*Original Article*

# FAmily-CEntered (FACE) Advance Care Planning Among African-American and Non-African-American Adults Living With HIV in Washington, DC: A Randomized Controlled Trial to Increase Documentation and Health Equity

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## Abstract

**Context.** No prospective studies address disease-specific advance care planning (ACP) for adults living with HIV/AIDS.

**Objective.** To examine the efficacy of FAmily-CEntered (FACE) ACP in increasing ACP and advance directive documentation in the medical record.

**Methods.** Longitudinal, two-arm, randomized controlled trial with intent-to-treat design recruited from five hospital-based outpatient HIV clinics in Washington, DC. Adults living with HIV and their surrogate decision-makers ($N = 233$ dyads) were randomized to either an intensive facilitated two-session FACE ACP (Next Steps: Respecting Choices goals of care conversation and Five Wishes advance directive) or healthy living control (conversations about developmental/relationship history and nutrition).

**Results.** Patients ($n = 223$) mean age: 51 years, 56% male, 86% African-American. One hundred ninety-nine dyads participated in the intervention. At baseline, only 13% of patients had an advance directive. Three months after intervention, this increased to 59% for the FACE ACP group versus 17% in the control group ($P < 0.0001$). Controlling for race, the odds of having an advance directive in the medical record in the FACE ACP group was approximately seven times greater than controls (adjusted odds ratio = 6.58, 95% CI: 3.21−13.51, $P < 0.0001$). Among African-Americans randomized to FACE, 58% had completed/documented advance directives versus 20% of controls ($P < 0.0001$).

**Conclusions.** The FACE ACP intervention significantly improved ACP completion and advance directive documentation in the medical record among both African-American and non-African-American adults living with HIV in Washington, DC, providing health equity in ACP, which can inform best practices. J Pain Symptom Manage 2019;57:607−616. © *2018 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

***Key Words***

*HIV, advanced care planning, African-American, advanced directive, electronic health records, decision-making*

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*Accepted for publication: November 14, 2018.*



0885-3924/$ - see front matter
https://doi.org/10.1016/j.jpainsymman.2018.11.014

## Introduction

Advance care planning (ACP) is a process that includes identification of a surrogate decision-maker (heretofore referred to as family), goals of care conversations, and documentation of goals of care and advance directives in the medical record.[1,2] ACP supports persons at any age or stage of serious illness and is not dependent on prognosis to ensure care received is the care desired.[1,2] The benefits of ACP[3–6] have seldom been studied in African-American adults and even more rarely in persons living with HIV (PLWHs).[7] Despite expressed interest in doing so, African-Americans are less likely to participate in ACP, have advance directives, or document their chosen surrogate decision-maker.[8–11] Likewise, rates of advance directive completion among PLWHs are low.[12,13]

African-Americans are disproportionately impacted by the HIV epidemic. In Washington, D.C. (DC), among adults and adolescents living with HIV, there were 1084 AIDS-related deaths from 2012 to 2015.[14] DC has the highest prevalence of HIV infection of any city in the United States[14]; and although African-Americans in DC comprise just under half of DC residents, they account for 75% of HIV cases.[14]

The FAmily-CEntered ACP (FACE ACP) model was developed in the early 1990s through a community-based participatory research in response to adolescents living with HIV who wanted a voice in their end-of-life care but had no legal rights. Rarely were they included in the decision-making process, despite hospital and national policy recommendations.[15] A three-session FACE ACP intervention was developed/adapted through an iterative process involving the scientific and HIV community; adolescents living with HIV[16]; local and national focus groups with adolescents living with HIV; and bereaved parents. The model was then pilot tested.[17–19] The intervention was also informed by Folkman's and Lazarus' transactional model of stress and coping through problem solving[20,21]; as well as the patient's representation of illness model[22] and Leventhal's common sense model of self-regulation of health and illness behavior.[23] Building on the pilot, a longitudinal, single-blinded, multisite, randomized clinical trial of FACE ACP achieved its primary aim: to minimize suffering, decreasing HIV-specific symptoms through increasing families' understanding of the adolescents' end-of-life treatment preferences one year after intervention.[24] Participants also found the experience acceptable[25] and were willing to complete advance directives.[26]

Given the demonstrated benefits of ACP and the low utilization among African-Americans and adults living with HIV, we built on the adolescent FACE pACP model to test implementation of ACP among adults living with HIV receiving their medical care in DC. We reduced the number of sessions from three to two (Session 1: Next Steps: Respecting Choices, goals of care conversation[27]; Session 2: Completion of Five Wishes advance directive)[28] because adults living with HIV, in contrast to adolescents living with HIV, preferred a shorter intervention.

We hypothesized that African-Americans living with HIV in the FACE ACP intervention would complete ACP and have documented advance directives in the medical record at a rate comparable to non-African-Americans living with HIV, and at significantly greater rates compared to an active control.

## Methods

### Subjects

From October 2013 through March 2017, patients with HIV infection and their chosen surrogate decision-makers, heretofore referred to as families, were recruited from five DC hospital-based HIV-clinics. Participating hospitals are members of the DC Center for AIDS Research (DC-CFAR). FACE ACP enrolled dyads consisting of adults living with HIV aged 21 years or older and their chosen family member who was at least 18 years old. Inclusion criteria were amended to include all HIV-positive individuals receiving care at study sites to increase enrollment and consistent with current policy recommendations to include all stages of illness.[1,2] Participant inclusion criteria required knowledge of HIV diagnosis and ability to speak and understand English, as not all measures were translated and participants would be signing a legal document. To ensure competency to participate in decision-making, exclusion criteria were current ICU admission; being a ward of the state; known cognitive delay; or severe depression,[29] suicidality,[29] homicidality,[30] psychosis[30]; or HIV dementia on secondary screening.[31] The institutional review board at each site approved the protocol. Written, informed consent was obtained from all study participants. A Safety Monitoring Committee reviewed the study data and human subject's protections yearly. This study was registered at clinicaltrials.gov, Identifier: NCT01775436.

### Procedures

We conducted a two parallel-group, randomized controlled clinical trial with an intent-to-treat design. Providers identified potentially eligible PLWHs who were then approached during a clinic visit by a trained research assistant (RA). After baseline assessment, enrolled dyads were randomly assigned at a ratio of 2:1 to receive FACE ACP ($n = 155$ dyads) or healthy living control (HLC) ($n = 68$ dyads). This ratio was decided on out of ethical concerns, as previous studies using the FACE ACP model showed benefit with

adolescents living with HIV[22–26] and cancer.[32,33] The data coordinating center created a computer-generated randomly permuted block randomization scheme blocked by study site to ensure relative balance across conditions over recruitment. PLWH/family dyads independently completed questionnaires at baseline (before randomization) and three months after intervention.

### Measures

*Demographic Data.* Trained RA-Assessors obtained patient- and family-reported sociodemographic information and medical data. RA-Assessors reviewed the medical records to confirm patients' self-report of HIV status, hospitalizations, and comorbidities.

*Presence or Absence of Any Advance Directive.* A trained RA-Assessor abstracted the presence or absence of documentation of any advance directive at baseline and three months after intervention from the electronic health record (EHR) or paper medical chart onto a standardized data extraction form. RA-Assessors were not facilitators of the FACE ACP or HLC condition.

### Interventions

After randomization, FACE and HLC participants had two 60-minute sessions scheduled one week apart. Attendance was recorded. Eligible and enrolled participants were compensated at $25 per study visit. Both groups received an ACP booklet.

### FAmily-CEntered (FACE-HIV) ACP

Trained facilitators administered the *FACE Intervention Sessions 1 (~60 minutes)* and *2 (~60 minutes). Session 1*: *Next Steps: Respecting Choices Interview.*[27] The goals were to 1) facilitate goals of care conversations between the PLWHs and their family or family members and 2) prepare the family to be able to fully represent the PLWH's treatment preferences, if the patient could not communicate. The goals of *Session 2*: *Five Wishes*[28] were 1) to confirm patient's surrogate decision-maker and 2) to confirm end-of-life treatment preferences. The Five Wishes in addition to being an advance directive designates the health care power of attorney and two backups, if the first person is not available. The facilitator sent a secured e-mail to the treating physician after session completion with a brief summary of the goals of care conversation and a copy of the *Five Wishes*. The facilitator followed site-specific procedures for entering the documents into the medical record (paper chart or EHR).

### Healthy Living Control

*Control (HLC) Sessions 1 (~60 minutes) and 2 (~60 minutes). Session 1: Developmental history*[34] goal was to obtain a developmental history to control for time and attention spent with the participants in the FACE intervention. If the family member only knew the patient as an adult, the development of their relationship was discussed, using a structured questionnaire. All medical questions were removed to prevent any risk of contamination with the intervention. *Session 2: Nutrition (~60 minutes)* assessed nutritional status to counsel participants on optimal nutrition to boost immune functioning and to control for time and attention spent with the FACE intervention group.

### Intervention Fidelity

Training on the protocol to certification, validation of implementation by video, and standardized procedures were used to minimize differences by site. The selection, roles and responsibilities, and preparation of surrogate decision-makers were detailed in the three-day training sessions. *Days 1 and 2 RA-Facilitator Training:* In the first day of face-to-face training, the Next Steps: Respecting Choices Facilitation Certification Course was taught by certified trainers. This program included pre-course materials (e.g., online ACP course, manual), a classroom certification course, and validation of competency through review of individual video role-play demonstrations. The first author provided supplemental training at a later date when needed. All RA-facilitators were certified to administer the intervention. *Day 3 Training* oriented all RAs to the study, the protocol, and standardized procedures for recruitment, screening, and enrollment. RAs for the control condition were trained by the first author to administer the control condition. RA-Assessors were also trained by the first author to conduct the screening, baseline, and follow-up assessments to prevent process interviewer bias in the data collection.

The first five videos/audiotapes from Session 1 of both the FACE and HLC study arms from each study site were reviewed by two study investigators. Subsequently, 10% of recordings were reviewed randomly. A *Respecting Choices Competency Criteria Checklist*[27] was used to ensure fidelity for Session 1 of FACE. Two certified investigators conducted monthly supervision conference calls with the Respecting Choices facilitators. One study site had one facilitator throughout the study who was a social worker. A second site had two facilitators, a clinical psychologist and a social worker. Three study sites shared facilitators from the Coordinating Center, who were graduate students in Public Health (1), Counseling (1), and Clinical Psychology (2). There were seven facilitators, four of whom were African-Americans. Face-to-face booster sessions were held separately with RA-Interventionists, RA-Controls, and RA-Assessors one year after starting enrollment to maintain skills. The coordinating center

had weekly staff meetings to track recruitment, enrollment, implementation fidelity, data integrity, dissemination activities, and trouble shooting. Monthly conference calls were held with clinical coordinators and coinvestigators throughout the study. On-site monitoring for fidelity to the protocol and adherence to regulatory requirements occurred yearly.

### *Analysis*

Details including power analysis to determine sample size are published elsewhere.[7] The original enrollment goal of 288 dyads was amended to 223 dyads, due to a revised power analysis based on findings from related studies.[18,32] As this manuscript focuses on racial differences, we excluded those who declined to specify a race from the analyses ($n = 6$). Rate of completion of advance directives among PLWHs at baseline and three months after intervention and the rate disparity between African-American and non-African-American participants were tested using the two-tailed Pearson chi-square test (or Fisher's exact test if any cell frequency is <5 in a contingency table). Generalized estimating equations were also used to examine the effect of the FACE ACP intervention on the odds of completion of advance directives, controlling for covariates using the baseline (T1) and three-month postintervention (T3) data.

## Results

We assessed 868 potential participants for eligibility. Reasons for declining or exclusion are in Figure 1. Of 192 patients who did not meet eligibility criteria, 176 (92%) could not identify a surrogate decision maker and 14 (8%) did not meet inclusion criteria. Among the 302 decliners who agreed to give us demographic information (302/453), decliners were significantly more likely to be male (76% males vs. 24% females) and African-American (58% African-Americans vs. 37% non-African-American). All transgender persons ($n = 4$) and persons living with perinatally acquired HIV ($n = 6$) who were approached agreed to participate. Of those eligible/enrolled, 223 dyads were randomized. Of those participants who started Session 1, Next Steps: Respecting Choices conversation of the FACE ACP intervention (145 dyads), 98% returned to attend Session 2 (142/145 dyads), completing the Five Wishes advance directive. Retention at three-month follow-up for all study participants was 80% (176/223 dyads).

Demographic and health characteristics of patients and their families are listed in Table 1. Briefly, 56% of PLWHs were male and 86% were African-Americans; mean age was 51 years with approximately one-fourth were aged 22-39 years ($n = 44$), one-half aged 40-60 years ($n = 128$), and one-fourth aged 61-77 years ($n = 51$). Almost half reported family income of equal to or below the federal poverty line. Two-thirds had comorbidities, including liver disease, diabetes, cancer, and heart disease. Half received federal disability benefits. At baseline, 94% of PLWHs reported ever being hospitalized at least once; 31% reported being hospitalized more than five times in their life. Number of hospitalizations ranged from 0 ($n = 13$) to 60 ($n = 1$). Hospitalization data were missing for four PLWHs.

Few PLWHs had a pre-existing advance directive in medical their record (13%, 28/212). Among those 28, 24 were African-Americans and four were non-African-Americans; however, the racial difference was not statistically significant ($P = 0.5328$).

### *Primary Outcome—Advance Directive Completion and Documentation in Medical Record*

Among all study PLWHs, FACE ACP significantly increased the likelihood of documentation of an advance directive in the medical record at three months after intervention compared to HLC (59% [73/124] vs. 17% [8/47], $P < 0.0001$; Table 2). At three months after intervention, African-Americans in the FACE group had a record of 58% of completed advance directives in the medical record; and non-African-American in the FACE group had a record of 67% of completed advance directives in medical record. We examined within-group differences among African-Americans by study arm and found that the completion of an advance directive and documentation was also significantly higher for FACE ACP compared to HLC (58% [64/110] vs. 20% [8/40], $P < 0.0001$). The ability to find the advance directive in the medical record for those in the FACE group at three months after intervention ($n = 124$) differed significantly by study site (17/47, 36%; 20/30, 67%; 24/35, 69%; 8/8, 100%; 4/4, 100%; $P = 0.0002$). Data were missing for one participant.

Selected results of generalized estimating equations model are shown in Table 3. Although the main effect of intervention was not statistically significant (OR = 1.46, 95% CI: 0.87−2.44, $P = 0.1510$), the interaction between intervention and time is significant (OR = 6.58, 95% CI: 3.21−13.51, $P < 0.0001$), indicating that the adjusted odds of locating an advance directive being in the medical record at three months after intervention was 6.58 times higher for FACE participants than controls. In addition, controlling for intervention effect, racial differences were not statistically significant (OR = 0.95, 95% CI: 0.39−3.33, $P = 0.9179$).

### *Adverse Events*

No adverse events or serious adverse events were reported. One patient and two surrogates died during the study period. Causes of deaths were not study related.

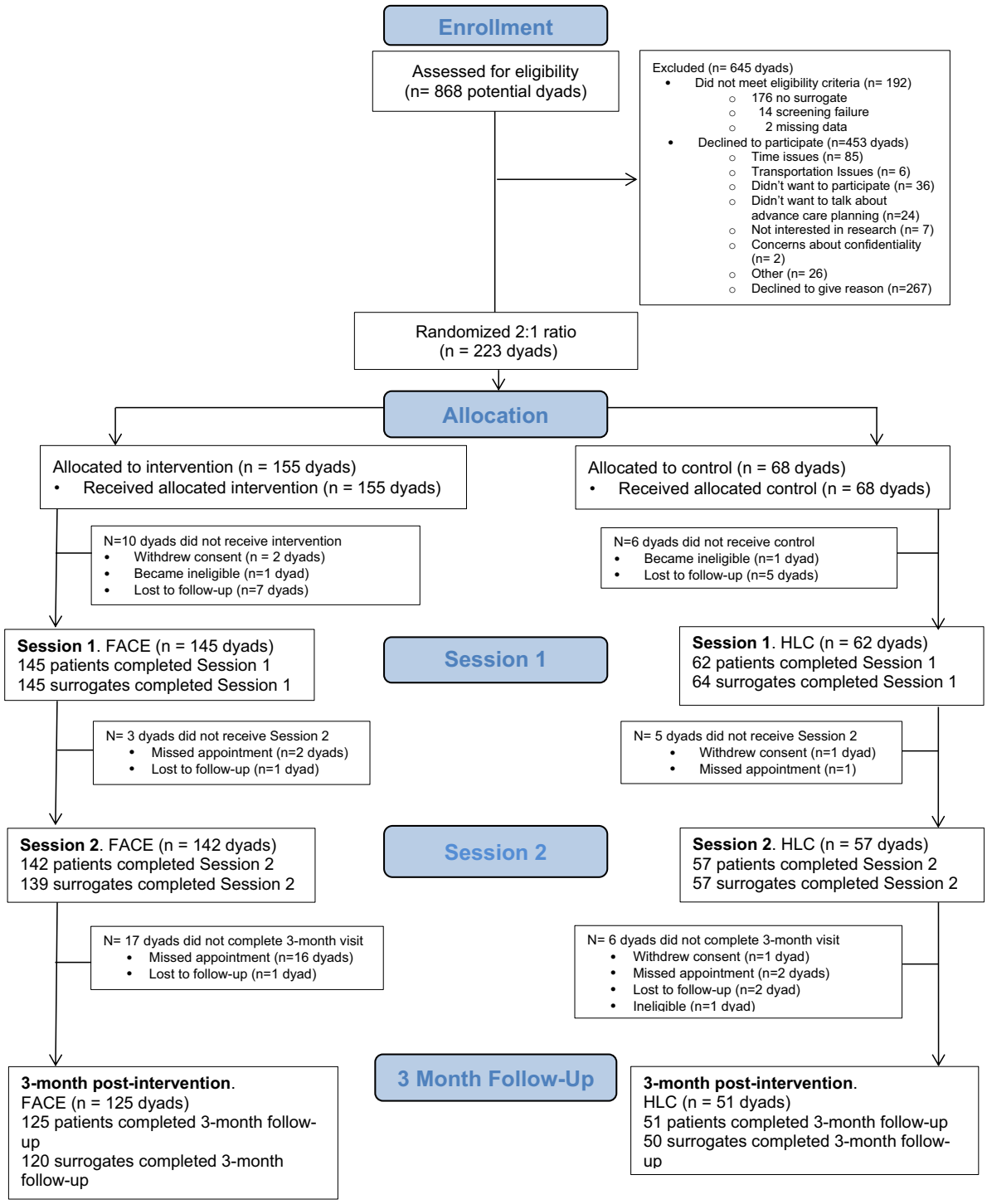


Fig. 1. Consort diagram: Flow of participants through FACE-ACP trial. FACE ACP = FAmily-CEentered advance care planning; HLC = healthy living control.

## *Discussion*

This longitudinal randomized controlled clinical trial is the first to prospectively examine the efficacy of a disease-specific ACP intervention for adults living with HIV. The odds of ACP completion and documentation of an advance directive in the medical record for the FACE group was approximately seven times greater than that for the control group at three months after intervention. Furthermore, among African-Americans, advance directive completion was significantly greater for participants in FACE ACP than HLC. The FACE trial overcame previously identified barriers to ACP completion and documentation

*Table 1*
**Baseline Characteristics for Adults With HIV/AIDS and Their Surrogate Decision-Maker**

| Demographic | Patient ($N = 223$) | Surrogate ($N = 226$) |
|---|---|---|
| Age | | |
| Mean (SD) | 50.8 (12.3) | 49.6 (14.2) |
| Range | 22–77 | 18–82 |
| Gender, *n* (%) | | |
| Male | 125 (56.1) | 99 (43.8) |
| Female | 94 (42.2) | 126 (55.8) |
| Transgender | 4 (1.8) | 1 (0.4) |
| Race, *n* (%) | | |
| American Indian or Alaska Native | 1 (0.5) | 2 (0.9) |
| Asian | 0 (0) | 1 (0.4) |
| African American | 192 (86.1) | 190 (84.1) |
| White/Caucasian | 19 (8.5) | 21 (9.3) |
| Biracial | 5 (2.2) | 4 (1.8) |
| Declined | 6 (2.7) | 8 (3.5) |
| Ethnicity, *n* (%) | | |
| Hispanic/Latino | 8 (3.6) | 9 (4.0) |
| Non-Hispanic/non-Latino | 202 (90.6) | 205 (90.7) |
| Declined | 13 (5.8) | 12 (5.3) |
| Sexual orientation, *n* (%) | | |
| Heterosexual | 148 (66.4) | 156 (69.0) |
| Nonheterosexual | 75 (33.6) | 70 (31.0) |
| Source of transmission, *n* (%) | | |
| Behaviorally infected | 156 (70.0) | |
| Perinatally infected | 6 (2.7) | |
| Unknown | 61 (27.4) | |
| Education, *n* (%) | | |
| High school or lower | 93 (41.7) | 103 (45.6) |
| Some college or higher | 130 (58.3) | 123 (54.4) |
| Income, *n* (%) | | |
| Equal, below federal poverty line | 86 (39.5) | 67 (30.7) |
| Higher than federal poverty line | 87 (39.9) | 105 (48.2) |
| Unknown/unreported | 45 (20.64) | 54 (23.9) |
| Current employment status, *n* (%) | | |
| Part-time student | 3 (1.3) | |
| Full-time student | 4 (1.8) | |
| Part-time employed or self-employed | 14 (6.3) | |
| Full-time employed or self-employed | 37 (16.7) | |
| Unemployed | 29 (13.1) | |
| Disability/SSI or SSD | 110 (49.6) | |
| Retired | 19 (8.6) | |
| Other, such as homemaker | 6 (2.7) | |
| Time since diagnosis of HIV positive (years) | | |
| Mean (SD) | 17.5 (8.2) | |
| CD4 count <500, *n* (%) | | |
| Yes | 88 (41.1) | |
| No | 126 (58.9) | |
| Advance directive in chart, *n* (%) | | |
| Yes | 29 (13.3) | |
| No | 178 (81.7) | |
| Do not know | 11 (5.1) | |
| Is patient prescribed HIV medication? | | |
| Yes, *n* (%) | 208 (94.6) | |
| No, *n* (%) | 12 (5.5) | |
| Adherence score, *n* (%) | | |
| ≥90% | 171 (81.4) | |
| <90% | 39 (18.6) | |
| Viral load undetectable (<50), *n* (%) | | |
| Yes | 167 (75.2) | |
| No | 55 (24.8) | |
| Dialysis, *n* (%) | | |
| Yes | 6 (2.7) | |
| No | 213 (97.3) | |
| Ever hospitalization, *n* (%) | | |
| Yes | 206 (94.1) | |
| No | 13 (5.9) | |
| Currently drug and/or alcohol dependent, *n* (%) | | |
| Yes | 9 (4.1) | |
| No | 212 (95.9) | |
| Current cigarette smoker, *n* (%) | | |
| Yes | 82 (36.9) | |
| No | 140 (63.1) | |
| Comorbidities[a], *n* (%) | | |
| Liver disease including Hep B and Hep C | 63 (28.3) | |
| Diabetes | 35 (15.7) | |
| Cancer or malignancies | 25 (11.2) | |
| Heart disease or heart failure including heart attack or stroke | 25 (11.2) | |
| Renal disease (kidney disease) | 18 (8.1) | |
| HIV-associated neurological disorder (HAND) | 3 (1.3) | |
| Any comorbidities? | | |
| Yes, *n* (%) | 146 (65.5) | |
| No, *n* (%) | 77 (34.5) | |
| HIV positive, *n* (%) | | |
| Yes | 223 (100.0) | 72 (31.9) |
| No | | 146 (64.6) |
| Do not know | | 3 (1.3) |
| Declined | | 5 (2.2) |

SD = standard deviation.
[a]More than one comorbidity could be chosen.

for PLWHs[35,36] and ethnic/racial minorities.[37–41] Furthermore, approximately 40% of this sample of PLWHs reported incomes below the federal poverty level and a high school education or less, suggesting this model also overcame socioeconomic barriers to ACP completion found in previous studies.[35–41] Three-fourths of the sample had an undetectable viral load, a marker of disease severity, indicating a willingness to engage in these conversations even with well-controlled HIV; this said, almost half of patients had identified comorbidities and half received disability benefits from the government. FACE ACP intervention was adapted/developed to be respectful of and responsive to the health beliefs and practices of African-Americans and PLWHs. The FACE ACP model is particularly important for African-Americans who prefer family-centered decision-making.[39] This model was also successful in engaging sexual minorities,[36,42] who comprised one-third of this sample.

Study findings contrast with a systematic review that concluded African-Americans prefer informal discussions about ACP to formal documentation of preferences.[40] However, few of the reviewed studies involved interventions to engage both African-American families and patients. Furthermore, historically based geographical/regional racial and HIV stigma experiences may account for geographical/regional differences in willingness to engage in formal ACP and documentation.[40,41] Consistent with a qualitative study of early ACP for African-Americans, FACE ACP

*Table 2*
**Presence of Advance Directive in Chart by Intervention Group at Three Months After Intervention ($N = 167$)[a]**

| Presence of Advanced Directive in Chart | FACE-ACP ($N = 122$), $n$ (%) | HLC ($N = 45$), $n$ (%) | $P$ value[b] |
|---|---|---|---|
| No | 36 (30) | 34 (76) | <0.0001 |
| Yes | 72 (59) | 8 (18) | |
| DK | 14 (11) | 3 (7) | |

FACE ACP = FAmily-CEntered advance care planning; HLC = healthy living control; DK = do not know.
Information was unavailable in the medical record or in the electronic health record (EHR).
[a]Six patients who were enrolled in the study at three months after intervention but did not report their race identity were excluded from the analysis.
[b]Fisher's exact test.

demonstrated that respectful and rapport building communication, which treated the family as an asset, successfully engaged African-Americans living with a serious illness in early ACP.[43]

There is a debate about whether the ultimate goal of ACP should be between patient preferences and the care actually received; and whether or not this outcome is measurable.[44,45] This may be particularly salient for PLWHs because the trajectory to death is less predictable and may trigger hospital admissions for potentially life-extending interventions, even for those indicating a preference for less-aggressive HIV-specific care.[46] One patient died during the study in a DC hospital from heart-related complications and not at the hospital where he received his HIV care. This patient had expressed a desire for limitations of care, but because the crisis was due to a condition unrelated to HIV, aggressive care was initially provided. Later, when decisions were being made about life-sustaining treatment, his surrogate asked the study investigator for a copy of the patient's advance directive, highlighting the importance of surrogates keeping a copy of ACP documents.

*Table 3*
**Impact of the FACE ACP Intervention on Documentation of Advance Directives in the Medical Record—Selected Results of Generalized Estimating Equations (GEEs) Model**

| Variable | OR (95% CI) | $P$ value |
|---|---|---|
| Time | | |
| T1 | — | — |
| T3 | 1.46 (0.87–2.44) | 0.1510 |
| Intervention Arm | | |
| Control | — | — |
| FACE | 0.99 (0.42–2.35) | 0.9853 |
| African-American | | |
| No | — | — |
| Yes | 0.95 (0.39–2.33) | 0.9179 |
| Interaction between time and intervention | — 6.58 (3.21–13.51) | — <0.0001 |

OR = odds ratio; — = Reference group.

An unexpected finding was the large proportion of advance directives, completed during Session 2 of the FACE ACP intervention, which were not accessible in the medical record. Block randomization by study site was intended to control for clinic-level factors, but we did not control for EHR system factors. This study took place during the transition from paper to electronic records, which may also account for the lack of easy access to advance directives. Similarly, in a study of older adults admitted to the hospital through the emergency department 40% reported they had a living will and had appointed a health care proxy, but for only 4%–5% could this documentation be found in the EHR.[47] Many systems do not have a dedicated document tag to mark where advance directives are stored. Study findings support recommendations to improve ACP standards for EHR vendors and health system documentation, so ACP information is within a central location in the EHR, easy to retrieve, and portable across health care systems.[48,49]

### *Limitations*

Complete blinding of the RA-Assessors was difficult to maintain at some study sites because of space constraints and patients and their families could be seen entering and leaving the office where the intervention was taking place. However, none of the RA-Assessors were intervention facilitators and they received training to minimize bias. Face-to-face assessments potentially created social desirability bias. Yet, face-to-face assessments served as an effective engagement, safety monitoring, and data maximization strategy, while overcoming obstacles of low literacy, education, or vision impairment. Of those potentially eligible, one-third agreed to participate, a rate within the norm of dyadic palliative care studies.[50]

Of note, 92% of potentially eligible PLWHs were not eligible to enroll because they could not identify a surrogate decision-maker, a problem also found in our adolescent trial.[51] Anecdotally, barriers to identifying surrogates included practical considerations: unable to get time off from work, living in another state, or unaware of HIV infection. The Institute of Medicine 2015 report, *Dying in America*, emphasizes the need for physicians and institutions to have clear guidance on how to handle the care of the "unbefriended" and the inappropriateness of health care providers stepping into that role.[52] Without ACP conversations, patient care may be compromised and the opportunity to have thorough and thoughtful consideration of the patient's preferences unrealized.[53,54] Alternative models are needed for those without broadly defined family support.

There was no accounting for contamination at the provider level. However, the randomized clinical trial design limits provider contamination effects. If there

was contamination, it would have minimized differences between groups, but a large intervention effect was found.

The intervention may not generalize beyond DC. The group of six patients who declined to give race remains unexamined and may reflect a subpopulation with unique characteristics with respect to ACP.

Despite these limitations, this research was scientifically rigorous in undertaking a gold-standard RCT with an active control, a priori consideration of sample size, predefined missing data approaches, predefined intervention assessment, use of an advance directive document that is legal in DC, prespecified study variables, appropriately trained data collectors who were not the study investigators, report of attrition, consideration of bias, and attention to a diverse study population.

## Conclusions

The FACE ACP model improved identification and documentation of a surrogate decision-maker (at enrollment and in Session 2: Five Wishes advance directive), engaged PLWHs/families in goals of care conversations (Session 1: Next Steps: Respecting Choices conversations), and increased advance directive completion and documentation (Session 2 and postsession facilitator placement of Five Wishes in the medical record) for PLWHs in DC. These outcomes meet the consensus definition for successful ACP.[45] The FACE ACP model requires the presence of a surrogate decision-maker, the person who will make decisions for the patient, if the patient is unable to communicate. One of the primary purposes of ACP is to prepare the surrogate decision-maker for the role of advocating on the patient's behalf. Our research has consistently shown that without ACP conversations, families are significantly less likely to understand the patients' treatment preferences[22,24,26,32,33,55] or to make accurate judgments about the patient's quality of life[56]. The FACE model does not require the involvement of physicians in the two one-hour conversations but does provide physicians an extra level of support. The family has an important role as the keeper of ACP documents, so that if ACP documents are not easily found in the EHR or a medical crisis occurs elsewhere, patient's preferences can be honored. The FACE ACP model may move the field toward health equity, while avoiding stereotyping based on race or specific cultures.[57,58]

## Disclosures and Acknowledgments

The authors have no financial relationships relevant to this article to disclose.

The authors are deeply grateful to the patients and their surrogates who participated in this trial. The authors also thank our funders, the National Institute of Nursing Research (NINR), National Institutes of Health (NIH) Award Number R01NR014−052−06 (no cost extension); NIH National Center for Advancing Translational Sciences CTSI-CN UL1RR031988; and our study sites and staff from Children's National Health System, MedStar Georgetown University Hospital, The George Washington Medical Faculty Associates, MedStar Washington Hospital Center, and the Washington DC Veterans Affairs Medical Center, all of which are members of District of Columbia−Center For AIDS Research (DC-CFAR). This research has been facilitated by the services and resources provided by the District of Columbia Center for AIDS Research, an NIH funded program (AI117970), which is supported by the following NIH Co-Funding and Participating Institutes and Centers: NIAID, NCI, NICHD, NHLBI, NIDA, NIMH, NIA, FIC, NIGMS, NIDDK, and OAR. These institutions were not involved in the design and conduct of the study; collection, management, analysis, and interpretation of the data; or preparation, review, or approval of the manuscript. This content is solely the responsibility of the authors and does not necessarily represent the official views of the NINR or the NIH or CTSI-CN.

The authors thank the FACE Palliative Care Consortium, including Linda Briggs, David Parenti, Fred Gordon, Connie Trexler, as well as our consultants Bruce Rapkin, Bea Krauss, and Linda Koenig, for their dedicated efforts toward the completion of this study. Special thanks also to our clinical coordinators: Brittney Lee, Jessica Gaines, Allison Kimmel from the Coordinating Center at Children's National; Ginny Levin formerly of George Washington University Medical Faculty Associates; and Chelsea Tanous formerly of Georgetown University Hospital.

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