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A randomized clinical trial of adolescents with HIV/AIDS: pediatric advance care planning

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Abstract

The objective of this study is to determine if pediatric advance care planning (pACP) increases adolescent/family congruence in end-of-life (EOL) treatment preferences longitudinally. Adolescents aged 14–21 years with HIV/AIDS and their families were randomized ($N=105$ dyads) to three-60-minute sessions scheduled one week apart: either the pACP intervention (survey administered independently, facilitated conversation with adolescent and family present, completion of legal advance directive document with adolescent and family present) or an active control (developmental history, safety tips, nutrition and exercise education). This longitudinal, single-blinded, multi-site, randomized controlled trial was conducted in six pediatric hospital-based HIV-clinics, located in high HIV mortality cities. The Statement of Treatment Preferences measured adolescent/family congruence in EOL treatment preferences at immediately following the facilitated pACP conversation (Session 2), and at 3-month post-intervention. The mean age of adolescent participants was 18 years (range 14–21 years); 54% were male; and 93% were African-

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American. One-third had an AIDS diagnosis. Immediately post-intervention the Prevalence Adjusted Bias Adjusted Kappa showed substantial treatment preference agreement for pACP dyads compared to controls (High burden/low chance of survival, PABAK = 0.688 vs. 0.335; Functional impairment, PABAK = 0.687 vs. PABAK = 0.34; Mental impairment, PABKA = 0.717 vs. 0.341). Agreement to limit treatments was greater among intervention dyads than controls (High burden: 14.6% vs. 0%; Functional impairment = 22.9% vs. 4.4%; and Mental impairment: 12.5% vs. 4.4%). Overall treatment preference agreement among pACP dyads was high immediately post-intervention, but decreased over time. In contrast, treatment agreement among control dyads was low and remained low over time. As goals of care change over time with real experiences, additional pACP conversations are needed.

Keywords

Advance care planning; pediatric; decision-making; end-of-life; palliative care; congruence

Introduction

Advance care planning (ACP) is the beginning of a conversation about goals of care at the end-of-life (EOL), if an individual with a serious illness could not speak for him/her self. ACP is patient-centered, giving patients a voice, involving surrogate decision-makers, and is appropriate from the time of diagnosis (Friebert, 2009; Kelley & Morrison, 2015). Surveyed adolescents with HIV and cancer agree, reporting a preference to participate in ACP conversations early in the course of their illness (while healthy 36.8%, 18.8%; at diagnosis 15.8%, 18.8%; or when first ill 5.3%, 0%), rather than waiting until they are hospitalized (0%, 0%) or dying (10.5% or 25%), or at each stage of life (31.6%, 37.5%) respectively (Garvie, He, Wang, D'Angelo, & Lyon, 2012; Jacobs et al., 2015). Other research confirms these findings (Hammes, Klevan, Kempf, & Williams, 2005; Hinds et al., 2009; Liberman, Pham, & Nager, 2014; Lotz, Jox, Borasio, & Fuhrer, 2015; Lyon et al., 2009; Walter, Rosenberg, & Feudtner, 2013; Wiener et al., 2008; Wiener et al., 2012).

Today, approximately 11,000 adolescents have ever had an AIDS diagnosis, increasing the risk for death (Centers for Disease Control and Prevention (CDC), June 2016a; Idele et al., 2014; Heron, 2016). African-Americans are disproportionately affected with higher rates of mortality (CDC, June 2016; Hall et al., 2012). In 2013, 109 youth aged 15–24 died of HIV or AIDS in the United States (CDC, July 2016b). These deaths are geographically clustered in southern states (CDC, 2014; Reif et al., 2014; Reif & McAllester, 2015). Treatment failure and loss of decision-making capacity through HIV Associated Neurological Disease (Allison, Wolters, & Brouwers, 2009) also make early pACP critical in this already disadvantaged population (Mosack & Wandrey, 2015; Selwyn & Forstein, 2003). Thus, despite the currently available chronic treatment options and improved life expectancy, complications can arise at any time, especially for those with perinatally acquired HIV who were born at a time when current treatments were not available, and who may have suffered critical medical events at a young age that may have latent health effects emerge as they age into adulthood. Thus, it is essential that family members of youth with HIV/AIDS know what their wishes are for their future treatment planning and care, so as to increase the

patient's quality of life (Field & Behrman, 2003; Institute of Medicine, 2014; National Institute of Nursing, 2015).

Avoiding these conversations may result in unwanted intensive care (Mack et al., 2015), neglect charges, court battles and legislative intervention (Fins & Schiff, 2015; Mercurio, 2007). Families may be torn apart by disagreements regarding EOL care decisions (Hinds et al., 2009; Hinds, Menard, & Jacobs, 2012; Maurer et al., 2010; Wijngaards-de Meij et al., 2008), rather than strengthened (Graham, Levetown, & Comeau, 2011; Wells-Di Gregorio, 2009).

Despite differences in cognitive and adaptive functioning observed, research has demonstrated adolescents with HIV are competent to contribute to informed treatment decisions, as decisional capacity is maintained (Chenneville et al., 2010). Pediatric policy recommendations (Feudtner, Friebert, & Jewell, 2013; Field & Behrman, 2003; World Health Organization, 2014) universally recommend pACP be an essential component of care and affirm the right of children to be involved in their health care decision-making (United Nation's Convention on the Rights of the Child, 1990). Pilot studies increased congruence in EOL treatment preferences among adolescents and their families with HIV and cancer immediately following a structured pACP intervention (Lyon et al., 2009; Lyon et al., 2009; Lyon, Jacobs, Briggs, Cheng, & Wang, 2013). The capacity of patient/surrogate dyads to sustain congruence in EOL treatment preferences over time has not been tested.

The present study

The present study tested the efficacy of an adapted pACP intervention against an active control, using a multi-site, randomized controlled design to determine if congruence in treatment preferences could be sustained over time. We tested the hypotheses that immediate post-intervention congruence in EOL treatment preferences could be sustained at 3-months post-intervention among intervention adolescent/family dyads compared to control dyads.

Methods

Participants

Between July 2010 and June 2014, adolescents aged 14–21 years with HIV/AIDS and a legal guardian (if adolescent under 18 years) or chosen surrogate decision-maker who was at least 18 years of age (herein referred to as “family”) were enrolled. Six pediatric hospital-based HIV clinics, located in high mortality urban areas (CDC, 2016) in the South participated. Dyads were randomized to a pACP intervention or control condition ($N = 105$ dyads). See Figure 1. Eligibility criteria included being able to speak and understand English, knowing one's HIV diagnosis, not being in foster care, not developmentally delayed, not severely depressed, suicidal (Beck, Steer, & Brown, 1996), homicidal or psychotic (Shaffer et al., 1993), or positive for HIV dementia at screening (Power, Selnes, Grim, & McArthur, 1995). Participating sites' Institutional Review Boards (IRB) approved this study. Informed written assent/consent was obtained from participants.

Prior to randomization, all participants were given ACP information. Three 60-minute sessions were conducted one week apart. All sessions were facilitated and a structured guide was used for every session.

pACP intervention

Session 1: Lyon Family Centered ACP Survey—*Adolescent and Surrogate version*® (Garvie et al., 2012) included assessment of adolescents' and surrogates' values, beliefs, and life experiences with illness and EOL care. The facilitator administered the survey independently to participants.

Session 2: Respecting Choices®—Next Steps ACP structured interview (Hammes & Briggs, 2007) is a facilitated pACP conversation with the adolescent and family present about their respective understanding of the adolescent's current medical condition, potential complications, fears, hopes and experiences. Next, the Statement of Treatment Preferences (SoTP) is used to encourage dialogue about goals and values in three "bad outcome" EOL situations and to document the adolescents' preferences. The need for future discussions as situations and preferences change is reinforced. The interview was adapted to adolescents living with HIV using community based participatory research with adolescents with HIV/AIDS and bereaved parents. The interview was administered by trained/certified facilitators.

Facilitators included non-clinician/paraprofessionals, such as case managers, as well as nurses, social workers and psychologists. The discussion and choices made were recorded, then shared with providers and placed in the medical record along with documentation of the conversation. This session was audio- or video-taped to ensure protocol fidelity.

Session 3: Five Wishes®—A legal advanced directive document was placed in the medical record and a copy given to the treating physician after the intervention (Towey, 1997). The facilitator completed the *Five Wishes*® with the dyad. For adolescents under age 18, the *Five Wishes*® was used as a tool to allow younger adolescents to participate in shared decision-making. Their parent or legal guardian signed the *Five Wishes*® to meet legal requirements.

Control condition

Session 1. Developmental history—The developmental history of the adolescent was taken independently by the research assistant (RA). The RA conducted the session in a structured interview format, administering The Barkley Developmental History form (Barkley, 1993) to the adolescent first and then the family member. Medical questions were removed to prevent risk of contamination with the intervention condition.

Session 2. Safety tips—The RA provided counseling on safety information provided to the adolescent and family using the American Academy of Pediatrics *Bright Futures* curriculum (Patrick, Spear, Holt, & Sofka, 2001). This included such topics as using a seat belt and having a smoke detector in the home. The session was audio- or video-taped.

Session 3: Nutrition and exercise—The RA provided counseling on exercise and nutrition to the dyad, using the *Bright Futures* curriculum (Patrick et al., 2001).

Measure

The Statement of Treatment Preferences (SoTP) (Hammes & Briggs, 2007) was administered to both intervention and control adolescents and families immediately following the pACP conversation in Session 2 and again at 3-month post-intervention follow-up. The SoTP documents specific treatment preferences of the adolescent's and the family's understanding of what the adolescent would want in three EOL situations: Situation 1 ("long hospitalization with many procedures and low survival"); Situation 2 (functional impairment, e.g., "never able to walk or talk again and would need 24-hour nursing care"); and Situation 3 (mental impairment, e.g., "never knowing who you are or who you are with and would need 24-hour nursing care"). Adolescents chose one of three options, "to continue all treatment to keep me alive as long as possible, staying alive to me is most important no matter what," "to stop all efforts to keep me alive, quality of life is more important than length of life," and "don't know." Adolescents were also asked if they wished to grant their family leeway to either "strictly follow my wishes" or "do what the family thinks is best at the time, knowing my wishes."

Procedures

Trained Research Assistants (RAs) approached participants who met initial eligibility criteria face-to-face in a private clinic room, after confirming appropriateness with the physician. The RA told potential participants that adolescents had told us they wanted to have a voice in their future medical care, if they could not speak for themselves. If this was something that interested them, an IRB approved Information Sheet was used to describe the study. Participants received compensation for their time and effort. Interested subjects were assented/consented, enrolled and further screened.

Following completion of baseline assessments dyads were randomized by computerized permuted block randomization by study site and route of HIV infection (perinatal vs. behavioral), employing an intent-to-treat paradigm. The RA-Assessors who collected outcome data were kept blinded. Otherwise, participants and RAs were not blind to group assignment. All follow-up questionnaires were administered separately to adolescents and their family, and were read orally by the RA-Assessor to ensure reading comprehension and complete responses.

Statistical analyses

All analyses were conducted using SAS 9.2 (SAS Institute Inc., 2011). In some situations when the prevalence of given response was very high or very low, the widely used Kappa statistic could be very low while the observed proportion of agreement is high. To address the encountered "Kappa paradox," we applied the "prevalence adjusted bias adjusted kappa" (PABAK) (Byrt, Bishop, & Carlin, 1993) to assess adolescent/family congruence in end-of-life treatment preferences. PABAK was calculated using the following formula: $PABAK = (k \cdot po - 1) / (k - 1)$ where $k = 3$ for this study; po is the overall observed proportion of agreement; PABAK difference between intervention groups was tested using bootstrap

technique based on 1000 bootstrap resamples. Interpretation of PABAK is just like Kappa (McGinn et al., 2004): 0.8–1.0 -almost perfect agreement; 0.6–0.79 -substantial agreement; 0.4–0.59 -moderate agreement; 0.2–0.39 -fair agreement; 0–0.19 -slight agreement; and 0 -no agreement. Fisher exact test was used to examine differences between groups in patients giving decision-making authority to parents.

Results

Sample characteristics

Three hundred twenty-six adolescent/family dyads met initial study eligibility criteria (Figure 1). Of potentially eligible dyads, 123 dyads did not meet inclusion criteria. Ninety-five dyads declined. One-hundred-eight dyads completed a secondary screening. Of these, one dyad was excluded because the adolescent reported homicidal ideation, which was immediately addressed. Two dyads withdrew without giving a reason.

Fifty-four dyads were randomized to intervention and 51 dyads randomized to control. In the week prior to the start of the intervention, six dyads randomized to the pACP intervention withdrew (1 dyad, both responded questions were too intrusive; 1 dyad, both responded too many appointments; 1 dyad, mother thought there was only one visit; 3 dyads, gave no reason). Two dyads randomized to control withdrew (1 dyad, both responded too many appointments; 1 family member reported for both participants that the topic of death/dying was too hard and she was worried about the emotional impact). The remaining dyads received the intended allocation.

Participants randomized to the pACP intervention completed 100% of Sessions 1, 2 and 89% completed Session 3. One dyad randomized to control withdrew after Session 1 and two more after Session 2. Three-month outcome data were obtained for 85% of dyads who began the intervention. The resulting analyses are based on these 82 dyads.

Baseline characteristics of adolescents are presented in Table 1. No significant differences existed between intervention and control adolescents at baseline, indicating successful randomization. No adverse events were documented at either time point based on independent adolescent and/or family reporting.

Outcomes

Immediate outcome—Figure 2 shows congruence in EOL treatment preferences was substantial (PABAK was approximately 0.70) among pACP dyads for all three disease-specific situations immediately post-intervention and negligible among control dyads.

Three-month follow-up—Though the congruence level decreased 3-months post-intervention, PABAK values still remained at moderate level ($40 < \text{PABAK} < 60$) for the high burden and mental impairment situations, while it was fair ($\text{PABAK} = 0.32$) for the functional impairment situation. In contrast, congruence among control dyads was fair for the high burden and mental impairment situations ($\text{PABAK} < 0.35$) immediately post-intervention, and remained at the same level three months later. There was almost no

congruence (PABAK was about 0.03) among the control dyads for the functional impairment situation at both time points.

Table 2 shows the percent of agreement on EOL treatment preferences between adolescent and surrogate dyads (to continue all treatments no matter what, to limit treatments or don't know) by situation (low chance of survival, high burden; physical impairment; mental impairment) immediately following Session 2 (facilitated ACP conversation or not) and at 3 month post-intervention.

Secondary outcomes—Figure 3 shows the percent of dyads who agreed to limit treatments. Immediately following the Respecting Choices Interview, pACP dyads were statistically more likely than control dyads to agree to limit treatments in a high burden situation (14.6% vs. 0%, $p = 0.013$) and a mental impairment situation (22.9% vs. 4.4%, $p = 0.015$), but not in a functional impairment situation (12.5% vs. 4.4%, $p = 0.269$). Congruence to limit treatments decreased slightly for pACP dyads, but remained higher compared to control dyads (high burden: 9.8% vs. 0%; functional impairment 20% vs. 4.9%, $p = 0.048$; mental impairment 19.5% vs. 7.3%). Changes in congruence in post-hoc analysis did not suggest intervention adolescents were more likely to change their minds than families. Rather there was substantial variance. The sample size was too small to determine if changes in treatment preferences of adolescents were related to viral load or health status.

Leeway—Agreement to give their family leeway to use his/her judgment when making EOL decisions, rather than strictly follow his/her wishes, were higher in the intervention than control arm, but without meeting statistical significance immediately post-intervention (62.5% vs. 45.7%, Fisher's Exact test two-sided, $p = 0.1012$) and at 3-month post-intervention (68% vs. 51%, $p = 0.1300$).

Discussion

This is the first longitudinal study of a pACP model in which adolescents and families effectively communicated to clarify goals of care and establish agreement on what treatments may or may not be appropriate to achieve these goals. Results suggest that a short (3 week) dyadic intervention, delivered in an out-patient hospital-clinic setting was associated with improvements in congruence in EOL treatment preferences. In each situation congruence remained higher for intervention dyads than for control dyads. The aim of the FACE intervention was not to have a dyad to agree to a certain outcome, but to provide patient/family-centered care by helping the adolescent and family “break the ice” so goals for end of life care could be talked about; and the family could “be on the same page”, regardless of treatment choice, based on the adolescent/family's goals and values. Intervention adolescent/family dyads arm were more likely to agree to limit treatments in some situations than control dyads immediately following the intervention and at 3-month follow-up, indicating conversations about treatment options enabled families to support their adolescents' wishes to limit treatments in some situations, rather than to favor life at all costs. Adolescents in pACP, more frequently than control adolescents, explicitly gave their families latitude to do what the family thought best at the time of an unfolding situation in light of their knowledge of their adolescents' goals for care, suggesting more trust. As goals

and values change over time with real experiences (Auriemma et al., 2014), additional pACP conversations are needed.

Study results demonstrate access to a structured pACP program in hospital-based clinics was successful in engaging an underserved cohort of largely young, poor, non-college educated, African-American and Latino/Hispanic adolescents and their families, thereby overcoming barriers to EOL research in this group (Grady, 2005; Huang, Neuhaus, & Chiong, 2016; Johnstone & Kanitsaki, 2009) and health disparities in ACP (AARP, 2003; Arenella, 2016; Boucher, Raghavan, Smith, Arnold, & Johnson, 2016). Training facilitators to certification and providing structure overcame other barriers, including clinicians not knowing the right thing to say, concerns about parents having unrealistic expectations, and lack of parental readiness (Davies et al., 2008; Durall, Zurakowski, & Wolfe, 2012; Sudore & Fried, 2010).

The high enrollment (Bakitas et al., 2009; Kirchoff & Kehl, 2008) and attendance rate confirm previous research indicating families are interested in pACP for their chronically ill adolescents (Liberman et al., 2014; Lotz et al., 2015) and adolescents want a voice (Wiener et al., 2012).

Limitations

Selection bias may exist with those who enrolled in the study likely representing individuals most comfortable discussing both HIV and pACP. Randomization minimized this risk. The sample size was too small to identify any patterns in the change in congruence over time. The black and white pACP choices on the SoTP do not reflect the more nuanced choices that can present significant challenges for family decision-making. However, the SoTP is a useful tool for stimulating adolescents to engage in authentic, meaningful conversations with their families.

Implications

Findings from this study support pACP as an ongoing process. Results also support a routine, structured approach for pACP for pediatric chronic life-threatening conditions as a new standard of care (Tsai, 2008; Weaver et al., 2015), decreasing the taboo associated with pACP (Walter et al., 2013). If widely implemented, health disparities in access to pACP could be reduced. Effective medication adherence and the search for a cure existed simultaneously (Selwyn & Forstein, 2003) with a pACP process.

Conclusion

Study results suggest that a structured pACP intervention was effective in: increasing congruence in EOL treatment preferences between adolescents and their families; engaging adolescents/families to begin these conversations early and to continue these conversations over time; and demonstrating safety.

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Figure 1.
Participant flow diagram.

Figure 2.
Dyadic congruence on end of life treatment preferences.

Figure 3.
Dyads agreeing to limit end of life treatments.

Table 1

Baseline characteristics for randomized intervention and control adolescents.

Characteristic	Intervention <i>n</i> = 54	Control <i>n</i> = 51	<i>P</i> -value
	<i>N</i> (%)	<i>N</i> (%)	
Age (in years)			
Mean (SD)	17.9 (1.88)	17.7 (1.99)	
Range	14.0–20.0	14.0–20.0	0.63 ^a
Gender			
Males	29 (53.7)	26 (51.0)	
Females	25 (43.3)	25 (49.0)	0.85 ^b
Race/Ethnicity			
Black/African American	50 (92.6)	48 (94.1)	1.00 ^b
Hispanic/Latino/non-African American	4 (7.4)	3 (5.9)	1.00 ^b
Mode of HIV Transmission			
Perinatal Infection	41 (75.9)	37 (72.6)	
Non-perinatal Infected	13 (24.1)	14 (27.5)	0.82 ^b
Self-reported sexual orientation			
Non-Heterosexual	19 (35.2)	12 (23.5)	
Heterosexual	35 (64.8)	39 (76.5)	0.21 ^b
CDC Classification			
A 1–3 (asymptomatic)	22 (40.7)	24 (47.1)	
B 1–3 (symptomatic)	17 (31.5)	13 (25.5)	0.75 ^b
C 1–3 (AIDS)	15 (27.8)	14 (27.5)	
Education			
No high school diploma/in high school	29 (53.7)	27 (52.9)	
HS or GED equivalent	15 (27.8)	19 (37.3)	0.46 ^b
Some college/no bachelors	9 (16.7)	5 (9.8)	
Family Income ^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)	0.11 ^b
Greater than 300% of federal poverty line	13 (24.1)	5 (9.8)	
Unknown	6 (11.1)	6 (11.8)	
Marital status			
Single	54 (100.0)	50 (98.0)	
Married/living together	0 (0)	1 (2.0)	0.49 ^b
Housing status ^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)	

	Intervention <i>n</i> = 54	Control <i>n</i> = 51	
Characteristic	<i>N</i> (%)	<i>N</i> (%)	<i>P</i> -value
A shelter or someone else's house or apartment	1 (1.9)	0 (0)	0.93 ^b
Other	0 (0)	1 (2.0)	

^a *t* test.

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

^c Family income data are from surrogates because adolescents did not always know their family income.

Note: CDC, Centers for Disease Control and Prevention; SD, standard deviation.

Percent of agreement on the end-of-life treatment preferences between adolescent/surrogate decision-maker dyads.

Table 2

Situation	Group	Answer			Total agreement N (%)
		Continue treatment N (%)	Discontinue treatment N (%)	Don't know N (%)	
Post-Session 2 (N = 93, HLC = 45, FACE = 48)					
1	FACE	28 (58.3)	7 (14.6)	3 (6.3)	38 (79.2)
	HLC	24(53.3)	0 (0.0)	1 (2.2)	25 (55.5)
2	FACE	30 (62.5)	6 (12.5)	2 (4.2)	38 (79.2)
	HLC	10 (22.2)	2 (4.4)	4 (8.9)	16 (35.5)
3	FACE	24 (50.0)	11 (22.9)	4 (8.3)	39 (81.2)
	HLC	19 (42.2)	2 (4.4)	4 (8.9)	25 (55.5)
3 month post-intervention follow-up (N = 82, HLC = 41, FACE = 41)					
1	FACE	25 (61.0)	4 (9.8)	0 (0.0)	29 (70.8)
	HLC	20 (48.8)	0 (0.0)	2 (4.9)	22 (53.7)
2	FACE	13 (32.5)	8 (20.0)	1 (2.5)	22 (55.0)
	HLC	12 (29.3)	2 (4.9)	4 (9.8)	18 (44.0)
3	FACE	14 (34.2)	8 (19.5)	3 (7.3)	25 (61.0)
	HLC	17 (41.5)	3 (7.3)	2 (4.9)	22 (53.7)

Situation 1: Low likelihood of survival, high burden, long hospital stay, many treatments.

Situation 2: High likelihood of survival, physical impairment, 24 h nursing care.

Situation 3: High likelihood of survival, mental impairment, 24 h nursing care.