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The Impact of Cell Phone Support on Psychosocial Outcomes for Youth Living with HIV Nonadherent to Antiretroviral Therapy

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Introduction

In the United States (U.S.), the Centers for Disease Control and Prevention estimate that one-third of all new HIV diagnoses are among people under 25 years old. The development of antiretroviral therapy (ART) has resulted in rapid declines in HIV-associated morbidity and mortality, allowing youth living with HIV (YLWH) to manage their illness as a chronic disease [1]. With updated guidelines calling for earlier commencement of ART, YLWH are fast becoming the largest group of ART initiators. However, YLWH are frequently poorly adherent to ART regimens [2]. Therefore, it is vitally important to develop interventions to promote medication adherence, addressing the complex psychosocial needs of YLWH.

Since cell phone access has steadily increased among adolescents and young adults over the past decade [3], mobile health (mHealth) intervention is a convenient, developmentally appropriate, and promising avenue for promoting medication adherence in this age group. One efficacious mHealth intervention for improving ART adherence is cell phone support

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(CPS) [4]. CPS goes beyond automated adherence reminders, involving frequent, short phone calls from an adherence facilitator (AF). A randomized controlled trial found that YLWH receiving CPS reported significantly improved adherence and had decreased viral load during the 24-week intervention, and 24 weeks post-intervention, compared with participants in usual care. Participants found CPS, with 81% reporting they wanted the intervention to continue longer and 100% reporting they would recommend the intervention to a friend [5].

To date, it is not clear how interventions like CPS improve adherence to ART. CPS was guided by theories of social support. Specifically, developers hypothesized that CPS would promote medication adherence through providing social support focused on taking ART. It was hypothesized that a consistent, accessible and supportive relationship with a caring, helpful adult could provide YLWH with a basis for finding solutions to barriers to adherence and developing strong medication-taking routines [4]. The goal of the present study is to evaluate the impact of CPS on a range of psychosocial outcomes that may help explain its positive impact on adherence. This study is a secondary analysis of an existing RCT [4]. Reviews of psychosocial facilitators or barriers related to ART adherence suggest that factors such as perceived stress, coping, self-efficacy, motivation, service utilization, depression, and substance abuse may be important targets for adherence interventions [e.g., 6]. Therefore, these psychosocial variables were measured and examined in this study.

Methods

Procedures

During 2010, 37 participants were enrolled in a randomized pilot study (19 receiving the intervention; 18 receiving usual care) [3]. Inclusion criteria were HIV-positive status, aged 15—24 years old, and a history of ART non-adherence, defined as: (a) currently prescribed ART and reporting to care provider adherence < 90% and viral load greater than 1000 copies/ml over the past 4 weeks, or (b) discontinued ART in the past while documented < 90% adherent to last regimen, or (c) agreed to start ART but never initiated. YLWH were recruited from {MASKED FOR REVIEW}. The protocol was approved by each site's Institutional Review Board. A certificate of confidentiality was obtained from the National Institutes of Health. Written informed consent was obtained from young adults, while minors required parental consent with youth assent. Participants were randomized within sites to either the intervention or usual care in equal proportions using permutated block randomization. Usual care consisted of access to comprehensive services including physicians, nurses, case manager/social workers, mental health providers and other staff experienced with YLWH.

CPS involved receiving calls Monday through Friday for 24 weeks from an AF. AFs were either case managers or research assistants, were knowledgeable about HIV and treatment, and had participated in a 2-hour CPS training. Each approximately 5-minute call followed an outline that included medication review, problem-solving support, and providing relevant referrals. AFs arranged calls to occur at a time after the youth were scheduled to take their ART (as a check-in to see if medications had been taken correctly). Participants received compensation towards their cell phone plan each month unless they missed >20% of calls

for 2 consecutive months or 14 consecutive days. All calls were recorded and forwarded to a quality assurance manager.

Measures

Self-report measures were collected via audio computer-assisted self-interview (ACASI) at 0, 12, 24, 36, and 48 weeks.

Perceived Stress.—The Perceived Stress Scale (4-item shortened version) assessed the degree of to which participants consider situations in their lives to be stressful [7]. Scores on this measure ranged from 1 to 5. Cronbach's alphas ranged from .65 – .79 for each assessment period.

Coping.—The Adolescent Coping Orientation for Problem Experiences was administered to assess how participants manage stressors [8]. Items from the Distraction Coping subscale (conceptualized as avoidant coping) and the Problem-Solving Coping subscale (conceptualized as active coping) were analyzed in this study. "Distraction Coping" had Cronbach's alphas ranging from .60 – .79, and scores ranged from 8 to 40. "Problem-Solving Coping" had Cronbach's alphas ranging from .71 – .90, and scores ranged from 6 to 30.

Self-Efficacy for Adherence.—Self-efficacy was measured using a modified version of the Self-Efficacy for Health Promotion and Risk Reduction scale [9]. Six items ask about confidence in taking medications and attending appointments on a five-point Likert scale. Scores ranged from 1 to 5. Cronbach's alphas ranged from .70 – .91.

Motivation for Adherence.—Rollnick's Readiness Ruler [10] was used to measure how ready youth were to take medications and fill prescriptions using a visual analogue scale, ranging from 1 (not at all ready) to 10 (totally ready). Cronbach's alphas ranged from .78–.92.

Depression.—The depression subscale from the Brief Symptom Inventory (BSI) was analyzed [11]. This subscale asks participants how distressed by a series of issues (e.g., thoughts of ending your life, feeling lonely) based on a five-point Likert scale ranging from 0 (not at all) to 4 (extremely). Cronbach's alphas ranged from .89 – .94.

Substance Use.—The Alcohol, Smoking and Substance Involvement Screening Test (ASSIST) was used to measure substance use in the last three months [12]. The ASSIST has demonstrated good to excellent reliability, with average test–retest reliability coefficients ranging from 0.58 to 0.90.

Healthcare Utilization.—All documented health care utilization, including visits to the HIV clinic, other outpatient clinic visits, emergency room visits and inpatient stays, was collected via medical record review. For these analyses, the total number of health care visits over the 12 weeks prior to each assessment time point was summed.

Data Analysis

We examined baseline demographics (e.g. age, gender, race, and ethnicity) and HIV-related characteristics (e.g. mode of HIV-1 transmission). Psychosocial measures, including perceived stress, coping, self-efficacy, motivational readiness, healthcare service utilization, depression, and substance use, were examined at each study visit and over time. The non-parametric (Kruskal-Wallis) test (for continuous measures) or Fisher's exact test (for categorical measures) were used to compare the visit-specific differences between CPS and usual care. Mixed effect models with repeated measurements (for continuous measures) and generalized linear models (for ordinal measures) were used to examine the intervention effect on selected measures over time from baseline to week 24 and then extended to week 48. Statistical significance was set at $p < .05$. SAS Version 9.3 and above was used for all analyses.

Results

The mean age of participants was 20.43 ($SD = 2.57$) years old. The majority were male (62.2%) and African American (70.3%). Fifty-four percent acquired HIV behaviorally and 46% perinatally. There were no significant differences in demographic characteristics between the intervention and control participants at baseline. Table 1 shows a summary of measures of all other psychosocial characteristics by study visit for the intervention and control groups.

Intervention group participants showed significant reductions in perceived stress at Week 12 ($p = .02$) and Week 48 ($p = .02$), relative to the control group participants. The mixed model indicated significant reductions over time, from entry through 24 weeks ($p < .05$) and from entry through 48 weeks ($p = .02$). Neither problem-solving (i.e., active) coping nor distraction (i.e., avoidant) coping differed significantly between study conditions at any assessment period. Overall mixed model results showed no significant differences in coping between the intervention and control groups over time. Participants in the intervention group reported significantly higher total self-efficacy for adherence at Week 12 ($p = .04$), but not afterward. The mixed models showed no significant changes in self-efficacy. There were no significant differences between the groups in motivational readiness.

Intervention participants showed a significant reduction in depression at Week 24 ($p = .02$), a marginal reduction at Week 36 ($p = .08$), but no reduction at Week 48 ($p = .17$). However, the mixed effect model showed no significant difference between the intervention and control group from entry through 24 weeks or from entry through 48 weeks. Intervention participants reported significantly greater reductions in substance use, compared with the control participants, at Week 12 ($p < .05$), Week 24 ($p < .05$), and Week 48 ($p = .02$). Controlling for baseline substance use in the mixed models, the intervention group reported a significant reduction in substance use compared to the control group from entry through 24 weeks ($p = 0.02$) and this result persisted for the entire 48 weeks ($p = .02$). The intervention group had significantly fewer healthcare visits at baseline, compared with the control group ($p = .01$). Otherwise, there were no significant differences in service utilization between the conditions over time.

Discussion

Previous publications have described how participants receiving CPS reported significantly improved medication adherence and had greater viral suppression compared with participants receiving usual care, both during and for 24 weeks after the intervention was completed [3]. While this secondary analysis was not sufficiently powered to test mediators of treatment efficacy, examining how the intervention may have impacted psychosocial variables could suggest hypotheses for how CPS works.

Some psychosocial variables appeared to change in response to CPS, and others did not. Neither coping, motivation, nor service utilization differed by condition. During the intervention, CPS recipients reported significantly greater self-efficacy and fewer depressive symptoms. However, both of these psychosocial variables were no longer significantly different by condition after CPS was concluded. This suggested that while YLWH received frequent supportive calls, they may have felt more confident about their ability to adhere to ART and more positive about themselves and their future. Unfortunately, this shift in mindset was not sustained, which suggests additional intervention approaches would be necessary to fully address depression or low self-efficacy. Similarly, although perceived stress was significantly reduced through 24 weeks and through 48 weeks according to mixed models, at 36 weeks, perceived stress was not significantly different between CPS participants and those in usual care. These results suggest CPS has some impact on perceived stress, but pressures and worries may reemerge after the intervention stops, perhaps due to the loss of the AF's support. On the other hand, substance use was reduced through the 24 and 48 week assessments. It is not clear why CPS appeared to have a more durable impact on substance use than depression or self-efficacy. It is possible that referrals to substance use treatment or case management could have helped participants solve ongoing problems in their lives, access helpful resources, or reduce alcohol or drug use. However, the lack of differences in healthcare utilization does not provide evidence in favor of this hypothesis.

This population of YLWH has been shown to have high rates of depression and substance misuse, as well as face structural barriers and stigma related to having HIV, or racial, ethnic, or sexual minority status. Clinical experience suggests that these YLWH frequently have limited social support networks, including a lack of reliable friends or family members. Having an AF who makes contact five days each week may provide YLWH with sufficient social support to overcome barriers to medication adherence. Considering the challenges referenced above, it may be worth considering whether Mohr's theory of supportive accountability provides a helpful explanatory model for the impact of CPS [13]. The supportive accountability model posits that "human support increases adherence through accountability to a coach who is seen as trustworthy, benevolent, and having expertise." It could be that improvements in psychosocial functioning occur through CPS directly, rather than participants learning to cope with stressors through problem-solving or greater healthcare engagement. However, to fully explore this possible explanatory model, a broader examination of the interpersonal AF-patient relationships needs to be undertaken with a larger sample.

Limitations

This study had several limitations, including the small sample size, which precluded mediation analyses that would more directly test explanatory models. The small sample size also limits generalizability, although recruiting a geographically diverse sample was a strength. Although CPS was built on theories of social support, quantitative measures of this construct were not collected. However, in exit interviews, intervention participants did report feeling supported by AFs [4]. In addition, the original randomized trial took place in 2010. HIV treatment guidelines have changed substantially since then, which could impact adherence and psychosocial experiences of YLWH. Additionally, the Kruskal-Wallis and Fisher's exact tests, which focused on statistical differences at single points in time, had less power than mixed models which took advantage of repeated measurements. Due to the small sample size, the results from single time points should be replicated in future studies with larger samples. Finally, the lack of significant differences in healthcare utilization between CPS and usual care participants may indicate that all patients in this study, regardless of condition, accessed high levels of clinic support. All {MASKED FOR REVIEW} sites involved in this study have staff who are experienced working with YLWH, and the physicians, nurses, social workers, and case managers on these treatment teams may have provided supports similar to CPS to usual care patients, although very rarely would such support be offered daily. This may have reduced the measured impact of CPS on psychosocial variables. Trials of CPS against less comprehensive healthcare services would be a purer test of this intervention's impact on emotions, attitudes, and behaviors.

Conclusions

Delivering adherence interventions to YLWHs through ubiquitous devices like cell phones is promising in terms of efficacy and cost-effectiveness. Several randomized trials of different interventions ranging from automated or interactive text messaging to social media interventions to mobile applications are underway across the U.S. Some of these are likely easier to implement than CPS, which requires human support and incentives for answering calls, and perhaps some non-adherent YLWH can improve adequately with these less costly or intensive interventions. However, many of these less intensive technology-based interventions may not take advantage of the benefits of the relationship developed between a human provider and a patient. If supportive accountability does explain some of CPS's positive impacts, it may be critical to include human support in the landscape of adherence interventions designed for YLWH.

Future researchers should evaluate what drives the impact of mHealth interventions like this one. Supportive accountability, or other models, may help explain positive effects and guide future intervention development. Researchers should attend to whether psychosocial changes are maintained after the intervention is complete. This information could support the idea of tapering treatment or supporting generalization of psychosocial skill development. Finally, determining which elements are necessary in mHealth interventions and future analysis of psychosocial variables may lead to the development and dissemination of more effective adherence and wellness interventions for this vulnerable population of YLWH. We suggest that mHealth investigators undertake rich examinations of how participants experience phone-based interventions, what kind of support they perceive, and how interpersonal

dynamics between human interventionists and YLWH promote changes in stress, coping, health behaviors, and mental health and substance use.

Compliance with Ethical Standards

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All authors declare they have no conflicts of interest. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study.

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Table 1.

Assessments of Psychosocial Characteristics by Study Visits and Intervention Status

	Baseline		Week 12		Week 24		Week 36		Week 48		p-value	
	Intervention (*n* = 19)	Control (*n* = 18)	Intervention (*n* = 17)	Control (*n* = 16)	Intervention (*n* = 15)	Control (*n* = 16)	Intervention (*n* = 13)	Control (*n* = 13)	Intervention (*n* = 14)	Control (*n* = 17)	Entry - Wk 24	Entry - Wk 48
Perceived Stress	3.84 (2.06)	5.00 (2.20)	2.65 (2.42)*	4.25 (1.65)*	2.73 (2.34)	3.81 (2.32)	3.46 (185)	4.31 (2.25)	2.57 (2.59)*	4.47 (1.91)*	<0.05*	0.02*
Coping												
Distraction	25.53 (6.05)	23.11 (3.69)	23.18 (7.54)	24.06 (3.96)	21.80 (5.41)	24.50 (5.03)	22.46 (7.61)	22.92 (5.74)	23.79 (7.83)	23.65 (4.60)	0.94	0.92
Problem Solving	14.68 (3.06)	15.00 (3.24)	14.24 (4.38)	14.38 (3.50)	15.07 (4.43)	14.75 (2.24)	14.54 (4.01)	13.77 (2.59)	14.43 (3.80)	14.18 (3.19)	0.85	0.92
Self-efficacy	4.19 (0.69)	4.03 (0.79)	4.39 (0.51)*	4.04 (0.50)*	4.28 (0.74)	4.14 (0.55)	4.38 (0.51)	4.21 (0.51)	4.45 (0.64)	4.24 (0.55)	0.17	0.17
Motivational Readiness	7.97 (2.03)	9.11 (0.98)	9.18 (1.30)	8.78 (1.43)	9.13 (1.45)	8.22 (184)	8.88 (1.75)	8.23 (2.01)	8.89 (1.77)	8.03 (1.75)	0.81	0.80
Service Utilization	1.78 (0.81)*	3.11 (1.97)*	3.77 (3.35)	3.14 (1.88)	5.17 (5.24)	3.33 (2.71)	6.10 (11.05)	4.91 (5.89)	5.50 (10.19)	4.93 (6.16)	0.99	0.85
Depression	1.20 (1.24)	1.22 (0.87)	0.73 (0.82)	1.22 (1.07)	0.54 (1.03)*	1.10 (0.88)*	0.59 (0.82)	1.15 (1.11)	0.82 (1.22)	1.13 (1.10)	0.39	0.26
Substance Use	3.42 (4.72)	8.44 (8.12)	3.06 (6.06)*	6.31 (6.11)*	2.73 (4.88)*	8.06 (10.18)*	2.77 (4.11)	5.38 (7.39)	2.50 (5.05)*	7.88 (8.50)*	0.02*	0.02*

*$p<0.05$

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