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An Exploratory Study of Spirituality in HIV Infected Adolescents and their Families: Family CEntered Advance Care Planning and Medication Adherence

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Abstract

Purpose—To explore the impact of spirituality and religious beliefs on Family CEntered (FACE) Advance Care Planning and medication adherence in HIV+ adolescents and their surrogate decision-makers.

Methods—A sample of HIV+ adolescents (n=40) and their surrogates, age 21 or older, (n=40) was randomized to an active Healthy Living Control group or the FACE Advance Care Planning intervention, guided by transactional stress and coping theory. Adolescents' spirituality was assessed at baseline and 3 months post-intervention, using the FACIT-SP-4-EX, as was the belief that HIV is a punishment from God.

Results—Control adolescents increased faith and meaning/purpose more so than FACE adolescents (p=0.02). At baseline more behaviorally (16%) vs. perinatally (8%) infected adolescents believed HIV was a punishment from God, but not at 3-months post-intervention. Adolescents endorsing HIV was a punishment scored lower on spirituality (p=.05) and adherence to HAART (p=.04). Surrogates were more spiritual than adolescents (p<.0001).

Conclusion—Providing family support in a friendly, facilitated, environment enhanced adolescents' spirituality. Facilitated family conversations had an especially positive effect on behaviorally infected adolescents' medication adherence and spiritual beliefs.

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Keywords

adolescents; advance care planning; family intervention; HIV/AIDS; medication adherence; pediatric end-of-life care; pediatric palliative care; spirituality

Spirituality as a protective factor for coping with HIV has been understudied in adolescents [1–2]. Youth living with HIV/AIDS (YLWHA) are more likely to wonder “whether God has abandoned me [1].” Adolescent spirituality is associated with less anxiety and depression [3] and adaptive coping with a chronic illness [4]. This paper presents secondary analyses from the FAmily CEntered (FACE) Advance Care Planning study [5–7]. We hypothesized: a) high spirituality would predict high medication adherence and stage of illness; and b) belief “HIV is punishment from God” would decrease medication adherence.

Methods

Participants

From 2006–08 YLWHA and their families/surrogates were recruited from two hospital-based outpatient clinics for YLWHA. YLWHA were 14–21 years old, not in foster care, and had a legal guardian/surrogate decision-maker (≥ 21 years old) who knew their HIV-status.

FACE Intervention & Healthy Living Control (HLC)

Teenagers want to participate in decision-making with their family about their own EOL care. We created/adapted the FACE protocol to promote these conversations. Study methods are reported elsewhere [5,6,7], <http://clinicaltrials.gov/ct2/show/NCT00723476>. Forty dyads were randomly assigned to three, weekly, 60-minute sessions with 38 dyads completing all sessions. Dyads were surveyed separately about their values, beliefs and experiences with dying. Next, FACE elicited the experiences of the teens’ medical condition, causes and complications. Finally, the dyad chose who would speak for the youth, and completed an advance directive.

The study was IRB approved.

Measures were administered at baseline and 3-month post-intervention

Demographic/clinical variables—Medical chart abstraction.

Spiritual Well Being Scale of the Functional Assessment of Chronic Illness Therapy – Version 4 [FACIT-Sp-EX-4;8] contains 23-items with two dimensions: faith (comfort and strength in one’s beliefs) and meaning/peace (sense of meaning, purpose, and peacefulness in life). Subscale reliability coefficients range from 0.81 to 0.91. Higher scores indicate higher spirituality.

Medication Adherence Self-Report Inventory [MASRI; 9] is a visual analogue adherence scale with documented good reliability and validity.

Data Analysis

Descriptive statistics were calculated. There was 100% 3-month post-intervention assessment completion with no missing data. Using multiple logistic regression, we introduced terms in the model, both main and interactive effects by study group (FACE vs. HLC) to test for the effect on spirituality while controlling for baseline spirituality levels. We explored whether CDC stage of illness or level of spirituality moderated the intervention effect. Analyses used Stata 10.0.

Results

Forty dyads enrolled, but two dyads never started the intervention. Analyses included 38 dyads. Baseline adolescent characteristics are in Table 1.

At 3-month post-intervention, FACE exposure demonstrated an impact on adolescent spirituality, but was unrelated to adherence, CDC stage of illness, transmission mode, gender or time since diagnosis.

Between-group differences in Meaning/Purpose and Faith Subscales were statistically non-significant at baseline (Table 2). These subscales predicted 3-month post-intervention scores ($p < 0.0001$). FACE adolescents' mean Meaning/Purpose scores increased, but controls mean spirituality score increased significantly more ($p = 0.045$). Item analyses revealed controls vs. FACE “feel a sense of purpose” (very much, quite a bit, 95% vs. 65%; $p = 0.017$); “life lacks meaning of purpose (not at all 100% vs. 65%, $p = 0.019$); “feel a sense of harmony” (very much, quite a bit 94% vs. 50%).

On the Faith subscale FACE adolescents' scores decreased slightly, while HLC scores significantly increased from a mean of 44.27 to 49.57 ($p = 0.002$). Item analyses revealed controls vs. FACE “feel a sense of thankfulness” (quite a bit/very much=94.45% vs. 70%, $p = 0.032$) and “feel a sense of thankfulness for what others bring to my life” (88.89% vs. 80%, $p = 0.050$).

There were no statistically significant differences between FACE vs. HLC adolescents or surrogates on, “Do you believe your HIV is a punishment from God?” at baseline or at 3-months post-intervention. However, at baseline Behaviorally Infected Youth (BIY) vs. Perinatally Infected Youth (PIY) believed this was not at all true (54% vs. 88%), a little true (31% vs. 4%), somewhat true (8% vs. 4%), very much true (8% vs. 4%) ($p = 0.03$). This difference no longer remained at 3-month post-intervention. YLWHA who persisted in beliefs that HIV was a punishment from God had lower spirituality scores ($p = 0.05$) and poorer HAART adherence ($p = 0.04$) than those who did not have this belief.

Surrogates reported being more spiritual than adolescents ($p < 0.001$); higher family spirituality associated with lower adolescent spirituality ($ICC = -0.49$).

Discussion

The FACE family-focused intervention unexpectedly impacted spirituality, while confirming hypotheses of an association between the belief that HIV is a punishment from God and low medication adherence, but not spirituality, adherence or stage of illness. Findings are consistent with the transactional stress and coping model [10]. Given family support in a friendly facilitated environment, the FACIT Meaning/Purpose subscale increased for both groups, but significantly more for controls. Controls apparently benefited from talking about jobs/scholarships and safety tips.

The Faith subscale for FACE group decreased slightly, while increased for HLC. Controls' experience with talking about safety tips, jobs/scholarships may have enhanced feelings of gratitude, in contrast to FACE adolescents, who engaged in difficult conversations about death. Perhaps FACE, which facilitated discussion increasing adolescents' control over future medical care in a secular/medical environment, decreased the need to rely on faith as a mechanism for coping with death. Alternatively, FACE adolescents may have felt angry at God. Or possibly, locus of control changed from external (Let Go, Let God) to internal, by enhancing control. Future research should examine these hypotheses, given 63% of teens relied on faith and desire control over their future.

High family spirituality may have inversely related to adolescent scores because of developmental issues related to individuation/differentiation.

A serendipitous finding unrelated to stress/coping model suggests that family/facilitator support benefited BIY who believed at baseline HIV was punishment from God, changing this view, and increasing HAART adherence at 3-month follow-up.

Study limitations include: secondary analysis that restricts causal inferences; self-report measures; only one spirituality measure; and validity and reliability of a single-item measure, “HIV/AIDS is a punishment from God.”

Study strengths include: longitudinal, prospective, RCT design; excellent retention; theoretically guided hypotheses; and multilevel modeling analyses. Longitudinal studies relating to spirituality and religion among HIV+ adolescents should be pursued.

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Abbreviations

YLWHA	Youth Living with HIV/AIDS
BIY	Behaviorally Infected Youth
CDC	Centers for Disease Control
FACE	FAMily CEntered Advance Care Planning
HIV/AIDS	Human immunodeficiency virus/Acquired immune deficiency syndrome
HLC	Healthy Living Control
PIY	Perinatally Infected Youth

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Table 1

Baseline Characteristics for Intervention and Control Adolescents with HIV/AIDS (N=38) Testing for Effects of Randomization.

	Intervention n=20	Controls n=18	Significance
Age (in years)			p=0.838NS*
Mean (SD)	16.65 (SD=2.11)	16.58 (SD=2.38)	
Range	14–21	14–20	
Gender			p=1.0 NS**
Males	8 (40%)	7 (39%)	
Females	12 (60%)	11 (61%)	
Transgender (M>F)	0 (0%)	0 (0%)	
Race/Ethnicity			p=1.0 NS**
Black/African American	17 (94%)	18 (90%)	
White/Caucasian	1 (6%)	1 (5%)	
American Indian/Alaskan	0 (0%)	1 (5%)	
Mode of HIV Transmission			p=0.489 NS**
Perinatal infection	15 (75%)	11 (61%)	
Behavioral infection	5 (25%)	7 (39%)	
CDC Classification ¹			0.061 NS**
A 1–3 (asymptomatic)	5 (26%)	11 (61%)	
B 1–3 (symptomatic)	6 (32%)	5 (28%)	
C 2–3 ² (AIDS)	8 (42%)	2 (11%)	
Income			0.805 NS**
= or < of Federal poverty line	7 (35%)	6 (33%)	
100%–200% of Federal poverty line	1 (5%)	3 (17%)	
201%–300% of Federal poverty line	4 (20%)	4 (22%)	
>300% of Federal poverty line	6 (30%)	3 (17%)	
Unknown	2 (10%)	2 (11%)	

SOURCE: Lyon ME, Garvie, PA, McCarter R, Briggs L, He J, D'Angelo L. Who Will Speak for Me? Improving End-of-Life Decision-Making for Adolescents with HIV and Their Families. *Pediatrics* 2009;123(2):e1–e8.

NS=Not statistically significant difference

*
t test

**
Fisher's exact test. No significant differences between groups, showing success of randomization. (95% confidence interval).

¹Centers for Disease Control and Prevention. (1992). 1993 revised classification system for HIV infection and expanded surveillance case definition for AIDS among adolescents and adults. *MMWR* 41:1–17.

²No patient had category C1.

Table 2

Adolescent means, confidence intervals and t-test results for Meaning/Peace and Faith subscales of the FACIT-SP-EX-4 (N=38) at baseline prior to randomization and at 3-month post-intervention controlling for baseline levels.

Group	Observations	Baseline prior to randomization			3-month post-intervention		
		Mean	95% CIs	p value	Mean	95% CIs	p value
MEANING/PEACE Subscale							
Control Baseline	18	50.5	46.95, 54.05	0.134 NS	52.84	49.74, 55.78	0.045
Intervention Baseline	20	46.9	43.48, 50.32		48.35	45.16, 51.35	
FAITH subscale							
Control Baseline	18	44.27	39.99, 48.57	0.573 NS	49.57	47.03, 51.98	0.002
Intervention Baseline	20	45.8	42.11, 49.49		43.49	40.72, 46.09	

NS = Not Significant

CIs=Confidence Intervals

Note: FACIT-SP-EX-4 = Functional Assessment of Chronic Illness – Spiritual Well-Being Scale, Expanded, Version 4