻³⁵

This study was approved by the Children's National Medical Center institutional review board. Intervention development and preliminary satisfaction data have been previously presented,^{13,15,36,37} with a complete description currently in preparation.

FAMILY-CENTERED ACP INTERVENTION

Three sessions of approximately 60 minutes were conducted weekly.

Session 1

The Lyon Family-Centered ACP Survey-Adolescent and Surrogate version¹² is a 31-question survey designed to assess the adolescents' and surrogates' values, beliefs, and life experiences with illness and EOL care. Dyads were administered the survey separately.

Session 2

The Respecting Choices disease-specific ACP interview^{38,39} was customized to apply to adolescents with cancer. Facilitators elicited the adolescent's and surrogate's understanding of the current medical condition, prognosis and potential complications, fears, hopes, and experiences; explored the adolescent's understanding of ACP; reviewed the rationale for future medical decisions; used the statement of treatment preferences¹ to encourage dialogue about goals and values in real "bad outcome" situations; promoted understanding of the adolescent's goals and values with the surrogate; and addressed the need for future discussions as situations and preferences change.

Session 3

Adolescents completed Five Wishes,⁴⁰ an advanced directive document, with their family present. For adolescents younger than 18 years, Five Wishes was used as a tool⁴¹ to help them participate in shared decision making. The parent or legal guardian signed the Five Wishes document to make it legally sufficient.

Intervention facilitators were certified through a standardized, competency-based training program. Video and audio recordings and weekly supervision were used to monitor procedures and ensure protocol fidelity.

STANDARD-OF-CARE CONTROL

All participants were given a brochure with information on ACP during the baseline assessment, but control dyads did not receive the 3 session-facilitated conversations. Rather, assessments were administered at the same 5 points in time as the intervention dyads (baseline; sessions 1 through 3; and 3-month follow-up).

OUTCOME MEASURES

The statement of treatment preferences¹ was administered to participants during study visit 3. It documents specific treatment preferences of patients and the surrogates' understanding of what the patients would want. Six situations were presented. Patients and surrogates chose 1 of 3 options: "to continue all treatment and keep fighting," "to stop all treatment to prolong my life," and "don't know." This tool has been used in studies with adults¹⁻³ and a prior study with adolescents.⁴ An additional item, a latitude statement, clarified the decision-making authority a patient wished to grant the surrogate. Surrogates were asked to either "strictly follow my wishes" or "do what the surrogate thinks is best at the time, knowing my wishes."

The Decisional Conflict Scale⁴² was administered to adolescents only during study visit 3 after completion of the statement of treatment preferences. It was used to measure the degree of uncertainty about the course of action to take. The Decisional Conflict Scale consists of 3 subscales on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree) (eg, "This decision was hard for me to make."). The Decisional Conflict Scale demonstrated good test-retest item reliability ($r \geq 0.80$).⁴²

Quality of Participant-Interviewer Communication⁴³ was administered during study visits 2, 3, and 4 to adolescents and their families independently. Items were scored on a 5-point scale from "definitely no" to "definitely yes": attitude and wishes are known, interviewer cared, interviewer listened, and interviewer gave attention. Overall rating of communication was scored separately. Good internal consistencies have been reported in patients with AIDS (Cronbach $\alpha = 0.81$).⁴⁴ Total scores for quality of communication range from 0 to 20.

STUDY DESIGN AND DATA COLLECTION

Participants were approached by a trained research assistant (RA) who used the scheduling list to see who met age criteria and had an appointment in the upcoming week. The RA would then ask the treating health care professional whether this patient was appropriate to approach during his or her clinic visit or inpatient stay (eg, meeting disease criteria and not developmentally delayed). If the patient was cleared, the RA would approach the family face-to-face in a private clinic room or, if the physician deemed it necessary, the physician would give a brief introduction to the study, and if the family agreed, the RA would explain the study to the family using an institutional review board-approved information sheet. Interested individuals were enrolled and further screened. Baseline assessment forms scanned into the computer triggered randomization. Adolescent-surrogate dyads were created on an intent-to-treat paradigm and randomly assigned to 1 of 2 study conditions (**Figure 1**). Participants and RAs were masked to assignment until baseline assessments were completed. Otherwise, participants and RAs were not masked to group assignment. Power analysis indicated 30 dyads would be minimally sufficient to detect a difference.

An RA other than the interviewer (to prevent bias) administered postsession questionnaires orally to control for literacy. All responses were recorded by the RA on standardized forms.

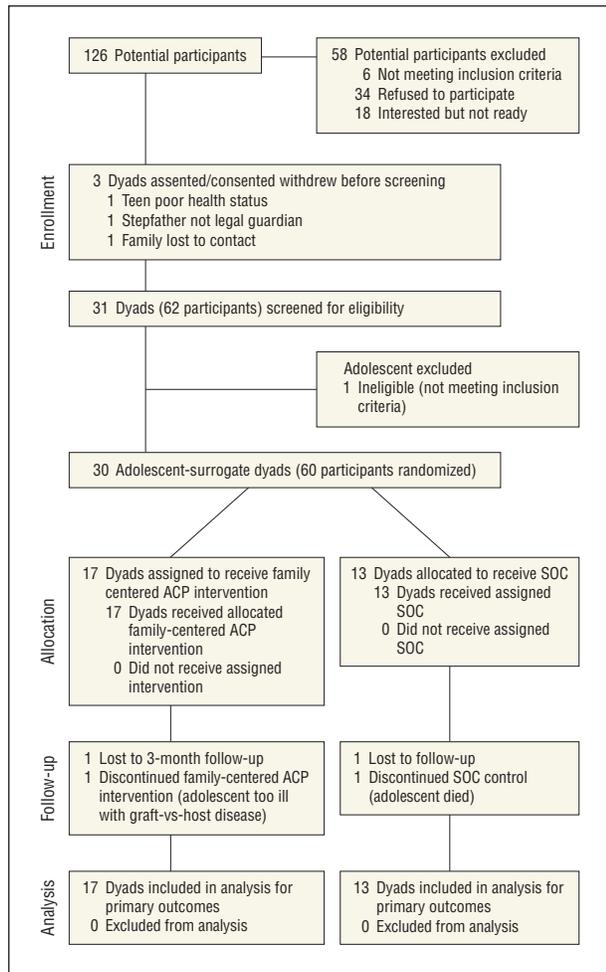


Figure 1. CONSORT diagram for family-centered advance care planning (ACP). SOC indicates standard of care. Of the 126 potential participants, if one individual declined or was not ready, the other was not approached.

STATISTICAL ANALYSES

Statistical analyses were performed using SAS statistical software, version 9.2 (SAS Institute, Inc). The κ coefficients assessed chance-adjusted agreement between surrogate and adolescent responses, and difference in κ coefficients between conditions was tested. Fisher exact tests were used to determine differences between the 2 conditions for the leeway question, and exact Wilcoxon tests were used to compare differences in decisional conflict between the 2 conditions. Quality of patient-interviewer and surrogate-interviewer communication was evaluated via exact Wilcoxon test and a growth curve analysis/generalized estimating equation model, assessing change in quality of communication by 3 sessions and over time (from session 1 to session 3 with an approximate 3-week interval) and comparing such change between the intervention and control groups. No data were missing.

RESULTS

SAMPLE CHARACTERISTICS

Potential participants were recruited from a pediatric oncology program in Washington, DC. During the study period, a population of approximately 290

patients met the age and disease eligibility criteria for the study. We approached 126 potentially eligible individuals, of whom 6 did not meet inclusion criteria, 34 refused participation, and 18 were interested but not ready (Figure 1). Reasons for declining were too busy ($n=12$), topic not helpful or appropriate ($n=3$), not interested in research in general ($n=7$) or in topic ($n=5$), topic uncomfortable ($n=3$), too ill to participate ($n=1$), and no reason given ($n=3$). After enrollment, 6 dyads withdrew: 1 teen had poor mental status, 1 stepfather was not the legal guardian, 1 family was unavailable for further contact, and 1 adolescent reported she did not have cancer.

We attained our intended sample size of 30 randomized dyads with 17 dyads randomized to intervention and 13 dyads randomized to control. Participants in both groups completed 100% of sessions 1, 2, and 3. Data were missing for only one variable from an adolescent.

Baseline characteristics are listed in **Table 1**. The mean age of the adolescents was 16 years; 36 (60%) were male, 30 (50%) white, 26 (43%) black, and 4 (7%) Asian. Most surrogates ($n=26$ [87%]) were biological parents and female. Approximately one-fourth had incomes below the federal poverty line, and one-fourth had incomes higher than 300% of the federal poverty line. Diagnoses were as follows: leukemia (14 patients [47%]), brain tumor (8 [27%]), solid tumor (6 [20%]), and lymphoma (2 [7%]). Ten patients (33%) had relapsed, 3 (10%) had not been undergoing therapy for longer than 4 years, and 22 (73%) were undergoing active treatment.

QUALITY OF COMMUNICATION

In both groups, there was almost no change over time in quality of communication, with mean values ranging from 18.16 to 19.06, indicating little intrarespondent variability or variability over time (**Table 2**). Only the score of the adolescent in the intervention group was significantly higher in session 2, using the exact Wilcoxon test ($P = .03$). The generalized estimating equation model also showed no significant difference between the intervention and control groups' score and rate of change over time.

No adverse events occurred. No confrontations emerged that triggered protocol referrals to the study ethicist or chaplain or a family problem-solving session.

CONGRUENCE IN TREATMENT PREFERENCES

Treatment preference congruence between dyads in the standard-of-care (SOC) group was low, and the κ statistics were not statistically significant in any of the 6 situations. In contrast, the treatment preference congruence was much higher in the intervention group. Except situation 5 (attempting cardiopulmonary resuscitation) ($\kappa = 0.34$, $P = .12$), the κ statistics, ranging from 0.59 to 1.00, were all statistically significant for the intervention group: situation 1 ("long hospitalization and low survival"), $P = .001$; situation 2 ("treatments would extend life by no more than 2 to 3 months, and side of effects of treatment are serious"), $P < .001$; situation 3 ("functional impairment, eg, never able to walk or talk again"),

$P < .001$; situation 4 (“not know who I was or who I was with”), $P < .001$; and situation 6 (“mechanical ventilation”), $P < .001$. **Figure 2** shows that the P values for testing equal the κ values comparing the control and intervention groups.

Table 3 lists the percentage agreement by the 3 treatment options: continue treatment, discontinue treatment, or do not know. In every situation, total congruence was higher for family-centered ACP dyads than for SOC dyads. The family-centered ACP families were more likely to have higher levels of congruence to limit treatments in every situation, whereas no dyads in the SOC condition chose to discontinue treatment in situations 1, 2, 3, and 6. The family-centered ACP discussions also increased uncertainty for the intervention families, with 24% agreeing they did not know their preferences in situation 3 or 4.

On the other hand, there was an agreement for both the family-centered ACP dyads (100%) and the SOC dyads (83.3%) to attempt mechanical ventilation. Approximately one-third of dyads in each condition agreed they would discontinue cardiopulmonary resuscitation if their physician determined that the adolescent was dying, had no reasonable chance of survival or little chance of survival if the heart stops, or resuscitation would cause significant suffering.

An ethnic difference was found in only one situation: 92% of African American families wanted to continue treatments in situation 1 compared with 47% of non-African American families (Fisher exact test, $P = .02$).

After completing the statement of treatment preferences, adolescents were asked how strictly they wanted their surrogate to follow their wishes. All family-centered ACP adolescents endorsed, “Do what he/she thinks is best at the time, considering my wishes,” whereas only 62% of SOC adolescents endorsed this choice (Fisher exact test, 2-sided, $P = .009$).

DECISIONAL CONFLICT

The family-centered ACP adolescents thought they were significantly better informed about EOL decisions than the SOC adolescents (eg, “I know which options are available to me, the benefits of each option, and the risks and side effects of each option”; informed subscore, $t = 2.93$; effect size, 0.961; 95% CI, 0.742-1.180; $P = .007$). Otherwise, no significant differences were observed between the groups.

COMMENT

To our knowledge, this pilot study is the first randomized controlled trial to examine the acceptability and efficacy of an ACP intervention with adolescents with cancer and their families. Adolescents were empowered during the family-centered ACP intervention to communicate their wishes for their own EOL care to their families in bad outcome situations. Furthermore, family-centered ACP provided an environment in which families could listen to their adolescents discuss fears, hopes, and preferences, which in some situations included discontinuing unnecessary or unwanted care. Moreover, fami-

Table 1. Baseline Characteristics for Adolescents With Cancer and Their Surrogates^a

Characteristic	Adolescents (n = 30)	Surrogates (n = 30)
Age, mean, y	16.3	43.9
Age, mode (range), y	14 (14-21)	46.0 (22-62)
Sex		
Male	18 (60)	2 (7)
Female	12 (40)	28 (93)
Race		
Asian	2 (7)	1 (3)
Black	13 (43)	13 (43)
White	15 (50)	15 (53)
Declined to report		1 (3)
Cancer diagnosis		
Leukemia	14 (47)	
Lymphoma	2 (7)	
Solid tumor	6 (20)	
Brain tumor	8 (27)	
Disease status ^b		
Active treatment (n = 22)		
Control	10 (77)	
Intervention	12 (71)	
Remission (n = 16)		
Control	7 (54)	
Intervention	9 (53)	
Relapse (n = 10)		
Control	4 (31)	
Intervention	6 (35)	
Educational level		
In high school or no high school diploma	24 (80)	1 (3)
High school graduate or GED equivalent	2 (7)	5 (16)
Some college or no bachelor's degree	4 (13)	13 (43)
College or higher educational level		11 (36)
Income		
Equal or below the federal poverty level		4 (13)
200% of federal poverty line		2 (7)
300% of federal poverty line		6 (20)
>300% of federal poverty line		14 (47)
Unreported		4 (13)

Abbreviation: GED, general educational development.

^aData are presented as number (percentage) of adolescents unless otherwise indicated.

^bFisher exact test (2-sided) for treatment status (active or remission or relapse) was not significantly different by study arm.

lies verbalized a commitment to honor these requests. The protocol was designed for communication of the adolescent's preferences to his or her health care professional (s), thus meeting the reported desire of most clinicians to have these conversations.¹⁶ There may also have been an advantage of this discussion being conducted with trained facilitators who were not part of the health care team because physicians often cite not knowing what to say as a barrier to having these discussions.¹⁶

A discussion of prognosis⁴⁵ was unimportant using the family-centered ACP model, which focused on the patient's goals of care within the context of the family's values and experiences with death and dying. Family-centered ACP takes care of first steps (identifying someone to speak for you if you cannot speak for yourself) and next steps (letting your wishes for future medical care

Table 2. Quality of Communication by Study Arm and Study Visit

Group	No. of Participants	Mean (SD) Quality of Communication Score ^a			P Value ^b
		Session 1 (Survey)	Session 2 (Interview)	Session 3 (Advance Directive)	
Adolescent					
Control	13	18.3 (1.7)	18.1 (1.4)	18.2 (1.6)	.77
Intervention	17	18.5 (1.4)	19.2 (1.2)	19.2 (1.1)	
P value ^c		.93	.03	.06	
Family					
Control	13	18.6 (1.5)	19.0 (1.2)	18.8 (1.3)	.24
Intervention	17	19.2 (1.1)	19.6 (0.6)	19.1 (1.0)	
P value ^c		.33	.25	.62	

^aQuality of communication score is the sum of 4 items: “Do you think your attitudes are known by the interviewer?” “Did you feel that the interviewer cared about you as a person?” “Did you feel that the interviewer listened to what you said?” “Did you feel that the interviewer gave you enough attention?” Total scores on the 5-point Likert scale from definitely no to definitely yes could range from 5 to 20.

^bComparing the control and intervention for 3 sessions using the generalized estimating equations.

^cComparing the control and intervention groups in each session using the exact Wilcoxon test.

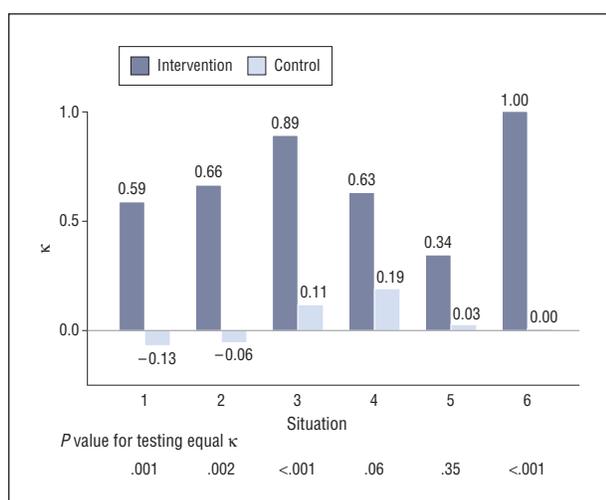


Figure 2. Comparison of κ statistics by study arm and situation with P values for testing equal κ values.

be known, so your wishes will be honored if you cannot speak for yourself). Our information sheet reads, “Everybody needs to think about his or her whole future. No one can predict when a medical emergency will occur. By planning ahead, your legal guardian . . . or you . . . can control decisions about medical care for you . . . if you are unable to speak for yourself. . . .”

Family-centered ACP resulted in statistically higher congruence in 4 of the 6 situations identified by physicians as likely to confront an adolescent patient with cancer compared with controls. Family-centered ACP families were more likely than controls to choose to discontinue treatment in 5 situations. Knowing the adolescent’s perspective may “help relieve families of the almost impossible burden of making difficult health care decisions for someone they deeply care about. . . .”⁴⁶ Deferring these conversations or avoiding them may result in stressful or difficult decisions or feelings of regret.⁴⁷⁻⁵² Family-centered ACP adolescents reported being better informed about ACP than their SOC peers.

These results confirm the findings of a 2-site randomized clinical trial with teens with human immunodeficiency

virus or AIDS,⁴ as well as recent adult studies.^{1-3,5} Our findings support interviews with adolescents with serious medical conditions, indicating that they are capable of participating in and understanding the consequences of their decision(s),⁵³ value autonomous decision making without excluding parents,^{11,31,54-56} and want to participate in shared decision making.^{11,31,54-60} Families also want to know their child’s wishes^{9,11} and share in decision making regarding resuscitation,⁵⁸ the place of their child’s death,⁵⁹ and pain control.⁶⁰ All family-centered ACP adolescents were willing to give their families leeway in making decisions for them, in contrast to SOC adolescents. This finding suggests a potential for avoiding conflict during a medical crisis. This hypothesis should be tested in a larger study.

This study had several strengths. It is a randomized controlled trial of a reproducible EOL intervention. Two populations that are historically underrepresented in this type of research (adolescents with life-threatening disease and African American families) were represented. Unique is the finding that African American families did not consistently choose to continue treatments in all situations, in contrast to earlier studies.^{4,61,62} Quality of communication was equally good for both groups and significantly higher for intervention adolescents for the Respecting Choices interview (session 2). This result suggests that the responses are trustable and comparable. Family-centered ACP emphasizes ACP as a process rather than a one-time event, allowing for open ongoing discussion, continuing review, and revision as needed. By using the same outcome measures as in other disease-specific ACP studies,^{1-5,47} our results contribute to a body of evidence-based solutions to ACP, enabling replication and comparison across studies. A potential benefit in need of further research is that family-centered ACP adolescents gave their surrogates leeway to use their judgment, knowing what their wishes were, potentially eliminating or minimizing conflict during a medical crisis. Family-centered ACP is theoretically grounded,⁶³⁻⁶⁷ consistent with research showing the importance of having some control in a low-control situation.⁶⁸

This model was implemented so there were no surprises for adolescents or families who felt cared about and

Table 3. Percentage of Observed Agreement by Intervention Group and Situation

Situation ^a	Group	Specific Response Agreement, No. (%)			Overall Response Agreement	
		Continue Treatment	Limit Treatment	Don't Know	No. (%)	Odds Ratio
1	Intervention	11 (65)	1 (6)	2 (12)	14 (82)	2.1
	Control	9 (69)	0	0		
2	Intervention	10 (59)	3 (18)	1 (6)	14 (82) ^b	10.5
	Control	3 (23)	0	1 (8)		
3	Intervention	10 (59)	2 (12)	4 (24)	16 (94) ^b	13.7
	Control	7 (54)	0	0		
4	Intervention	7 (41)	2 (12)	4 (24)	13 (76)	3.8
	Control	4 (31)	2 (15)	0		
5	Intervention	5 (29)	6 (35)	0	11 (65)	1.6
	Control	2 (15)	5 (38)	0		
6	Intervention	16 (94)	1 (6)	0	17 (100)	>20
	Control	10 (83)	0	0		

^aSituation 1: "long hospital stay with many treatments and chance of living through this complication is low"; situation 2: "cancer has spread and treatments will extend my life by no more than 2 to 3 months, and the side effects of the treatment are serious"; situation 3: "functional impairment (eg, can't walk or talk) and would need 24-hour nursing care"; situation 4: "mental disability (never know who I was or who I was with) and would need 24-hour nursing care"; situation 5: "I want cardiopulmonary resuscitation attempted unless my physician determines any one of the following: I have an incurable illness or injury and am dying"; and situation 6: "mechanical ventilation."

^bStatistically significant at the .05 level using the Fisher exact test.

listened to, addressing frequently expressed fears and concerns about conducting EOL studies.⁶⁹⁻⁷³ Family-centered ACP is individualized so that those who prefer to defer to their physician or family are honored, as are families who believe that ACP with one's child is inappropriate or harmful.

One limitation is that those who participated likely represent families most comfortable discussing ACP, thereby limiting generalizability. Fewer than half of eligible patients were approached to participate in the study because the targeted sample size of 30 dyads was achieved and to enable us to conduct future research with the remaining eligible population in a fully powered, multi-site study. There was a sizable representation of re-lapsed patients (30%) likely to encounter EOL issues shortly, indicating that the sample did not only represent a good prognosis group. In addition, the small sample suggests study results may not be generalizable, although the results replicate findings from a human immunodeficiency virus-positive adolescent sample.^{4,10} Finally, treatment condition masking was not maintained.

Giving adolescents a voice through family-centered ACP has the potential to overcome the communication barrier between physicians and parents of terminally ill adolescents regarding treatment goals and care at EOL¹⁶ and to lessen suffering and improve quality of life. Future studies should examine whether family-centered ACP produces a sustained effect on decision-making congruence,⁷⁴ whether the patients' demonstrated wishes change over time,⁷⁴ and whether these wishes are actually implemented in the event of the patients' death. Family-centered ACP facilitated access to ACP for adolescents and African American families, potentially decreasing health disparities. Advance care planning may be facilitated without going into personal prognosis. Family-centered ACP may be a model for a system change to implement existing American Academy of Pediatrics²⁸ and Institute of Medicine²⁰ recommendations ethically.⁷⁵

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