Advance Care Planning and HIV Symptoms in Adolescence

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abstract

OBJECTIVES: To determine the effect of family-centered pediatric advance care planning (FACE pACP) on HIV-specific symptoms.

METHODS: In this single-blinded, randomized controlled trial conducted at 6 US hospital-based HIV clinics, 105 adolescent-family dyads, randomly assigned from July 2011 to June 2014, received 3 weekly sessions in either the FACE pACP arm ([1] pediatric advance care planning survey, [2] Respecting Choices interview, and [3] 5 Wishes directive) or the control arm ([1] developmental history, [2] safety tips, and [3] nutrition and exercise tips). The General Health Assessment for Children measured patient-reported HIV-specific symptoms. Latent class analyses clustered individual patients based on symptom patterns. Path analysis examined the mediating role of dyadic treatment congruence with respect to the intervention effect on symptom patterns.

RESULTS: Patients were a mean age of 17.8 years old, 54% male, and 93% African American. Latent class analysis identified 2 latent HIV-symptom classes at 12 months: higher symptoms and suffering (27%) and lower symptoms and suffering (73%). FACE pACP had a positive effect on dyadic treatment congruence (β = .65; 95% CI: 0.04 to 1.28), and higher treatment congruence had a negative effect on symptoms and suffering (β = −1.14; 95% CI: −2.55 to −0.24). Therefore, FACE pACP decreased the likelihood of symptoms and suffering through better dyadic treatment congruence (β = −.69; 95% CI: −2.14 to −0.006). Higher religiousness (β = 2.19; 95% CI: 0.22 to 4.70) predicted symptoms and suffering.

CONCLUSIONS: FACE pACP increased and maintained agreement about goals of care longitudinally, which lowered adolescents' physical symptoms and suffering, suggesting that early pACP is worthwhile.

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WHAT'S KNOWN ON THIS SUBJECT: Evidence supports the feasibility, acceptability, and initial efficacy of the family-centered pediatric advance care planning intervention for increasing congruence in end-of-life treatment preferences in adolescents with HIV and their families in a small randomized clinical trial.

WHAT THIS STUDY ADDS: Families' understanding of their adolescent's treatment preferences increased classification in the lower HIV symptoms group 12 months postintervention. Lack of understanding predicted more HIV symptoms. FACE pACP families had 3 times the odds of understanding their adolescents' treatment preferences, compared with controls.

ARTICLE

Despite medical advances, adolescents living with HIV or AIDS still have mortality rates 6 to 12 times greater than the general US population.[1–3] Globally, AIDS is the second leading cause of adolescent deaths and the leading cause of adolescent deaths in Africa.[4] HIV is a serious illness (with risk of morbidity and mortality) for which pediatric advance care planning (pACP) is appropriate.

In pACP, providers aim to relieve the suffering of children living with serious illness at any stage of disease[5,6] by supporting family engagement in understanding their child's goals for care, by communicating goals of care and end-of-life treatment preferences to the physician, and by documenting treatment preferences (similar to adult advance care planning [ACP]).[5,6] Family-centered pediatric advance care planning (FACE pACP)[7–10] is used to engage adolescents and families in the first 2 steps of the 3-step Respecting Choices model[11]: (1) identifying a surrogate decision-maker (for those who are ≥18 years or age), heretofore referred to as family; and (2) engaging in goals-of-care conversations with their families to create advance care plans.

The FACE pACP protocol is grounded in transactional stress and coping theory, whereby problem solving[12] provides some control in low-control situations.[13] Evidence supports the effects of problem-focused coping on survival among adult patients with cancer.[14–16] Perceived control is associated with decreased pain[17] and buffered mortality risk.[18] Social support is associated with HIV-related symptom reduction[19] and decreased mortality risk.[20] Transactional stress and coping theory also indicates that religious coping influences symptoms in complex ways.[21] Religious struggle is associated with poor health outcomes,[22] whereas positive religious coping is associated with

improved health outcomes in adults with HIV.[23,24] Threat appraisal is related to coping and reappraisal. Our pilot study findings[25] and research with children of divorce and bereaved children[26,27] suggest that one form of threat appraisal (loss of others or objects) significantly influences symptoms.

Session 2 of the FACE pACP intervention also builds on the representational approach to patient education.[28] Intervention trials reveal improved symptom management and decreased cancer pain in adults.[29–31]

In this trial, we tested a full theoretical model of pACP. The primary outcome was to reduce HIV-specific symptoms and suffering. We hypothesized that compared with an active control, (1) FACE pACP would maintain congruence in end-of-life treatment preferences (ie, the family would know what the adolescent would want) 1 year postintervention, and (2) higher treatment congruence would mediate lower HIV-specific symptoms and suffering by increasing control for adolescents' coping through making choices, through problem solving, and through patient representation of illness (eg, adolescents' understanding of current and past symptoms) and by strengthening family support (communication about treatment preferences). We further hypothesized that higher religiousness would limit the benefits of higher congruence on symptoms and that loss of others or objects would indirectly increase symptoms.

METHODS

Design

FACE pACP was a 2-parallel group, single-blinded, randomized controlled clinical trial with an intent-to-treat design (Fig 1). Adolescents and their families independently completed questionnaires at 3, 6, 12, and

18 months postintervention administered by research assistants (RAs) who were blinded to randomization. The sample size of the 18-month follow-up was not large enough to conduct a latent class analysis (LCA); thus, in the present analysis, we evaluated outcomes through 12 months postintervention. The institutional review board at each site approved the protocol. Participants provided written informed consent or assent and were compensated.

Setting and Participants

Adolescents ages 14 to 21 years old with HIV or AIDS and legal guardians (for minors) or chosen surrogate decision-makers who were at least 18 years old were enrolled in FACE pACP. Adolescent-family dyads were recruited between July 2011 and June 2014 from 6 pediatric and/or adolescent, hospital-based HIV clinics: Children's National, Johns Hopkins University, and Howard University ($n = 32$); St. Jude Children's Research Hospital ($n = 19$); University of Miami Miller School of Medicine ($n = 26$); and Children's Diagnostic and Treatment Center ($n = 28$). Inclusion criteria included a knowledge of the diagnosis and the ability to speak and understand English. Exclusion criteria for all participants included being a ward of the state; having known cognitive delay; being identified on secondary screening as severely depressed,[32] suicidal,[32] homicidal,[33] or psychotic[33]; and being positive for HIV dementia.[34] Further study details are published elsewhere.[35,36]

Randomization and Interventions

After the completion of baseline assessments, dyads were randomly assigned by the coordinating center to either the FACE pACP arm or the control arm using a computerized, 1:1 randomly permuted block design. Randomization was blocked by study
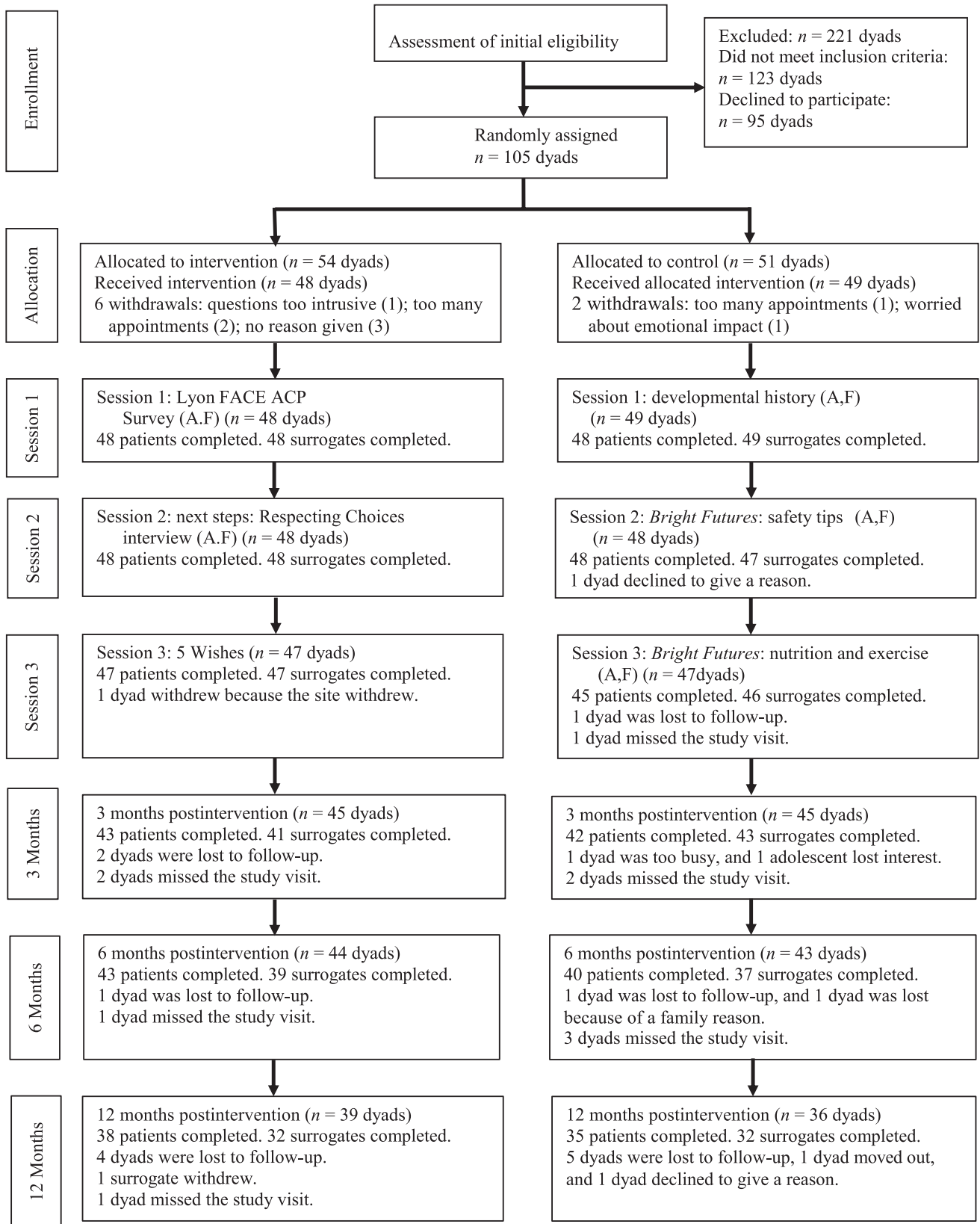
Enrollment

Assessment of initial eligibility

Excluded: $n = 221$ dyads
Did not meet inclusion criteria:
$n = 123$ dyads
Declined to participate:
$n = 95$ dyads

Randomly assigned
$n = 105$ dyads

Allocation

Allocated to intervention ($n = 54$ dyads)
Received intervention ($n = 48$ dyads)
6 withdrawals: questions too intrusive (1); too many
appointments (2); no reason given (3)

Allocated to control ($n = 51$ dyads)
Received allocated intervention ($n = 49$ dyads)
2 withdrawals: too many appointments (1); worried
about emotional impact (1)

Session 1

Session 1: Lyon FACE ACP
Survey (A.F) ($n = 48$ dyads)
48 patients completed. 48 surrogates completed.

Session 1: developmental history (A,F)
($n = 49$ dyads)
48 patients completed. 49 surrogates completed.

Session 2

Session 2: next steps: Respecting Choices
interview (A.F) ($n = 48$ dyads)
48 patients completed. 48 surrogates completed.

Session 2: *Bright Futures*: safety tips (A,F)
($n = 48$ dyads)
48 patients completed. 47 surrogates completed.
1 dyad declined to give a reason.

Session 3

Session 3: 5 Wishes ($n = 47$ dyads)
47 patients completed. 47 surrogates completed.
1 dyad withdrew because the site withdrew.

Session 3: *Bright Futures*: nutrition and exercise
(A,F) ($n = 47$dyads)
45 patients completed. 46 surrogates completed.
1 dyad was lost to follow-up.
1 dyad missed the study visit.

3 Months

3 months postintervention ($n = 45$ dyads)
43 patients completed. 41 surrogates completed.
2 dyads were lost to follow-up.
2 dyads missed the study visit.

3 months postintervention ($n = 45$ dyads)
42 patients completed. 43 surrogates completed.
1 dyad was too busy, and 1 adolescent lost interest.
2 dyads missed the study visit.

6 Months

6 months postintervention ($n = 44$ dyads)
43 patients completed. 39 surrogates completed.
1 dyad was lost to follow-up.
1 dyad missed the study visit.

6 months postintervention ($n = 43$ dyads)
40 patients completed. 37 surrogates completed.
1 dyad was lost to follow-up, and 1 dyad was lost
because of a family reason.
3 dyads missed the study visit.

12 Months

12 months postintervention ($n = 39$ dyads)
38 patients completed. 32 surrogates completed.
4 dyads were lost to follow-up.
1 surrogate withdrew.
1 dyad missed the study visit.

12 months postintervention ($n = 36$ dyads)
35 patients completed. 32 surrogates completed.
5 dyads were lost to follow-up, 1 dyad moved out,
and 1 dyad declined to give a reason.

FIGURE 1
Consort diagram: FACE pACP trial. A, adolescent; F, family.

TABLE 1 FACE pACP Intervention

	Session Foundation	Session Goals	Session Process
Session 1	Lyon FACE ACP survey: adolescent and surrogate versions to set stage for EOL conversations	(1) To assess the adolescent's values, spiritual and other beliefs, and life experiences with illness and EOL care and (2) to assess when to initiate ACP.	(1) Orient family to study and issues, (2) survey adolescent privately, and (3) survey surrogate privately with regard to what the surrogate believes the adolescent prefers.
Session 2	Next steps: ACP Respecting Choices interview (Hammes and Briggs[11])	(1) To facilitate conversations and share decision-making between the adolescent and surrogate about palliative care, providing an opportunity to express fears, values, spiritual and other beliefs, and goals with regard to death and dying; and (2) to prepare the guardian or surrogate to be able to fully represent the adolescent's wishes.	In stage 1, the teenager's understanding of the condition is assessed. In stage 2, the teenager's philosophy about EOL decision-making is explored. In stage 3, the rationale for future decisions the teenager would want the surrogate to act on is reviewed. In stage 4, the SoTP is used to describe scenarios and choices. In stage 5, the need for future conversations is summarized, and referrals are made.
Session 3	The 5 Wishes directive is a legal document that is used to help a person express how he or she wants to be treated if seriously ill and unable to speak for himself or herself. Unique among living will and health agent forms, all of a person's needs are addressed in it: medical, personal, emotional, and spiritual.	(1) Which person the teenager wants to make health care decisions for him or her, (2) the kind of medical treatment the teenager wants, (3) how comfortable the teenager wants to be, (4) how the teenager wants people to treat him or her, (5) what the teenager wants loved ones to know, and (6) any spiritual or religious concerns the teenager may have.	For adolescents <18 years of age, the 5 Wishes directive must be signed by their legal guardian. Processes, such as labeling feelings and concerns as well as finding solutions to any identified problem, are facilitated (with appropriate referrals). These sessions may include other family members or loved ones.

National Cancer Institute; National Institutes of Health. Research-tested intervention programs (RTIPs). Available at: https://rtips.cancer.gov/rtips/programDetails.do?programId=17054015. Accessed June 5, 2018. EOL, end-of-life.

site and mode of HIV transmission. Study coordinators were notified of randomization, and weekly intervention or control sessions 1 to 3 were scheduled. Sessions were facilitated by using a structured guide. Session 2 was videotaped and/or audiotaped and reviewed for fidelity.

Intervention: FACE pACP

Intervention dyads received usual care, an ACP booklet, and FACE pACP. Sessions were conducted by trained and/or certified RA interventionists (either clinicians or graduate students in nursing, psychology, counseling, and public health). Three 60-minute sessions were conducted ~1 week apart (see Table 1 for details; session 1, ACP survey[37–39]; session 2, Respecting Choices ACP Next Steps facilitated interview and statement of treatment preferences [SoTP][11]; and session 3, 5 Wishes directive[40]). For adolescents <18 years of age, their legal guardian's signature was required on the 5

Wishes directive. A copy was given to the family.

RA interventionists e-mailed the treating physician a summary of the goals-of-care conversation, a copy of the SoTP, and the signed 5 Wishes directive. Documents were entered into the medical record per institutional practices.

Active Control

Dyads who were randomly assigned to the control arm received usual care, an ACP booklet, and the control condition (session 1, developmental history: adolescent developmental history was taken[41] separately, and medical questions were removed to prevent risk of contamination; session 2, safety tips: the RA for the control arm provided counseling on safety information to the dyad using *Bright Futures* guides[42]; session 3, nutrition and exercise: the RA for the control arm provided counseling on exercise and nutrition to the dyad using *Bright Futures* guides[42]).

Primary Outcome Measure

The Pediatric AIDS Clinical Trials Group General Health Assessment for Children [43,44] HIV-related symptom subscale was used. On a 6-point Likert scale, adolescents rated the degree of distress experienced with 17 HIV-related physical symptoms. For analysis, each symptom was dichotomized (0: not at all; 1: at least some). Higher scores reflected more symptoms.

Secondary Outcome Measures

The Brief Multidimensional Measurement of Religiousness/Spirituality (adapted) was developed to assess health-relevant domains of religiousness and/or spirituality. Reliability and validity is well established with adolescents.[45–48] On the basis of our previous research, the following 5 items were preselected on the basis of correlations with social, emotional, and school quality of life[48]: "I feel God's presence"; "How often do you pray privately?"; "How often

do you go to religious services?"; "To what extent do you consider yourself a religious person?"; and "To what extent do you consider yourself a spiritual person?" In a previous analysis, 2 latent classes for religiousness in the same sample were identified: a higher religiousness and/or spirituality group (70% of dyads) and a lower religiousness and/or spirituality group (30%) for adolescents.[48] This latent class variable was used in modeling for this study.

The Threat Appraisal Scale[27] reliability and validity is well established among adolescents.[26,27] On the basis of our pilot data,[25] only the loss of desired others or objects subscale was examined. Items on the subscale included the following: "When you learned you were HIV-positive, you thought that you might…not get to do something that you wanted to do," "…not get to spend time with someone you like," "…not go somewhere that you wanted to go," and "…have to give up things you own." Responses were on a 5-point Likert scale. We hypothesized that loss of desired others or objects at baseline would mediate the effect of FACE pACP on symptom and suffering classification.

The Medication Adherence Self Report Inventory[49] is a self-report measure of antiretroviral medication adherence and indicates the estimated percentage of time adolescents took their HIV medications in the last month. This visual analog scale has excellent validity.[49]

An SoTP[11] was used to explore and document specific treatment preferences of the adolescent and obtain the families' understanding of the adolescents' goals. Three poor outcome situations included the following: "long hospitalization with many procedures and low chance of survival," "never be able to walk or talk again and would need 24-hour nursing care," and "never knowing who you are or who you are with and would need 24-hour nursing care." Choices included the following: "to continue all treatment so I could live as long as possible" ("Staying alive is most important to me no matter what"), "to stop all efforts to keep me alive" ("My definition of living well is more important than length of life"), or, "unsure." FACE pACP dyads discussed the SoTP together in session 2, whereas control dyads completed it individually after session 2.

Statistical Analysis: Congruence

A longitudinal latent class analysis (LLCA) was applied to analyze the longitudinal pattern of adolescent-family congruence on treatment preferences in the 3 HIV-related situations over time. Congruence on treatment preferences between adolescents and families in the 3 situations (measured at session 2 and at 6 and 12 months postintervention) was used as the outcome indicator in LLCA. The latent class variable was saved as an observed categorical variable for analysis.

Statistical Analysis: Symptoms

Instead of using the 17 self-reported HIV-specific symptoms as outcome variables in our analytical model, the LCA[50] was applied as a data reduction tool to generate a categorical latent variable reflecting the pattern of the HIV-specific symptoms at 12 months postintervention. The latent class variable was used as a categorical outcome in the path model. The sample size for the path analysis was estimated on the basis of assumptions for structural equation modeling (at least 5 observations per variable).[51,52] With only 11 variables in our model, the minimum sample size needed was $n = 66$. Our 12-month sample size was $n = 73$. In the path analysis model, the dyadic congruence latent profile variable was treated as a mediating factor through which the intervention indirectly influenced the pattern of HIV-specific symptoms. The religiousness and/or spirituality profile was treated as a moderating factor. A Bayesian estimator was applied for modeling to overcome small sample size shortcomings of the maximum likelihood estimator.[51] All the models were implemented by using Mplus 7.4.[53]

RESULTS

Sample Description

Of those initially eligible and enrolled, 108 adolescent-family dyads completed a secondary screening (Fig 1). Of these, 1 adolescent reported homicidal ideation, and 2 dyads withdrew without reasons, resulting in 105 randomly assigned dyads. Retention rates were 83% (87 of 105) and 71% (75 of 105) for 6- and 12-month follow-ups, respectively. Nine cases were unblinded. No significant baseline differences existed in symptoms by study arm. No adverse events were reported.[54]

Adolescents were a mean age of 18 years old (range: 14–21 years old), 54% male, 93% African American, and 55% of adolescents had viral suppression (Table 2). Family participants were a mean age of 45 years old (range: 20–77 years old), 82% female, and 90% African American. One-third of families reported they were HIV-positive; 62% had a high school education or less, and half lived in households with incomes below the federal poverty level.

Model Results: Congruence

The LLCA of dyads revealed 2 latent classes: class 1 ($N = 50$ [52%]) and class 2 ($N = 46$ [48%]; Fig 2, Supplemental Table 4). Congruence probabilities were high in class 1 in all 3 situations (.82, .69, and .80, respectively) immediately postintervention (session 2) and remained moderately high at 6-month (.71, .72, and .62,

TABLE 2 Baseline Characteristics for 105 Randomly Assigned Intervention and Control Adolescents

Characteristic	Intervention, n = 54	Control, n = 51	P
Age, y			
Mean (SD)	17.9 (1.88)	17.7 (1.99)	—
Range	14.0–20.0	14.0–20.0	.63[a]
Sex, n (%)			
Male	29 (53.7)	26 (51.0)	—
Female	25 (43.3)	25 (49.0)	.85[b]
Race and/or ethnicity, n (%)			
African American	50 (92.6)	48 (94.1)	—
Hispanic non–African American	4 (7.4)	3 (5.9)	.99[b]
Mode of HIV transmission, n (%)			
Perinatal infection	41 (75.9)	37 (72.6)	—
Nonperinatal infection	13 (24.1)	14 (27.5)	.82[b]
Self-reported sexual orientation, n (%)			
Nonheterosexual	19 (35.2)	12 (23.5)	—
Heterosexual	35 (64.8)	39 (76.5)	.21[b]
CDC classification, n (%)			
A: 1–3 (asymptomatic)	22 (40.7)	24 (47.1)	—
B: 1–3 (symptomatic)	17 (31.5)	13 (25.5)	.75[b]
C: 1–3 (AIDS)	15 (27.8)	14 (27.5)	—
Viral suppression (<400 copies per mL on most recent viral load test), n (%)	28 (57.1)	30 (66.7)	.34[b]
Dialysis since last medical visit	1 (2.0)	0 (0)	.99[b]
Adolescent education, n (%)			
No high school diploma or in high school	29 (53.7)	27 (52.9)	
HS or GED equivalent	15 (27.8)	19 (37.3)	
Some college or no bachelor's	9 (16.7)	5 (9.8)	.46[b]
Surrogate education, n (%)			
No high school diploma or in high school	13 (24.1)	10 (19.6)	—
HS or GED equivalent	(37.0)	22 (43.1)	—
Some college or higher education	21 (38.9)	19 (37.3)	.77[b]
Family income, n (%)[c]			
Equal of below federal poverty line	28 (51.9)	24 (47.1)	—
101%–200% of federal poverty line	4 (7.4)	11 (21.6)	—
201%–300% of federal poverty line	3 (5.6)	5 (9.8)	—
>300% of federal poverty line	13 (24.1)	(9.8)	—
Unknown	6 (11.1)	(11.8)	11[b]
Marital status, n (%)			
Single	54 (100.0)	50 (98.0)	—
Married or living together	0 (0)	1 (2.0)	.49[b]
Housing status, n (%)[c]			
Living in own house or apartment	48 (88.9)	45 (88.2)	—
Living in someone else's house or apartment	5 (9.3)	5 (9.8)	—
A shelter or someone else's house or apartment	1 (1.9)	0 (0)	—
Other	0 (0)	1 (2.0)	.93[b]

CDC, Centers for Disease Control and Prevention; GED, general equivalency diploma; HS, high school; —, not applicable.

[a] t test.

[b] Fisher's exact test. No statistically significant difference indicating success of randomization.

[c] Family income data are from families because adolescents did not always know their family income.

respectively) and 12-month (.65, .64, and .70, respectively) follow-ups. Situation-specific congruence probabilities in class 2 were low (.51, .44, and .53, respectively) immediately postintervention (session 2) and declined longitudinally. FACE pACP dyads were more likely to be in the high congruence class compared with control dyads (odds ratio: 3.11 [95% confidence interval (CI): 1.14 to 8.46]; P = .03), controlling for age, sex, race, parental education, family income, and transmission mode. A post hoc analysis revealed treatment congruence had no effect on HIV-medication adherence or viral suppression.

Model Results: Symptoms

The LCA identified 2 latent classes or groups on the basis of the 17 dichotomous measures of HIV-specific symptoms (Fig 3, Supplemental Table 3). Of adolescents, 27% were classified into class 1 (the higher symptoms and suffering group), and 73% were classified into class 2 (the lower symptoms and suffering group). The probabilities of symptoms and suffering were much higher in class 1 compared with class 2.

Model Results: Path Analysis

A Bayesian estimation of the model reached convergence. The 95% CI for the difference between the observed and the model estimated χ^2 statistics (−24.920 to 20.643) centered around 0, and posterior predictive P value (P = .567) indicated an almost perfect fit. The path analysis model results are shown in Fig 4. FACE pACP did not directly affect HIV symptom patterns (β = −.92; 95% CI: −3.86 to 1.66). FACE pACP increased the likelihood of higher dyadic treatment congruence (β = .65; 95% CI: 0.04 to 1.28). Higher treatment congruence decreased the likelihood of being classified in the higher symptoms and suffering class (β = −1.14; 95% CI: −2.55 to −0.24). As such, FACE pACP indirectly negatively affected symptom classification through treatment congruence (β = −.686; 95% CI: −2.14 to −0.006); that is, patients in the intervention group were less likely to be classified into the higher symptoms and suffering class. The variable loss of desired others and objects directly predicted the effect of the intervention on symptom classification (β = .29; 95% CI: 0.06 to 0.60); however, it did not mediate the FACE pACP intervention effect on symptoms because FACE pACP did not significantly affect loss of desired others or objects (β = .50; 95% CI: −0.85 to 1.86). Religiousness
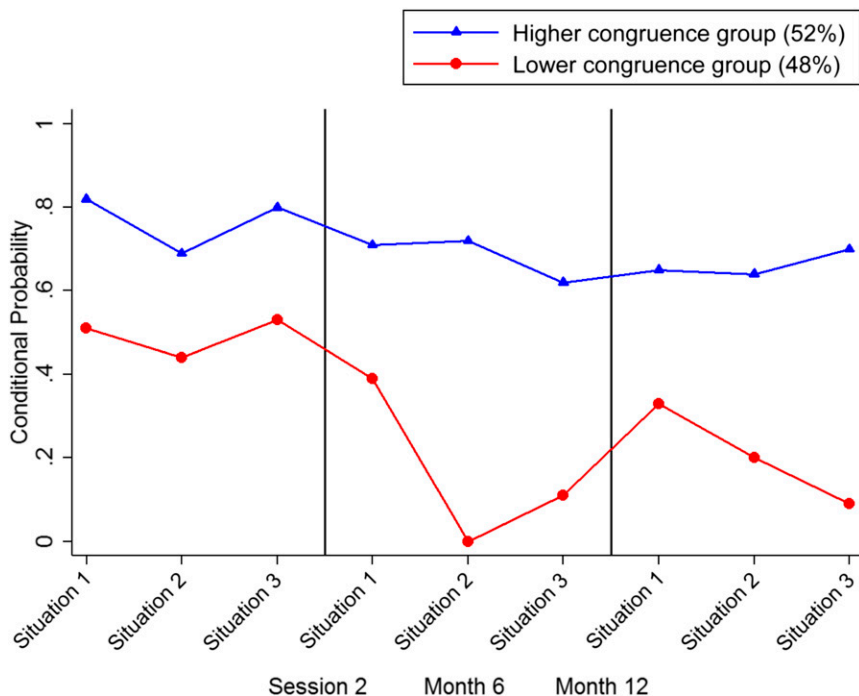
FIGURE 2
Results of the LLCA on treatment congruence over time. Situation 1 indicates a long hospital stay with many treatments and a low chance of survival. Situation 2 indicates a physical disability with 24-hour nursing care. Situation 3 indicates mental disability with 24-hour nursing care. Congruence means that the family understood and accurately reported what that adolescent would want for end-of-life treatment preferences.

and/or spirituality had a significant positive effect on symptom classification (β = 2.18; 95% CI: 0.22 to 4.70); that is, patients in the high religiousness and/or spirituality class were more likely to have a higher probability of being in the higher symptoms class. However, religiousness and/or spirituality did not significantly moderate the FACE pACP intervention effect because its interaction with the intervention was not statistically significant (β = −.11; 95% CI: −2.82 to 2.86). Adolescents who reported taking their antiretroviral medication (≥90% of the time) had a lower probability of being in the higher symptoms class (β = −2.10; 95% CI: −3.93 to −0.82). Older adolescents were more likely to be in the higher symptoms class (β = .58; 95% CI: 0.14 to 1.10). Additionally, sex, ethnicity, and perinatal HIV infection did not significantly affect classification of HIV symptoms.

DISCUSSION

To our knowledge, this is the first study in which a full theoretical model of pACP is tested and is the first longitudinal randomized clinical trial of pACP, the gold standard of research.[55] The hypotheses that there would be a direct intervention effect between FACE pACP and HIV-latent symptom class was not supported. However, the a priori hypothesis that there would be an indirect intervention effect through dyadic treatment congruence on classification of HIV symptoms and suffering was supported. FACE pACP families were significantly more likely to understand adolescents' treatment preferences. In turn, if families accurately reported their understanding of their adolescents' end-of-life treatment preferences, their adolescents were more likely to be in the lower symptoms and suffering class at 12 months postintervention. In contrast,

families in the lower congruence class had adolescents more likely to be in the higher symptoms and suffering class. Higher congruence suggests good communication and social support, which are demonstrated to decrease HIV-specific symptoms in adults.[19]

Consistent with theories of coping through problem solving[12–18] and the representational approach to patient illness interventions,[28–31,56] pACP gave adolescents control associated with lower symptoms, particularly with pain. The impact of higher dyadic congruence worked through 2 mechanisms to decrease symptoms and suffering: (1) social support (experienced through respectful and authentic conversations about adolescents' understanding of their illness) and (2) control (through being asked to make choices about treatments in poor-outcome situations with their family's support in a safe environment).[54] Future research could be used to explore whether higher congruence decreases disease-specific symptoms through enhanced immune function[57] by decreasing stress (weekly supportive facilitation) and providing problem solving support[19,58] ("breaking the ice" so that families understand their adolescents' treatment preferences), through patient representation of illness[28–31] (changing adolescents' representations of illness and acting on new information), and/or through control[17,18] (giving adolescents a voice so that preferences are honored by family, shared with their physician, and documented in the medical record).

Consistent with adult studies,[59,60] facilitated conversations improve families' understanding of their adolescents' end-of-life treatment preferences. Although results in adult studies have been inconsistent, some adult studies
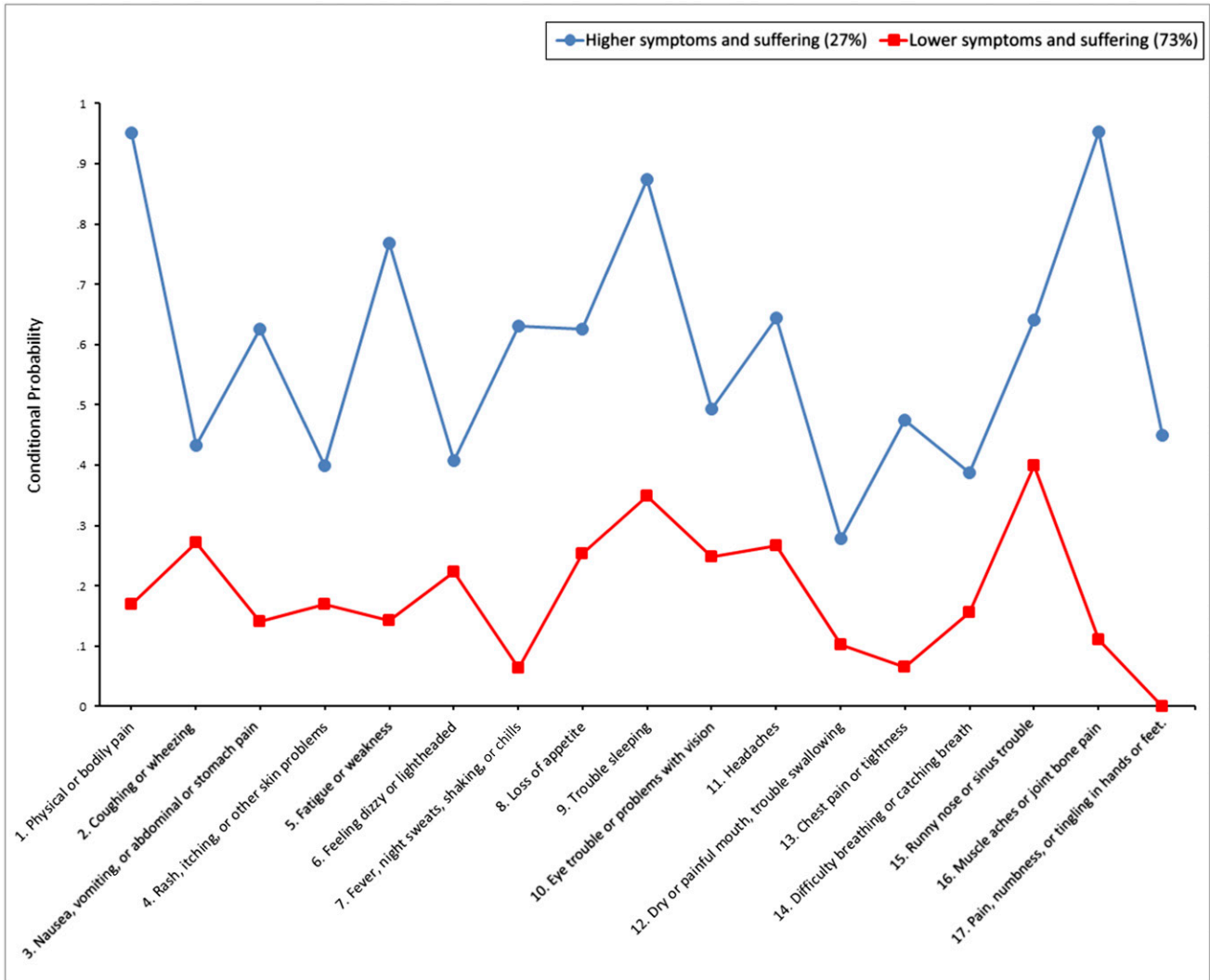
FIGURE 3
Results of the LCA on HIV-specific symptoms at 12 months postintervention.

have revealed an ACP effect on disease-specific symptoms. These inconsistencies may reflect lack of scientific rigor (as described in systematic reviews[61,62]) and/or failure to examine treatment congruence as a mediator of symptom outcomes.

One dimension of threat appraisal (loss of desired others or objects) directly increased the likelihood of being in the higher symptoms class regardless of study arm. Consistent with our pilot study[25] and previous research with children,[26,27] loss of others and objects is a significant

pathway to psychological symptoms over and above the effects of stressful events per se.

Religiousness directly increased the likelihood of adolescents being in the high symptoms latent class, with pain dominating symptoms. Future research may reveal the underlying mechanism, such as a belief that physical pain is a test of faith to be endured and not masked by medication[63] or a belief that redemption is achieved through suffering.[64,65] Clinicians might refer interested adolescents for consultation with a hospital-based chaplain to conduct a

spiritual assessment to understand how beliefs affect youths' health experiences.[66,67]

Strengths

This culturally sensitive model with a traditionally understudied and underserved population had high participation rates and a significant benefit (reducing HIV-specific symptoms and suffering). FACE pACP may contribute to health equity.[63,68,69] FACE pACP has features to foster replication and ease of implementation, including a structured conversation guide, family engagement, certified
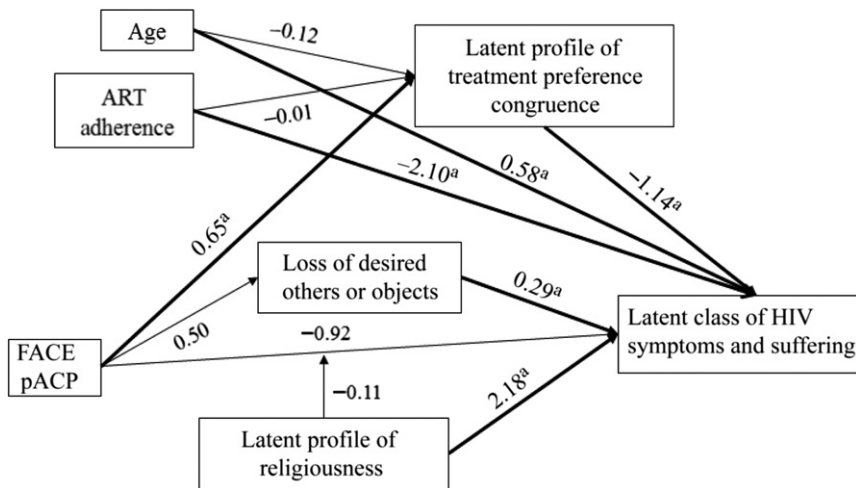
FIGURE 4
Results of the path analysis model. Covariates that do not have a significant slope coefficient are not included in the diagram. [a] Significant at the $P < .05$ level. ART, antiretroviral therapy.

nonphysician facilitators, face-to-face sessions, physician communication, and formalized documentation.

Limitations

Only adolescents who had an identified surrogate decision-maker were eligible, which limited generalizability[70] and was a challenge for all dyadic research.[71] Findings may not generalize beyond African American and Hispanic adolescents living with HIV or AIDS (an understudied cohort). Although viral load provided an indicator of disease progression, CD4[+] and comorbidity data were not collected. pACP conversations did not increase HIV-medication adherence in this sample, so this is an unlikely explanation for the symptom benefit.[72]

Whether early pACP will result in goal-concordant care[73] is unknown, although FACE pACP did maintain congruence over the course of 1 year, even as adolescents changed their mind. Importantly, the ideal of patient-centered care supports early pACP for adolescents living with HIV[37–39] because less than one-fourth of adolescents wanted to wait until hospitalization or they were dying to talk about pACP.

Although prognostication may have a role in ACP,[73,74] prognostication is complicated with HIV and AIDS comorbidities, medication adherence, and treatment side effects.[75] As noted earlier, most adolescent patients have indicated a strong preference for beginning these conversations while healthy, at time of diagnosis, or when first experiencing disease-specific symptoms.[37–39,76,77]

CONCLUSIONS

FACE pACP successfully decreased symptom burden, a goal of patient-centered care.[63,78] This model is responsive to calls for culturally sensitive interventions,[63,79–82] a beneficial approach that effectively provided access to and provision of pACP to underserved racial and ethnic groups. Study results provide an evidence base for effective pACP in pediatric, hospital-based HIV clinics to achieve quality improvement and to support policy recommendations to implement pACP as an individualized and structured part of care for interested families.[83–87] Trial findings may inform care and future interventions for young people with other serious illnesses.

ABBREVIATIONS

ACP: advance care planning
CI: confidence interval
FACE pACP: family-centered pediatric advance care planning
LCA: latent class analysis
LLCA: longitudinal latent class analysis
pACP: pediatric advance care planning
RA: research assistant
SoTP: statement of treatment preferences

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