

# Acceptability of Family-Centered Advanced Care Planning for Adolescents With HIV

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abstract

**BACKGROUND AND OBJECTIVE:** Small pilot studies support the appropriateness of engaging adolescents with chronic or life-limiting illnesses in pediatric advance care planning (pACP). We do not yet know if pACP is acceptable, feasible, and worthwhile, even if emotionally intense, in a fully powered randomized controlled trial.

**METHODS:** We conducted a prospective 2-arm randomized controlled trial at 6 US urban hospitals. Adolescent/family member dyads were randomized to receive the 1-session-a-week 3-session FAMILY-CENTERED Advance Care Planning (FACE) pACP intervention (1, ACP Survey; 2, Goals of Care Conversation/Treatment Preferences; 3, Completion of Advance Directive) or active comparator (1, Developmental History; 2, Safety Tips; 3, Nutrition/Exercise). The Satisfaction Questionnaire was administered to participants independently after each session by a blinded research assistant.

**RESULTS:** We enrolled 53% of eligible participants and intervened with 97 adolescent/family dyads. Adolescents ranged in age from 14 to 21 years; 54% were male individuals; 93% African American; and 73% perinatally infected. Attendance was 99% for all 3 sessions in each arm. At session 3, FACE adolescents and family dyad members, respectively, found the session useful (98%, 98%) and helpful (98%, 100%), despite feelings of sadness (25%, 17%). FACE adolescents' improvement in the total subscale A score (useful, helpful, like a load off my mind, satisfied, something I needed to do, courageous, worthwhile) was better than control adolescents at session 3 ( $\beta = 1.16, P = .02$ ). There were no adverse events.

**CONCLUSIONS:** FACE enabled worthwhile conversations, while simultaneously eliciting intense emotions. No participants withdrew, 99% of those enrolled completed each session, and there were no adverse events, evidence of pACP's feasibility, acceptability, and safety.



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**WHAT'S KNOWN ON THIS SUBJECT:** Despite policy recommendations to include adolescents with chronic and life-limiting conditions in decision-making about their own end-of-life care, barriers continue in clinical practice, including fear of distressing vulnerable adolescents and providers' beliefs that these conversations are potentially harmful.

**WHAT THIS STUDY ADDS:** Adolescents and families who participated in a highly structured advance care planning program facilitated by trained/certified research assistants experienced intense emotions compared with controls and found the experience acceptable, worthwhile, and helpful with 99% attendance at all 3 sessions.

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Improved approaches to pediatric advance care planning (pACP) are needed for the ~400 000 children living in the United States with life-limiting conditions.<sup>1,2</sup> pACP is a process of preparation and skill development, facilitating discussions about future medical care choices.<sup>3,4</sup> An estimated 9731 youth aged 13 to 24 were diagnosed with HIV in 2014; and in 2012, an estimated 57 200 youth aged 18 to 24 were living with HIV in the United States.<sup>5</sup> Despite improved treatment,<sup>2-4</sup> ~11 000 youth ages 13 to 24 in the United States received an AIDS diagnosis.<sup>5</sup> Ever having an AIDS diagnosis or being born with HIV increases an adolescent's risk of dying from an opportunistic infection or chronic illness,<sup>6</sup> underscoring the need for pACP interventions.

Critical barriers to adoption of pACP include (1) fear of distressing vulnerable adolescents<sup>7,8</sup>; (2) dread of the powerful emotions when facing a death that is "out of season"<sup>9,10</sup>; and (3) providers' beliefs that initiating end-of-life (EOL) discussions with teens is inappropriate, potentially harmful, or ineffective.<sup>4,11-13</sup> Barriers identified by pediatricians regarding pACP are (1) unrealistic expectations by parents, (2) parental difficulty in understanding prognosis, (3) lack of parental readiness, and (4) not knowing what to say.<sup>14</sup> A recent review of palliative care for children with cancer identified lack of time and cost as additional barriers to early pACP.<sup>15</sup>

Guidelines recommend adolescents be included in EOL discussions early, and that these conversations be shared among the adolescent, family, and health care providers in a structured, routine manner.<sup>16,17</sup> Furthermore, chronically ill adolescents express a desire to be included in EOL discussions.<sup>18-20</sup> Families also want to talk about EOL decisions for their children.<sup>21-26</sup>

Well-planned, structured pACP may improve quality of life and treatment

adherence, and increase access to information and choice.<sup>27-29</sup> Adult studies demonstrate advance care planning (ACP) increases congruence in treatment preferences between patients and their caregivers and increases in the likelihood patients' preferences will be honored at EOL.<sup>30-33</sup> Pilot studies demonstrate the initial feasibility and acceptability of a structured model for facilitating pACP discussions in an emotionally safe way.<sup>22,29,34</sup> Based on these promising results, the Longitudinal Pediatric and Palliative Care: Quality of Life and Spiritual Struggle study was designed in part to demonstrate the feasibility and acceptability outcomes of a pACP intervention in an adequately powered, multisite, randomized clinical trial.

## METHODS

A 2-arm longitudinal multisite randomized controlled trial was conducted from July 2011 with the intervention portion completed in July 2014. Adolescents living with HIV and their health care surrogates were recruited from 6 US urban hospitals with high AIDS rates.<sup>5</sup> Adolescents 18 years and older were asked to choose a health care surrogate decision-maker to participate in the study, and minor adolescents' legal guardians participated as their surrogate. Hereafter, surrogates will be referred to as family.

Adolescent/family dyads were randomized to receive either the FAmily-CEntered Advance Care Planning (FACE)-ACP intervention or the time-matched control condition, using a computerized 1:1 randomly permuted block design. Randomization controlled for clinic site and route of transmission effects (perinatal versus behavioral), as our earlier research had identified differences in outcome variables by route of transmission.<sup>28</sup> The design

and methods for this study have previously been published in detail.<sup>35</sup>

## Participants

Screening data were collected from 203 subjects. Adolescent inclusion criteria were as follows: between the ages of 14 and 21 years old at enrollment, aware of their HIV diagnosis, and able to understand English. Excluded were participants with a documented IQ score <70 or developmental delay, severe depression as assessed by the Beck Depression Inventory-II,<sup>36</sup> suicidal/homicidal ideation, psychosis as assessed by the National Institutes of Health Diagnostic Interview Scale for Children,<sup>37</sup> currently in an ICU, or in foster care. Participants who failed screening on the HIV Dementia Scale<sup>38</sup> also were excluded. The institutional review board for each site approved the protocol. Signed consent and assent were obtained before screening. Safety plans were in place at each site in case of emotional distress occasioned by the interventions or measures.

## Procedures

Participants were approached by study research assistants (RAs) for participation. Follow-up visits are still in process. All intervention sessions are complete. Study results reported here are from the data collected by a trained RA-Assessor, blinded to randomization, immediately after each of the intervention sessions.

## FACE ACP Intervention

Three 60-minute sessions were conducted, each 1 week apart, to give dyads time for reflection.<sup>28</sup> Facilitators were clinicians as well as nonclinician/research staff, trained to certification with validation of implementation by video, and standardized procedures implemented with fidelity.<sup>39</sup>

### Session 1

Lyon Family-Centered ACP Survey-Adolescent and Surrogate versions<sup>40</sup> were administered independently to the adolescent and family to assess adolescents' values, beliefs, and life experiences with illness and EOL care; and the family's understanding of their adolescent's values, beliefs, and life experiences.

### Session 2

Respecting Choices Next Steps ACP interview<sup>41</sup> was facilitated with the adolescent and family member(s) together to elicit their respective understanding of the adolescent's current medical condition; potential complications; fears, hopes, and experiences; and treatment preferences in 3 poor outcome situations. The interview was adapted to adolescents with HIV/AIDS.<sup>29</sup> This session was audio- or videotaped to ensure protocol fidelity.

### Session 3

The Five Wishes,<sup>42</sup> an advanced directive document, was completed with the adolescent and family present. For adolescents younger than 18, the Five Wishes was used as a tool<sup>43</sup> to allow younger adolescents to participate in shared decision-making. Their parent or legal guardian signed the Five Wishes to meet legal requirements.

The treating physician received an e-mail with the treatment preferences and Five Wishes and a brief summary of the conversation in session 2 for their records. These documents were also entered into the electronic health record.

### Control Condition

Before randomization, all participants were given an ACP booklet. Control dyads received no additional information or discussion around pACP.

### Session 1

Developmental history was reviewed with the adolescent and parent separately. The RA-Control conducted the session in a structured interview format, administering The Barkley Developmental History form.<sup>44</sup> Questions about the mother's pregnancy and participant's birth were removed to prevent risk of contamination with the intervention condition.

### Session 2

Safety tips were discussed by using Bright Futures<sup>45</sup> counseling on safety information. The RA-Control facilitated conversations between the adolescent and family about such things as using a seat belt and having a smoke detector in the home. The session was audio- or videotaped.

### Session 3

Nutrition and exercise were discussed by using Bright Futures<sup>45</sup> counseling on exercise and nutrition. The RA-Control facilitated conversations between the adolescent and family about the adolescent's physical activity level and good nutrition.

### Measures

We collected demographic and clinical data from participant self-report and chart review. Benchmarks for acceptability and feasibility were >50% enrollment of eligible dyads, attendance at >80% of all 3 sessions in both study arms, >90% satisfaction on the satisfaction item, and >90% data completeness.

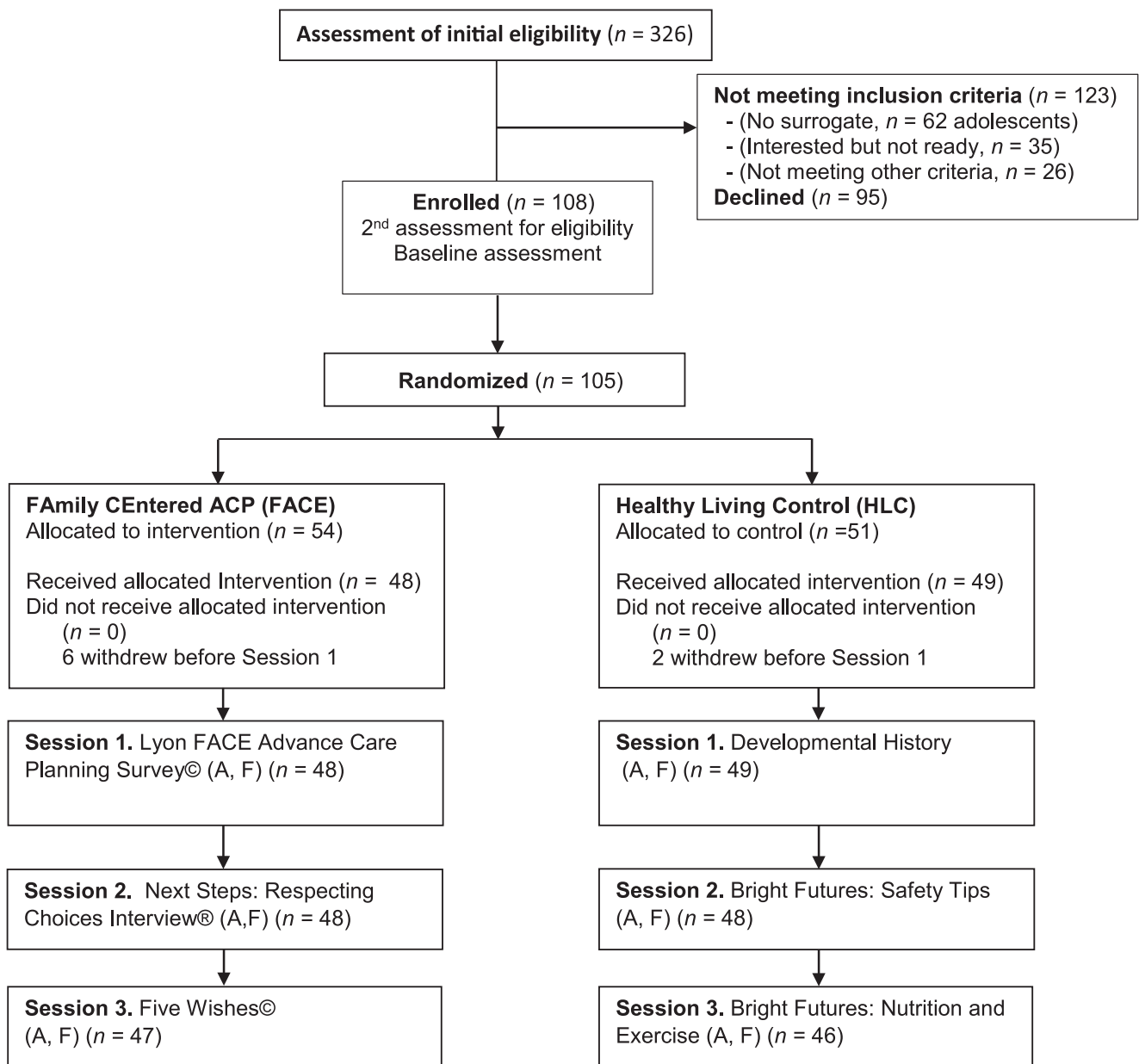
The Satisfaction Questionnaire was developed and pilot-tested for the FACE protocol among adolescents living with HIV/AIDS by using community-based participatory research.<sup>29</sup> The questionnaire has 13 items on a 5-point Likert scale, ranging from "strongly disagree" to "strongly agree." There are 2 subscales. Subscale A items are the following: useful, helpful, load off my

mind, satisfied, something I needed to do, courageous, worthwhile. Subscale B items are as follows: scared/afraid, too much to handle, harmful, angry, sad, hurtful. Higher scores on subscale A mean more positive emotions. A higher score on scale B means more negative emotions. The range of scores for subscale A is 7 to 35; the range of scores for subscale B is 6 to 30. The questionnaire was administered immediately after sessions 1, 2, and 3 separately to adolescents and their legal guardian or chosen surrogate in a private room by a trained blinded RA-Assessor.

An adverse event was operationally defined with the guidance of the primary site Institutional Review Board and Safety Monitoring Committee, by using a response pattern to the items on the Satisfaction Questionnaire. A serious adverse event was operationally defined as an emotional breakdown requiring hospitalization or inpatient behavioral health services for emotional distress very likely/certainly related to the study intervention.

### Analytic Plan

Sample size determinations for this randomized controlled trial have been previously reported.<sup>35</sup> Statistical analyses were conducted by using SAS 9.2 (SAS Institute, Inc., Cary, NC). Frequency distributions characterized demographic data, percent enrollment, attendance, retention, and completeness of data. Generalized estimated equation (GEE) models were used to test the intervention effects on satisfaction over time. GEE models were applied to analyze subscale A and subscale B item total scores controlling for age, sex, race, and mode of HIV transmission. In each model, 2 dummy variables were included to represent the 3 sessions, with session 1 as the reference group. Interaction between intervention and session was included in each model to test intervention effect on outcome



**FIGURE 1**

Flow of participants through each stage of a randomized clinical trial. Note: Intent to treat design used A: Adolescent; F: Family.

change over sessions. Satisfaction items were dichotomized as “agree or strongly agree” versus “other” for the GEE modeling, and analyzed by using GEE logit models. An effect was considered statistically significant if its *P* value (in a 2-tailed test) was less than the significance level of  $\alpha = 0.05$ .

## RESULTS

A total of 326 adolescent/family dyads met initial study eligibility

criteria (Fig 1). Of potentially eligible dyads, 123 dyads did not meet inclusion criteria: 50% of the 123 ineligible adolescents could not identify a surrogate decision-maker; 28% were undecided/needed more time to think about participating; and 21% did not meet other inclusion criteria (eg, in foster care). Ninety-five potential dyads declined. Reasons given for needing more time included scheduling conflicts related to school or work for the adolescent

and/or family, consideration of appropriate health care surrogate, or not interested in participating in research. Due to institutional review board restriction regarding obtaining data from those who declined participation, information related to health status or adherence was not collected from those who declined. After assenting/consenting, 108 dyads completed a secondary screening for exclusion criteria. Of these, 1 dyad was excluded. Two

dyads withdrew without giving a reason. Fifty-eight of those who assented/consented had an HIV RNA viral load of <400 copies/mL and 48 self-reported ≥90% adherence to their antiretroviral medications.

A total of 105 dyads were randomized: 54 dyads to FACE and 51 dyads to control. In the week before the start of the intervention, 6 dyads randomized to FACE withdrew. Two dyads randomized to control withdrew. The remaining 97 dyads received the intended allocation ( $n = 48$  FACE;  $n = 49$  Control). Their data were used in this analysis.

Participants randomized to the FACE intervention completed 100% of sessions 1 and 2. One FACE dyad did not complete session 3. One control dyad withdrew after session 1 and 2 dyads after session 2. Satisfaction data are missing in the control group for 1 family member after sessions 2 and 3, and in this same dyad, no adolescent data were collected.

Among adolescents randomized to the intervention arm, 22 (46%) had an undetectable viral load (<400 copies/mL) at baseline. Baseline characteristics of adolescents are presented in Table 1. No significant demographic or medical history differences existed between intervention and control adolescents at baseline, indicating successful randomization.

We enrolled 53% (108/203 dyads) of eligible adolescent/family dyads. We achieved 99% attendance at all 3 sessions (269/273 sessions). Completeness of data was 98%. The satisfaction rate across the 3 sessions for the item “I felt satisfied” was 84% for all adolescents, and 88% for all surrogates. For FACE adolescents, the response to “I felt satisfied” increased over sessions (session 1, 81%; session 2, 81%; session 3, 89%). For FACE families, the response to “I felt satisfied” also increased (session 1, 79%; session 2, 90%; session 3, 96%).

**TABLE 1** Baseline Characteristics for Intervention and Control Adolescents

	Intervention, $n = 48$	Control, $n = 48$	$P$
Age, y			
Mean (SD)	18.1 (1.87)	17.8 (1.95)	
Range	14.0–20.0	14.0–20.0	.39 <sup>a</sup>
Gender			
Boys	26 (54.2)	24 (50.0)	
Girls	22 (45.8)	24 (50.0)	.84 <sup>b</sup>
Race/Ethnicity			
Black/African American	44 (93.6)	45 (95.7)	
Other	3 (6.34)	2 (4.3)	.99 <sup>b</sup>
Mode of HIV transmission			
Perinatal infected	36 (75.0)	34 (70.8)	
Nonperinatal infected	12 (25.0)	14 (29.2)	.82 <sup>b</sup>
Self-reported sexual orientation			
Not heterosexual	17 (35.4)	12 (25.0)	
Heterosexual	31 (64.6)	36 (75.0)	.37 <sup>b</sup>
CDC classification			
A 1–3 (asymptomatic)	19 (39.6)	23 (47.9)	
B 1–3 (symptomatic)	16 (33.3)	13 (27.1)	
C 1–3 (AIDS)	13 (27.1)	12 (25.0)	.71 <sup>b</sup>
Education			
No high school diploma/in high school	23 (48.9)	25 (52.1)	
High school or GED equivalent	15 (31.9)	18 (37.5)	
Some college/no bachelor's	9 (19.2)	5 (10.4)	.50 <sup>b</sup>
Income			
≤ federal poverty line	24 (50.0)	21 (43.8)	
101%–200% of federal poverty line	4 (8.3)	11 (22.9)	
201%–300% of federal poverty line	3 (6.3)	5 (10.4)	
>300% of federal poverty line	12 (25.0)	5 (10.4)	
Unknown	5 (10.4)	6 (12.5)	.14 <sup>b</sup>
Marital status			
Single	48 (100.0)	47 (97.9)	
Living together as if married	0 (0)	1 (2.1)	.99 <sup>b</sup>
Housing status			
Living in own house or apartment	25 (52.1)	23 (47.9)	
Living in someone else's house or apartment	19 (39.6)	24 (50.0)	
Other	4 (8.3)	1 (2.1)	.31 <sup>b</sup>

CDC, Centers for Disease Control and Prevention.

<sup>a</sup>  $t$  test.

<sup>b</sup> Fisher's exact test. No statistically significant difference between groups, indicating success of randomization.

FACE pACP adolescents and families reported a wide range of feelings and reactions to each session immediately after each session, as evidenced in Table 2. For example, after session 2 (goals of care/treatment preferences), adolescents and surrogates respectively and independently reported feeling sad (21%, 25%) and afraid (10%, 6%), and found it hurtful (6%, 17%), despite at the same time reporting session 2 to be worthwhile (90%, 98%), useful (94%, 96%), and helpful (96%, 100%). No adverse or serious adverse events occurred.

As shown in Table 3, adolescents in FACE pACP had higher mean total

score on subscale A than control adolescents after both sessions 2 ( $P = .04$ ) and 3 ( $P = .02$ ), whereas there was no significant difference after session 1 ( $P = .20$ ). Adolescents in FACE pACP also had higher mean total scores on subscale B than control adolescents (session 1,  $P < .001$ ; session 2,  $P = .01$ ; session 3  $P = .02$ ), evidencing more self-reported negative emotion. Likewise, families in FACE pACP had higher mean total score on subscale A and subscale B than control families after all 3 sessions, as shown in Table 3.

Among adolescents, GEE model results (Table 4) indicate that over time improvement in the total



**TABLE 2** Individual Item Satisfaction Questionnaire Results for FACE pACP Intervention With Adolescents and Families

Satisfaction Questionnaire Items	Agree or Strongly Agree, <i>n</i> (%)					
	Session 1 pACP Survey	Adolescent Session 2 Goals of Care Conversation	Session 3 Complete Advance Directive	Session 1 pACP Survey	Family Session 2 Goals of Care Conversation	Session 3 Complete Advance Directive
It was useful <sup>a</sup>	44 (91.7)	45 (93.8)	46 (97.9)	45 (93.8)	46 (95.8)	46 (97.9)
It was helpful <sup>a</sup>	43 (89.6)	46 (95.8)	46 (97.9)	45 (95.7)	48 (100.0)	47 (100.0)
I felt scared or afraid <sup>b</sup>	5 (10.4)	5 (10.4)	3 (6.4)	3 (6.4)	3 (6.3)	2 (4.3)
It felt like a load off my mind <sup>a</sup>	26 (55.3)	33 (70.2)	35 (74.5)	26 (55.3)	37 (77.1)	42 (89.4)
It was too much to handle <sup>b</sup>	3 (6.3)	4 (8.3)	2 (4.3)	3 (6.4)	4 (8.3)	3 (6.4)
I felt satisfied <sup>a</sup>	39 (81.3)	39 (81.3)	42 (89.4)	37 (78.7)	43 (89.6)	45 (95.7)
It was harmful <sup>b</sup>	1 (2.1)	1 (2.1)	4 (8.5)	1 (2.1)	2 (4.2)	1 (2.1)
I felt angry <sup>b</sup>	0 (0)	3 (6.3)	1 (2.1)	1 (2.1)	0 (0)	0 (0)
It was something I needed to do <sup>a</sup>	28 (58.3)	40 (83.3)	39 (83.0)	40 (85.1)	45 (93.8)	44 (93.6)
I felt sad <sup>b</sup>	4 (8.3)	10 (20.8)	4 (8.5)	11 (23.4)	12 (25.0)	8 (17.4)
I felt courageous <sup>a</sup>	21 (43.8)	29 (60.4)	25 (53.2)	25 (53.2)	33 (68.8)	33 (70.2)
It felt hurtful <sup>b</sup>	2 (4.2)	3 (6.3)	1 (2.1)	8 (17.0)	8 (16.7)	4 (8.5)
It was worthwhile <sup>a</sup>	37 (77.1)	43 (89.6)	41 (87.2)	45 (95.7)	47 (97.9)	47 (100.0)
Subscale A items <sup>a</sup> (Cronbach $\alpha$ )	0.80	0.76	0.86	0.84	0.77	0.79
Subscale B items <sup>b</sup> (Cronbach $\alpha$ )	0.87	0.87	0.89	0.84	0.77	0.74

<sup>a</sup> Subscale A items: useful, helpful, like a load off my mind, satisfied, something I needed to do, courageous, worthwhile.

<sup>b</sup> Subscale B items: scared/afraid, too much to handle, harmful, angry, sad, hurtful.

**TABLE 3** Descriptive Statistics of Overall Satisfaction Scores

Session	Group	<i>n</i>	Total Subscale A Scores <sup>a</sup>				Total Subscale B Scores <sup>b</sup>			
			Adolescent		Surrogate		Adolescent		Surrogate	
			Mean	SD	Mean	SD	Mean	SD	Mean	SD
1. pACP Survey	HLC	48	26.0	4.5	27.4	4.5	8.9	2.7	9.1	2.9
	FACE	48	27.1	3.7	29.4	4.1	11.5	3.9	10.9	4.3
	<i>P</i> value		.1929		.0236		.0003		.0178	
2. Goals of care	HLC	48	26.7	3.9	28.7	3.7	9.9	4.4	8.8	2.7
	FACE	48	29.1	3.8	30.8	3.2	12.2	4.4	11.1	3.6
	<i>P</i> value		.0036		.0039		.0118		.0006	
3. Advance directive	HLC	46	27.0	5.3	28.2	4.1	8.8	3.3	8.6	2.6
	FACE	47	29.3	3.6	31.2	3.2	10.5	3.8	10.5	3.1
	<i>P</i> value		.0173		.0001		.0184		.0017	

HLC, healthy living control.

<sup>a</sup> Subscale A items: useful, helpful, like a load off my mind, satisfied, something I needed to do, courageous, worthwhile.

<sup>b</sup> Subscale B items: scared/afraid, too much to handle, harmful, angry, sad, hurtful.

score of subscale A was statistically significant only at session 3 ( $\beta = 1.16, P = .02$ ) with adolescents reporting higher scores regardless of intervention assignment. Both the intervention main effect and the interactions between intervention and sessions were not statistically significant. There was no significant change over time in the total score of subscale B among adolescents in both FACE pACP and control groups, as both the main effects of session 2 ( $\beta = 0.92, P = .14$ ) and session 3 ( $\beta = -0.28, P = .40$ ) were not statistically significant. Further, the interactions

between intervention and sessions also were not statistically significant; however, the average total score of the subscale B items was significantly higher at session 1 in the FACE pACP group than in the control group ( $\beta = 2.38, P < .001$ ). This group difference remained unchanged over sessions, as all the corresponding interactions between intervention and sessions were not statistically significant.

Among families, the GEE model (Table 4) results indicate a significant increase over time in the total score of subscale A at session 2 ( $\beta = 1.38, P = .04$ ) regardless of intervention

groups, but such an improvement was no longer significant at session 3 ( $\beta = 0.98, P = .11$ ). There was a significant main effect of intervention with FACE families scoring significantly higher than control families on both total score of subscale A ( $\beta = 1.77, P = .04$ ); and total score of subscale B ( $\beta = 1.80, P = .02$ ). This indicates that the total scores of both subscales A and B at session 1 were higher for the FACE group than for control; and such a difference held over time as the interactions between intervention group and sessions were not statistically significant.

**TABLE 4** Selected Results of GEE Models

Variable	Total Score of Subscale A Items <sup>a</sup>				Total Score of Subscale B Worded Items <sup>b</sup>			
	Adolescent		Surrogate		Adolescent		Surrogate	
	Estimate	P	Estimate	P	Estimate	P	Estimate	P
Session 1	—	—	—	—	—	—	—	—
Session 2	0.77	.1613	1.38	.0446	0.92	.1425	−0.32	.4240
Session 3	1.16	.0210	0.98	.1108	−0.28	.4012	−0.45	.1205
Intervention group								
HLC	—	—	—	—	—	—	—	—
FACE	1.15	.1520	1.77	.0410	2.38	.0004	1.80	.0169
Interaction between Intervention and Session								
FACE session 2	1.12	.1371	0.07	.9358	−0.20	.7993	0.46	.5048
FACE session 3	1.00	.1189	0.78	.3210	−0.67	.2270	−0.11	.8356
Adolescent age	0.25	.2218	0.27	.1601	0.07	.6610	−0.08	.5845
Sex								
Girls	—	—	—	—	—	—	—	—
Boys	−0.53	.4513	0.51	.5066	−0.87	.1943	−1.30	.0107
Race								
Non-black	—	—	—	—	—	—	—	—
Black	0.69	.3104	1.04	.3991	0.46	.7318	0.72	.2662
Mode of HIV transmission								
Nonperinatal infected	—	—	—	—	—	—	—	—
Perinatal infection	−1.51	.0500	0.63	.3377	1.20	.0854	−0.41	.4107

HLC, healthy living control; —, Reference group.

<sup>a</sup> Subscale A items: useful, helpful, like a load off my mind, satisfied, something I needed to do, courageous, worthwhile.

<sup>b</sup> Subscale B items: scared/afraid, too much to handle, harmful, angry, sad, hurtful.

There were no effects by age or race. Male surrogates had significantly lower total subscale B scores on average than female surrogates ( $\beta = -1.30, P = .01$ ). Perinatally infected adolescents had significantly lower total subscale A scores on average than behaviorally infected adolescents ( $\beta = -1.51, P = .05$ ).

## DISCUSSION

FACE pACP struck a balance between the innately intense emotions elicited by discussions of EOL treatment options; and the worthwhile experience of helpful and useful engagement in authentic and meaningful conversations about goals of care and values between adolescents and families. More than half of the adolescents and almost three-fourths of families described themselves as feeling courageous. After participation in session 1, 99% of dyads completed all 3 sessions. There were no adverse events. Participants enrolled at rates higher than usually found in adult EOL

studies in which only 30% to 47% of eligible patients participate.<sup>43,46–48</sup> By these measures, FACE enabled families to have quality EOL conversations with their teens, confirming pilot findings.<sup>22,29,34</sup> Our results are consistent with research demonstrating that adolescents find the process of using an ACP document helpful<sup>49</sup> and the benefits of seriously ill children participating in research outweigh the burdens.<sup>50</sup> The high levels of both positive and negative affect among FACE families adds to the research base of Feudtner and colleagues who also identified complex emotional expression in families of children with serious illness.<sup>51,52</sup> Our findings have important practical implications. First, providers' fear that initiating EOL discussions with teens is harmful is misplaced, provided the conversations occur in the context of a structured, patient-centered/family-supported, evidence-based protocol. Second, our findings may prove helpful in the ongoing debate about the inclusion of adolescent minors and families in EOL treatment

decisions. Families want to hear their child's own voice.<sup>52–55</sup> Third, pACP addresses the Healthy People 2020 goal of increasing the proportion of adolescents connected to a parent who they can talk to about serious problems.<sup>56</sup>

FACE pACP yielded a high rate of participation for African American families who are generally underrepresented in EOL research<sup>3,4,57</sup> and in ACP.<sup>58</sup> Our study suggests the FACE pACP model, which was developed and adapted with feedback from the African American community,<sup>29</sup> may contribute to decreases in pACP health disparities by providing an engaging framework in hospital settings.

Our study has several limitations. Families who participated may represent those more comfortable discussing EOL and pACP, limiting generalizability to those demonstrating readiness, and suggesting a readiness intervention addressing initial fears may be in order. Given pACP is not often

used,<sup>59</sup> engaging those families who are ready, approximately half of our study population, would advance implementation of policy recommendations.<sup>60–62</sup> We do not know enough about adolescents who could not identify a surrogate decision-maker, which was a major reason for not participating in this study. Future research should identify ways to include adolescents in foster care and “unsupported” young adults.

## CONCLUSIONS

Adolescents living with HIV and their families were able to handle a wide range of intense emotions elicited by pACP conversations, finding the experience worthwhile and helpful. The methods of this

study may extend to other chronic illnesses (eg, cancer, cystic fibrosis).

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## ABBREVIATIONS

ACP: advance care planning  
EOL: end of life  
FACE: FAMily-CEntered Advance Care Planning  
GEE: generalized estimated equations  
pACP: pediatric advance care planning  
RA: research assistant

This trial has been registered at [www.clinicaltrials.gov](http://www.clinicaltrials.gov) (identifier NCT01289444).

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## Acceptability of Family-Centered Advanced Care Planning for Adolescents With HIV

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