

Recruiting and Retaining High-Risk Adolescents into Family-Based HIV Prevention Intervention Research

Chisina T. Kapungu · Carla M. Nappi · Charu Thakral · Steven A. Miller · Catharine Devlin · Cami McBride · Emily Hasselquist · Gloria Coleman · Derek Drozd · Chinmayee Barve · Geri Donenberg · Ralph DiClemente · Larry Brown · Project STYLE Study Group

Published online: 1 July 2011
© Springer Science+Business Media, LLC 2011

Abstract The purpose of this study was to examine the effectiveness of evidence-based recruitment and retention strategies for a longitudinal, family-based HIV prevention intervention study targeting adolescents in psychiatric care by (1) determining consent rate (recruitment), rate of participation at the first intervention session (retention), and follow-up attendance rate (retention); and (2) examining socio-demographic factors, family-level processes, sexual risk-related indices, and intervention factors (i.e., treatment arm) associated with study retention. Only one-third of the families contacted ultimately enrolled in the study. 81% of those enrolled participated in the workshop and 72% attended the booster sessions with no significant differences between families on any variable based on attendance. Retention over 1 year was 85% and did not differ by treatment arm. Strategies employed were successful at

retaining families once they were enrolled. Findings highlight barriers to enrollment for adolescents in psychiatric care and suggest that it may be critical to integrate HIV prevention programs within community-based mental health services in order to counteract recruitment challenges.

Keywords Recruitment · Adolescents · HIV prevention · Family-based research

Introduction

Adolescents seeking psychiatric care engage in higher rates of sexual risk behavior than typically developing youth (Brown et al. 1997; Donenberg et al. 2001, 2002;

C. T. Kapungu (✉)
Department of Obstetrics and Gynecology, University of Illinois at Chicago, 820 S. Wood St., M/C 808, Chicago, IL 60612, USA
e-mail: ckapungu@psych.uic.edu

C. M. Nappi
University of California, San Diego, CA, USA

C. Thakral
Office of Diversity, University of Illinois at Chicago, 2620 University Hall, 601 South Morgan Street, Chicago, IL 60607, USA

S. A. Miller
Argosy University, Chicago, IL, USA

C. Devlin · E. Hasselquist · G. Coleman · C. Barve · G. Donenberg
Department of Psychiatry, Institute for Juvenile Research, University of Illinois at Chicago, 1747 W. Roosevelt Rd, Chicago, IL 60608, USA

C. McBride
Department of Psychology, Roosevelt University, Chicago IL, USA

D. Drozd
Illinois State University, Normal, IL, USA

R. DiClemente
School of Public Health, Emory University, Atlanta, GA, USA

L. Brown
Department of Psychiatry, Rhode Island Hospital and the Alpert School of Medicine of Brown University, Providence, RI, USA

Donenberg and Pao 2005), increasing their risk for sexually transmitted infections (STIs), including HIV. Psychiatric symptoms contribute to elevated rates of sexual risk behavior among these youth and compromise adjustment to and medical management of STIs, once acquired (Smith 2001). Thus, development of HIV prevention interventions designed for this subset of adolescents is critical to their physical and mental health and future well-being.

Family involvement in HIV prevention efforts is increasingly recognized as important to sustain adolescent behavior change (Kapungu et al. 2006, 2010; Pequegnat and Szapocznik 2000), especially among teens with psychiatric symptoms (Donenberg and Pao 2005; Nappi et al. 2007, 2009). Unfortunately, family-based prevention intervention studies are hampered by poor participation (approx. 3–35% per Spoth et al. 2007) and high attrition rates (e.g., Fox and Gottfredson 2003), compromising conclusions regarding if, and for whom, these interventions work.

With regard to HIV prevention intervention trials, minimal attention has been paid to specific techniques for engaging and retaining families, despite unique challenges posed by recruitment to and retention in HIV-focused programs (Rutledge et al. 2002). The potential consequences of these challenges are the inclusion of highly selected samples and/or differential attrition limiting the external and internal validity of findings. Minimizing threats to validity due to poor recruitment and retention in family-based HIV prevention trials is imperative given limited resources to conduct intervention studies.

Unfortunately, testing the effects of family inclusion in HIV prevention research for youth in psychiatric care *and* insuring that findings generalize involves several challenges. For one, psychiatric symptoms can interfere with study enrollment by reducing motivation (Haller et al. 2002) and compromising willingness to participate when benefits for psychiatric illness are not immediately apparent, or guaranteed. Teens diagnosed with mental illness and their families have competing demands for time and energy, including medication management visits and weekly therapy appointments. Interventions designed to prevent a potential problem (e.g., HIV), rather than treat a current one (e.g., depression), may take lower priority (Trauth et al. 2000).

Psychosocial stressors also interfere with participating in a prevention study for these families. Teens with psychiatric disorders often experience significant life stressors that contribute to mental health problems. These problems also compromise access to and ability to utilize healthcare (Heinrichs et al. 2005). High levels of conflict and poor communication in families of adolescents in psychiatric care may also compromise participation in prevention interventions (Zand et al. 2004). Families must be able to

agree to participate and organize means of attendance (Hough et al. 1996). Even among healthier families, engagement of more than one family member in intervention studies demands organization and flexibility in aligning multiple schedules. In fact, family systems factors and time conflicts are cited as a primary barrier to recruitment and retention in family-based research (e.g., McKay et al. 1996; Perrino et al. 2001).

Factors that have influenced engagement and retention into parent and family-centered prevention interventions include low income (McKay et al. 1996), low parent education (Spoth et al. 1999), family stress (Perrino et al. 2001) and perceived child maladjustment (Spoth et al. 2000). HIV-related prevention interventions face greater challenges to enrollment than other diseases or problem behaviors (Rutledge et al. 2002). First, adolescents in psychiatric care report low perceived vulnerability to HIV/AIDS (Dudley et al. 2002). Second, the target of HIV prevention programs (sexual risk behavior) and the means taught to prevent it (e.g., condom use) sometimes conflict with family values. A preference for abstinence-only education in this country (Silva 2002) and religious beliefs make HIV prevention programs that advocate comprehensive sex education difficult to conduct despite overwhelming evidence for their effectiveness. Third, parent reluctance to discuss sexual behavior with their children may diminish enthusiasm to participate. Few studies have examined factors that influence engagement and retention in HIV prevention programs. However, studies suggest parent–facilitator relationship quality, family income, family stress, and social support are significant predictors of engagement (Prado et al. 2002, 2006).

Finally, social and demographic factors impede recruitment and retention in intervention studies, regardless of targeted population. Participation in randomized clinical trials is related to age (Corbie-Smith et al. 2003), race/ethnicity (Gifford et al. 2002), employment status (Orr et al. 1992), and marital/relationship status (Vaughn et al. 2002). Studies that have examined factors associated with attrition in HIV prevention intervention programs (e.g., Beadnell et al. 2003; DiFranceisco et al. 1998; NIMH Multi-site HIV Prevention Trial 1997) suggest younger age, non-White ethnicity, and lower socio-economic status are related to program completion. Although some studies of HIV prevention interventions reported HIV-risk related factors (e.g., HIV/AIDS knowledge, condom use, presence of an STI, etc.) that promote (e.g., Wu et al. 2005) or diminish (e.g., DiFranceisco et al. 1998) enrollment, there are no published data that we know of to indicate how these factors affect family enrollment and attrition. Drawing on the Social Personal Framework for HIV-Risk Behavior (Donenberg and Pao 2005), we sought to extend existing research by identifying factors associated with recruitment

and retention in a unique population at high risk for STIs, including HIV. The model highlights the role of adolescent mental health, personal attributes, family interactions, and relationship concerns in adolescent sexual risk behavior.

The Current Study

The purpose of this study was to examine the effectiveness of evidence-based recruitment and retention strategies for a longitudinal, family-based HIV prevention intervention targeting adolescents in psychiatric care by (1) determining consent rate (recruitment), intervention participation rate (retention), and follow-up attendance rate (retention); and (2) examining socio-demographic factors, family-level processes, sexual risk-related indices, and intervention factors (i.e., treatment arm) associated with study retention. We hypothesized recruitment and retention rates in Project STYLE would be at least comparable to those reported in the literature for similar family-based intervention studies, and retention would not depend upon socio-demographic, family-level, sexual-risk related factors, or intervention arm.

Methods

Project STYLE (Strengthening Today's Youth Life Experience) was a longitudinal, randomized trial of a family-based HIV prevention intervention for adolescents receiving psychiatric care and their caretakers in three cities (Atlanta, Georgia, Providence, Rhode Island, and Chicago, Illinois). This study focused on subjects in Chicago, Illinois because data was collected on recruitment and retention barriers of adolescents referred from inpatient psychiatric hospitals and day treatment programs. Adolescents were eligible to participate if they: (1) received mental health services and (2) had a parent or adult caregiver who agreed to participate. Teens were excluded if they: (1) self-reported HIV infection ($N = 2$), (2) were pregnant, trying to get pregnant, or delivered a baby in the last 90 days ($N = 3$), (3) were currently participating in another HIV prevention study, (4) had been in treatment for sexually aggressive behavior ($N = 7$), or (5) demonstrated cognitive impairment ($N = 3$).

At the baseline assessment, adolescents and parents were consented/assented separately, and they independently completed structured, computer-assisted interviews of HIV-risk behavior, psychopathology/substance use, risk attitudes, and family processes, and a videotaped communication sample. The intervention occurred approximately 1–3 weeks following the baseline assessment in order to enroll 15 or more families for a single workshop. On the day of the workshop, families were randomly assigned to

one of the three conditions: a parent–adolescent HIV-prevention group that emphasized family communication, an adolescent-only HIV-prevention group, or an adolescent-only general health promotion control group. Adolescents in the health promotion condition received a curriculum based on general school health promotion programs which targeted exercise, nutrition, sleep, smoking and HIV information. All three conditions took place as a 1-day, 8-h group workshop. Families returned for a brief assessment 2 weeks after the workshop and a 3-h booster session 3 months after the workshop. Parents and teens completed follow-up assessments at 3-, 6-, and 12-months.

The following recruitment and retention strategies were informed by previously published trials (Leonard et al. 2003; McCormick et al. 2000; Prinz et al. 2001), and implemented at the University of Illinois at Chicago.

Recruitment Procedures

Community Collaboration

Community collaboration was an important focus. Following approval from site administrators to access the patient population, we made significant efforts to develop relationships with clinical staff. Project STYLE team members attended weekly meetings before and throughout the study to cultivate relationships and worked with hospital staff to incorporate referral systems into existing responsibilities with minimal burden. Hospital staff identified potential participants, informed families of the project, and requested permission to be contacted by the research team.

Incentives for Community Hospital Recruiters

Staff members at each recruitment site completed a recruitment form and received a \$5 gift certificate for every four families they informed about the study, regardless of family's agreement to participate. Project STYLE team members provided periodic in-service lunches as an opportunity to report on study progress, recruitment and enrollment for each site and staff member, and related mental health topics. The researchers sought and incorporated hospital staff feedback to improve the recruitment process.

Recruitment and Retention Coordinator

Project STYLE employed a full-time recruitment coordinator whose responsibility was to screen and schedule potential families, maintain close contact with participants throughout the study, and update locator information. The

coordinator explained the study in detail to eligible families and scheduled assessments. She sent reminder letters of scheduled appointments and telephoned families prior to appointments. The coordinator was available daily by cell phone, including weekends, to problem-solve scheduling conflicts, assist families in getting to the site, and contact those who did not show for scheduled appointments. Flexibility in meeting scheduling needs of the family was prioritized.

Retention Procedures

Adolescent and Parent Input

The first 18 months of Project STYLE were dedicated to adapting the content and process of the intervention and assessment through focus groups and pilot trials. A community advisory board comprised of clinical health providers, youth formerly in mental health treatment and their parents advised on program design and content. An iterative process incorporated adolescent and parent feedback to enhance cultural and developmental sensitivity. For example, the language and role-play scenarios were changed to represent racially/ethnically diverse families and more realistic situations. In response to concerns about the burden of multi-session interventions on parents' work schedules, the curriculum was adapted from four, 2½ h sessions to one full day workshop with 1 booster session. Family feedback about specific questionnaires and time constraints also informed the final assessment battery.

Tracking System

A database for tracking participant progress, contacts, and locator information was updated throughout the study. The recruitment and retention coordinator maintained detailed notes regarding each contact. Multiple phone calls and letters were used to remind participants about follow-up appointments. Missed appointments and no-shows were rescheduled as soon as possible. Families provided names and contact information for friends, family members, and schools attended at each assessment. The coordinator updated contact information, reasons for missed appointments, and effort (i.e., number of calls) in contacting families.

Incentives

Parents and adolescents were each paid \$50 to complete the baseline, 3-, 6-, and 12-month assessments and \$5 for arriving on time. Parents received \$10 for travel and parking. Families also received \$20 (and a \$5 on-time

bonus) to complete the 2-week follow-up interview. Families were not compensated for workshop or booster session attendance. Food was offered at each in-person contact, and holiday cards were mailed to maintain participant interest and motivation. A Project STYLE logo was used as a marketing technique and appeared on all printed materials, as well as on refrigerator magnets and T-shirts. These incentives, and free condoms, were given to families at the baseline intervention workshop.

Well-Trained Staff

An enthusiastic and committed staff was retrained to deliver the intervention each year to prevent drift. Facilitators were clinically trained and had prior experience working with adolescents in psychiatric care or HIV education. Facilitators engaged in regular supervision, didactic presentation of factual information, and personal discussion of skill application. Fidelity was monitored through live observation and supervision. Trained assessors conducted home visits for follow-up appointments if a family had transportation problems, and, when necessary, staff provided supervision for small children during the assessments and interventions. Research staff sometimes traveled long distances to complete follow-up assessments for families who relocated or needed evenings and weekend interviews.

Participants

The baseline enrolled sample included 305 caregivers and their 13–18 year old adolescents ($M = 14.90$, $SD = 1.32$). Youth were racially (53.4% African American, 29.5% Caucasian, 1.3% Asian, 1% American Indian, and .7% Native Hawaiian) and ethnically (12.8% Hispanic) diverse. There were slightly more females ($N = 173$; 56.7%), and caregivers were primarily women ($N = 268$; 87.9%). Parents reported that 65.9% of their adolescents were admitted to a psychiatric hospital overnight ($M = 11.07$ days admitted; $SD = 8.49$) and 46.2% attended a day treatment program ($M = 11.74$ days; $SD = 8.31$) in the past 3 months. Over two-thirds of adolescents (67.2%) were prescribed psychiatric medication, and 15% had participated in a drug/alcohol rehabilitation program. At baseline, 59.7% of the teens reported engaging in sexual activity, and 7.9% tested positive for an STI (chlamydia, gonorrhea, or trichomonas). Most of the caregivers were natural parents (72.1%). Caregiver education was variable; 2.0% reported completing middle school, 16.4% had some high school, 22.6% completed high school or a GED, 34.4% had some college, 19.0% received a college degree, 4.3% reported an advanced degree, and 0.7% had other

education. Approximately half (48.5%) of families reported household yearly incomes below \$30,000.

Measures

The Symptom Checklist (SCL-90)

The SCL-90 (Derogatis 1993) is a well-validated measure of current psychological distress completed by the parents. The Global Severity Index (GSI), a summary scale had excellent internal consistency in this sample, $\alpha = 0.98$.

Parent–Adolescent Sexual Communication Scale

The Parent–Adolescent Sexual Communication Scale (Miller et al. 1998) assesses quality of sexual communication between parents and adolescents using six items on a 7-point scale. Higher scores indicated better quality communication. In this sample, internal consistency was adequate for adolescents ($\alpha = .85$) and parents ($\alpha = .68$). We excluded one item, “My parent would think I am doing these things if I talk to him/her,” and “If my teen talked to me about sex, I would think she/he is doing these,” from adolescent and parent versions, respectively, to achieve adequate internal consistency.

Parenting Style Questionnaire (PSQ)

Youth and parents completed the Parenting Style Questionnaire, a well-validated measure of parental supervision and monitoring (Oregon Social Learning Center 1990). The perceived parental monitoring subscale was used in the current analyses. Items were measured on a 5-point Likert scale with higher scores indicating higher levels of monitoring. For the adolescent version, we excluded one item from the analysis, “How often, before you go, out do your parents ask you when you will be back?” to achieve adequate internal consistency ($\alpha = .67$). We also excluded one item from the analysis for the parent version, “How difficult is it for you to know where your teen is and what s/he is doing, now that s/he is getting older?” to achieve adequate internal consistency ($\alpha = .72$).

The Columbia Impairment Scale

Youth and parents completed the CIS, a well-validated (Bird et al. 1993) 13-item scale of global impairment across four areas of functioning: interpersonal relations, broad psychopathology, job/schoolwork, and use of leisure time. Each item is rated on a five point scale with higher scores indicating greater impairment. Internal consistency was adequate ($\alpha = 0.84$ and 0.82 for parent and adolescent report, respectively).

Diagnostic Interview Schedule for Children (DISC)

The DISC is a structured computer-assisted diagnostic interview that generates a full range of DSM-IV diagnoses and administered to parents and adolescents separately (Shaffer 1991). The psychopathology outcome used in the study was coded as a dichotomous variable (0 = No clinical diagnoses, 1 = subthreshold or full clinical diagnoses).

STI Test

Adolescents provided a urine sample to determine presence of chlamydia, trichomonas and/or gonorrhea (0 = No STI present, 1 = STI present).

Adolescent Risk Behavior Assessment (ARBA)

The AIDS Risk Behavior Assessment (ARBA; Donenberg et al. 2001) is a self-administered interview of adolescent HIV risk behavior derived from five well-established measures of sexual behavior and drug/alcohol use. A sexual risk behavior composite score was created from two questions that assessed whether the adolescent had ever had sexual intercourse and how often s/he practiced safe sex. This variable ranged from 0 to 5, as follows: 0 = never had sex (oral, vaginal or anal); 1 = always safe sex; 2 = almost always safe sex; 3 = sometimes safe sex; 4 = almost never safe sex; 5 = never safe sex. Safe sex was defined as no sexual activity, intimately touching one’s partner instead of having sex, or using a condom every time one has vaginal, anal or oral sex.

Participant Feedback Forms

Youth and parents answered 11 questions regarding intervention satisfaction (i.e. helpfulness, usefulness, interest in intervention) and rapport with facilitators (i.e. support, listening, encouraging).

Data Analysis

Univariate analyses examined group differences between families who did and did not participate in the intervention and booster session. Chi-square statistics tested categorical variables and general linear model evaluated continuous dependent variables. Multi-level model assessed group differences between families who did and did not participate in the intervention and the booster session according to parent and adolescent reports of socio-demographic, psychiatric, family-level, or sexual risk indices. Independent variables were attendance at the intervention and booster session. Lastly, nonlinear mixed modeling examined differences in retention across treatment arms at the

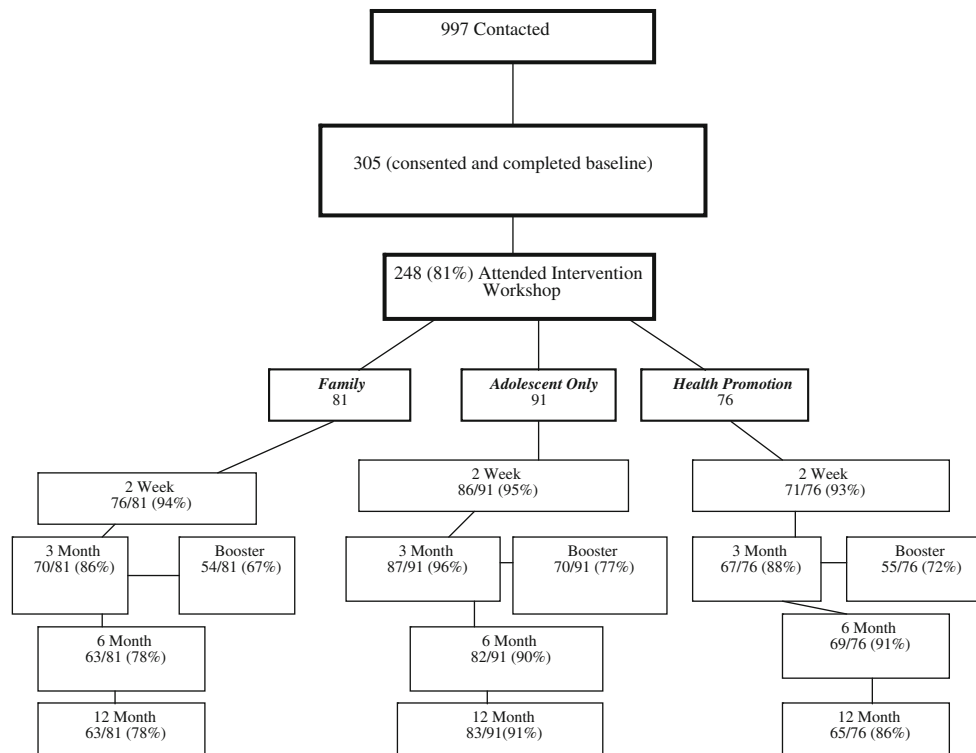


Fig. 1 Recruitment and retention in project STYLE Chicago

baseline assessment, 2-week visit, and 3-, 6-, and 12-month follow-ups.

Results

1,504 families agreed to be contacted and 997 families were reached. Three hundred and five families were ultimately consented and enrolled (see Fig. 1). One-third of the families contacted enrolled in the study. 81% of those enrolled participated in the workshop and 72% attended the booster sessions. The reasons for nonenrollment fell into five main categories: teen instability in 17% (e.g., rehospitalized, relocated, ran away), family factors in 11% (e.g., parent–child disagreement about participation, parent disability, illness or death), social-contextual factors in 26% (e.g. conflict with work/school schedule, distance, transportation difficulty), appropriateness of the intervention at time of contact in .04% (e.g. no interest given adolescent problems) and unknown in 45% (e.g. no further contact, no reason given).

Did Participants in the Workshop Differ from Non-Participants?

Table 1 presents group differences between families who participated in the workshop and families who did not

participate on socio-demographic, psychiatric, family-level, or sexual risk indices. Chi-square analyses revealed no significant differences between families who attended versus those who did not on any variable (see Table 1), including parent report of psychological distress, adolescent age, family income, and teen sexual risk ($p = .05$). Similarly, there were no significant differences between families who participated in the workshop and those who did not based on parent and adolescent report of global impairment, sexual communication and parental monitoring ($p = .80$). Approximately 95% of families reported enjoying the workshop, 94.3% held a favorable opinion of the facilitators, and 66.8% reported it was “very helpful” or “helpful most of the time.”

Did Participants in the Booster Session Differ from Non-Participants?

Of the 248 randomized families, 72.2% ($N = 179$) completed the 3-month booster session. Table 2 presents group differences between those who participated in the booster and those who did not participate based on socio-demographic, psychiatric and family variables. Chi-square analyses revealed no significant differences on any variable, including parent report of psychological distress, adolescent age, family income, and teen sexual risk ($p = .39$). There were also no significant differences

Table 1 Comparison of groups that did and did not attend the intervention workshop

| | Attended workshop (<i>N</i> = 248) <i>M</i> (<i>SD</i>) | Did not attend workshop (<i>N</i> = 57) <i>M</i> (<i>SD</i>) | χ^2 | <i>p</i> |
|---|--|---|------------------------|----------|
| Categorical variables | | | | |
| Adolescent race | .59 (.49) | .49 (.50) | 1.74 | .19 |
| Adolescent gender | .56 (.50) | .61 (.49) | .53 | .47 |
| Adolescent report of psychopathology | .73 (.44) | .79 (.41) | .67 | .41 |
| Parent race | .61 (.49) | .51 (.50) | 1.82 | .18 |
| Parent gender | .87 (.33) | .93 (.26) | 1.41 | .24 |
| Parent education | .81 (.39) | .82 (.39) | .03 | .87 |
| Parent report of adolescent psychopathology | .87 (.34) | .84 (.37) | .24 | .62 |
| | | | <i>F</i> (<i>df</i>) | <i>p</i> |
| Continuous variables | | | | |
| Adolescent age | 14.8 (1.30) | 15.3 (1.34) | 2.36 (1,280) | .05 |
| Family income | 4.34 (3.20) | 4.13 (2.91) | | |
| Parent report of psychological distress | .60 (.56) | .60 (.60) | | |
| Adolescent sexual risk outcome | 1.20 (1.41) | 1.61 (1.56) | | |
| Continuous dyadic variables | | | | |
| Parent report | | | | |
| Adolescent global impairment | 35.0 (9.03) | 35.5 (11.4) | .34 (1,280) | .80 |
| Sexual communication | 27.7 (5.72) | 28.7 (6.30) | | |
| Parental monitoring | 35.4 (5.71) | 35.3 (6.1) | | |
| Adolescent report | | | | |
| Adolescent global impairment | 31.6 (9.22) | 29.5 (8.36) | | |
| Sexual communication | 20.8 (9.47) | 21.2 (8.35) | | |
| Parental monitoring | 10.6 (3.32) | 10.7 (3.31) | | |

between families who participated in the booster and those who did not based on parent and adolescent report of global impairment, sexual communication and parental monitoring ($p = .13$). Following the 3-month booster session, 96% of families said they enjoyed the session, 88.1% had a favorable opinion of the facilitators, and 72.8% families described the booster session as “helpful most of the time” or “very helpful.”

Retention Barriers

Retention barriers for consented families ($N = 57$) included teen instability in 25% (e.g., ran away, psychiatric illness, juvenile detention), family factors in 12% (e.g., parent–child living apart, parent disability, illness or death), social-contextual factors in 18% (e.g. conflict with work/school schedule), appropriateness of the intervention at time of contact in .04% and unknown in 39% (e.g., no further contact, no reason given). Of the 94 families that did not attend the 3-, 6- or 12-month follow-up

appointments, 56% were unable to be contacted, withdrew from study, or missed follow-up appointments.

Impact of Treatment Arm on Retention

Multilevel modeling revealed the family arm ($b = -.58$, $t(304) = -1.00$, $p = .32$) and the adolescent only arm ($b = -.045$, $t(304) = -.07$, $p = .94$) did not differ from the health promotion arm in the likelihood of adolescent attendance at the baseline assessment. Similarly, adolescent attendance did not differ between the family arm and the adolescent arm from baseline assessment to 12 month follow-up ($b = .05$, $t(304) = 1.65$, $p = .10$). Adolescents in the health promotion arm were significantly less likely to participate over time ($b = -.083$, $t(304) = -3.60$, $p < .001$). Attendance in the family and adolescent only arm decreased over time however attendance did not significantly differ in the family arm ($b = -.019$, $t(304) = -.63$, $p = .53$), and the adolescent only arm ($b = .02$, $t(304) = .63$, $p = .53$) when compared to the health

Table 2 Comparison of groups that did and did not attend the booster

| | Attended booster (<i>N</i> = 180) <i>M</i> (<i>SD</i>) | Did not attend booster (<i>N</i> = 68) <i>M</i> (<i>SD</i>) | χ^2 | <i>p</i> |
|---|---|--|------------------------|----------|
| Categorical variables | | | | |
| Adolescent race | .58 (.49) | .60 (.49) | .07 | .79 |
| Adolescent gender | .55 (.50) | .60 (.49) | .49 | .49 |
| Adolescent report of psychopathology | .72 (.45) | .76 (.43) | .39 | .53 |
| Adolescent STI | .08 (.28) | .13 (.34) | 1.36 | .24 |
| Parent race | .61 (.49) | .62 (.49) | .009 | .92 |
| Parent gender | .89 (.31) | .82 (.39) | 2.36 | .13 |
| Parent education | .82 (.39) | .79 (.41) | .27 | .60 |
| Parent report of adolescent psychopathology | .88 (.33) | .84 (.37) | .67 | .41 |
| | | | <i>F</i> (<i>df</i>) | <i>p</i> |
| Continuous variables | | | | |
| Adolescent age | 14.8 (1.29) | 14.9 (1.31) | 1.04 (1,226) | .39 |
| Family income | 4.15 (3.12) | 4.83 (3.40) | | |
| Parent report of psychological distress | .62 (.58) | .54 (.51) | | |
| Adolescent sexual risk outcome | 1.13 (1.36) | 1.39 (1.51) | | |
| Continuous dyadic variables | | | | |
| Parent report | | | | |
| Adolescent global impairment | 35.3 (8.87) | 34.2 (9.46) | 1.93 (1,227) | .13 |
| Sexual communication | 27.4 (5.96) | 28.6 (5.00) | | |
| Parental monitoring | 35.6 (5.91) | 34.9 (5.15) | | |
| Adolescent report | | | | |
| Adolescent global impairment | 31.9 (9.4) | 30.8 (8.75) | | |
| Sexual communication | 20.7 (9.56) | 21.0 (9.31) | | |
| Parental monitoring | 10.8 (3.20) | 10.0 (3.57) | | |

promotion arm. A random effect due to person was significant ($\sigma = 1.90$, $p < .0001$).

Discussion

The purpose of this study was to examine the effectiveness of evidence-based recruitment and retention strategies implemented in a family-based HIV-prevention intervention for adolescents in psychiatric care. Of those consented, participation in the first intervention workshop and retention at the end of 1 year were excellent (81 and 85% respectively). Project STYLE's high retention rates underscore that once enrolled, families can be retained in a family-based HIV prevention intervention study for up to 12 months, even when intervention material (e.g., condom demonstrations and discussion of sexual values with parents) and assessment content (e.g., questions about sexual risk behavior, videotaped family conflict discussions, STI urine screen) are sensitive and potentially uncomfortable.

Low attrition in this study can likely be attributed to the evidence-based retention strategies outlined in this paper. Importantly, retention did not differ by treatment arm, promoting confidence in the study's internal validity. Results indicated that a third of families contacted were ultimately enrolled. This is similar to other studies that have investigated the effectiveness of empirically supported recruitment and retention strategies (2% in a review by McDonald 1999; 5.9% in Saunders et al. 2003; 16.9% in Spoth et al. 2007) and may reflect the general difficulty engaging people in prevention research. We found that the most common barrier was scheduling. This finding is consistent with other prevention studies (e.g., McKay et al. 1996) and likely reflects the low priority assigned to participation in prevention research by families, given other demands on their time. When we examined barriers most likely to compromise attendance at the intervention after completing the baseline assessment, scheduling was still reported by a significant percentage of participants (18%). However, factors associated with teen behavior (e.g., teen

ran away) were more frequent reasons for non-attendance (25%). Still, families who completed the baseline assessment but not the intervention did not differ on socio-demographic, psychiatric, family-level, and sexual risk indices.

This study makes a valuable contribution by extending the literature on the factors associated with recruitment and retention of adolescents in psychiatric care in a HIV randomized clinical trial. For a variety of behaviors, including substance abuse, delinquency, and HIV risk behavior, there is interest in understanding what factors increase the likelihood of participation in preventive interventions, as well as understanding factors that are barriers to recruitment and retention. Taken together, the diverse reasons for non-attendance imply the need for strategies or design changes to counteract participant barriers. Movement away from conducting HIV prevention intervention research at universities and academic medical centers and towards integration of research within community-based mental health services may increase the likelihood of greater enrollment among those in mental health treatment. Furthermore, the high rates of sexual risk behavior among adolescents in psychiatric care suggest implementation of programs developed in the context of research will need to eventually be implemented in community psychiatric hospitals and mental health centers. Conducting such programs in the sites where they will eventually be disseminated may result in effective programs reaching target populations more expeditiously. Facilitating self-directed family interventions and using videotapes to communicate information and model skills are other strategies for minimizing recruitment barriers and serving hard-to-reach populations (Haggerty et al. 2006).

This study has several limitations that should be noted. Several of strategies used, or nonspecific factors, may have contributed to participant recruitment and retention, and we cannot evaluate the relative importance of each approach. Future research (e.g., Spoth and Redmond 2000; Spoth et al. 2007) should evaluate the differential effects of specific strategies in order to improve recruitment and retention for family-based HIV prevention research. We are unclear about the reason for nonenrollment for a sizable number of families but this is not unusual since only limited information can be gathered in a brief phone call and many families were never contacted. Since we do not know the demographics and psychological characteristics of the unenrolled families it is impossible to know how representative they are of the population in mental health care. It is appropriate to be cautious in generalizing from families that agree to participate in a prevention intervention trial.

Despite limitations, findings from this study have implications for future family-based HIV prevention

studies and implementation of HIV prevention programs. First, effective strategies to retain families and conduct prevention research that families perceive as enjoyable and useful exist. Future research may benefit from considering the financial cost and time investment required to achieve high retention among difficult to reach and engage families. Second, integrating prevention research into existing community-based mental health treatment systems for families with limited resources, psychosocial stressors, and time constraints may be critical to enhance recruitment and external validity. Excellent recruitment strategies may not be sufficient to engage families if research and/or prevention programs are external to established mental health facilities. Rather, we need to take the research to the participants and their community-based providers.

References

- Beadnell, B., Baker, S., Knox, K., Stielstra, S., Morrison, D. M., DeGooyer, E., et al. (2003). The influence of psychosocial difficulties on women's attrition in an HIV/STD prevention programme. *AIDS Care, 15*, 807–820.
- Bird, H., Shaffer, D., Fisher, P., Gould, M., Staghezza, B., Chen, J. Y., et al. (1993). The Columbia Impairment Scales (CIS): Pilot findings on a measure of global impairment for children and adolescents. *International Journal of Methods in Psychiatric Research, 3*, 167–176.
- Brown, L. K., Danovsky, M. B., Lourie, K. J., DiClemente, R. J., & Ponton, L. E. (1997). Adolescents with psychiatric disorders and the risk of HIV. *Journal of the American Academy of Child and Adolescent Psychiatry, 36*, 1609–1617.
- Corbie-Smith, G., Viscoli, C. M., Kernan, W. N., Brass, L. M., Sarrel, P., & Horwitz, R. I. (2003). Influences of race, clinical, and other socio-demographic features on trial participation. *Journal of Clinical Epidemiology, 56*, 304–309.
- Derogatis, L. R. (1993). *Brief symptom inventory: Administration, scoring and procedures manual* (4th ed.). Minneapolis, MN: NCS, Pearson, Inc.
- DiFranceisco, W. M., Kelly, J. A., Sikkema, K. J., Somlai, A., Murphy, D., & Stevenson, L. Y. (1998). Differences between completers and early dropouts from 2 HIV intervention trials: A health belief approach to understanding prevention program attrition. *American Journal of Public Health, 88*, 1068–1073.
- Donenberg, G. R., Emerson, E., Bryant, F. B., Wilson, H., & Weber-Shifrin, E. (2001). Understanding AIDS-risk behavior among adolescents in psychiatric care: Links to psychopathology and peer relationships. *Journal of the American Academy of Child and Adolescent Psychiatry, 40*, 642–653.
- Donenberg, G. R., & Pao, M. (2005). Youths and HIV/AIDS: Psychiatry's role in a changing epidemic. *Journal of the American Academy of Child and Adolescent Psychiatry, 44*, 728–747.
- Donenberg, G., Wilson, H., Emerson, E., & Bryant, F. (2002). Holding the line with a watchful eye: The impact of perceived parental monitoring and parental permissiveness on risky sexual behavior among adolescents in psychiatric care. *AIDS Education Prevention, 14*, 138–157.
- Dudley, C., O'Sullivan, L. F., & Moreau, D. (2002). Does familiarity breed complacency? HIV knowledge, personal contact, and

- sexual risk behavior of psychiatrically-referred Latino adolescent girls. *Hispanic Journal of Behavioral Sciences*, 24, 353–368.
- Fox, D. P., & Gottfredson, D. C. (2003). Differentiating completers from non-completers in a family-based prevention program. *Journal of Primary Prevention*, 24, 111–124.
- Gifford, A. L., Cunningham, W. E., Heslin, K. C., Andersen, R. M., Nakazono, T., Lieu, D. K., et al. (2002). Participation in research and access to experimental treatments by HIV-infected patients. *New England Journal of Medicine*, 346, 1373–1382.
- Haggerty, K. P., MacKenzie, E. P., Skinner, M. L., Harachi, T. W., & Catalano, R. F. (2006). Predicting participation in parents who care: Program initiation and exposure in two different formats. *Journal of Primary Prevention*, 27, 47–65.
- Haller, D. L., Miles, D. R., & Dawson, K. S. (2002). Psychopathology influences treatment retention among drug-dependent women. *Journal of Substance Abuse Treatment*, 23, 431–436.
- Heinrichs, N., Bertram, H., Kuschel, A., & Hahlweg, K. (2005). Parent recruitment and retention in a universal prevention program for child behavior and emotional problems: Barriers to research and program participation. *Prevention Science*, 6, 275–286.
- Hough, R., Tarke, H., Renker, V., Shields, P., & Glatstein, J. (1996). Recruitment and retention of homeless mentally ill participants in research. *Journal of Consulting and Clinical Psychology*, 64, 881–891.
- Kapungu, C., Baptiste, D., Holmbeck, G., McBride, C., Robinson, M., Sturdivant, A., et al. (2010). Beyond the “birds and the bees”: Gender differences in sex-related communication among urban African American adolescents. *Family Process*, 49, 251–264.
- Kapungu, C., Holmbeck, G. N., & Paikoff, R. L. (2006). Longitudinal association between parenting practices and early sexual risk behaviors among urban African American adolescents: The moderating role of gender. *Journal of Youth and Adolescence*, 35, 787–798.
- Leonard, N. R., Lester, P., Rotheram-Borus, M. J., Mattes, K., Gwadz, M., & Ferns, B. (2003). Successful recruitment and retention of participants in longitudinal behavioral research. *AIDS Education and Prevention*, 15, 269–281.
- McCormick, A., McKay, M., Wilson, M., McKinney, L., Paikoff, R., Bell, C., et al. (2000). Involving families in an urban HIV preventive intervention: How community collaboration addresses barriers to participation. *AIDS Education and Prevention*, 12, 299–307.
- McDonald, P. W. (1999). Population-based recruitment for quit-smoking programs: An analytic review of communication variables. *Preventive Medicine: An International Journal Devoted to Practice & Theory*, 28, 545–557.
- McKay, M., McCadam, K., & Gonzales, J. (1996). Addressing the barriers to mental health services for inner-city children and their caregivers. *Community Mental Health Journal*, 32, 353–361.
- Miller, K. S., Kotchick, B. A., Dorsey, S., Forehand, R., & Ham, A. Y. (1998). Family communication about sex: What are parents saying and are their adolescents listening? *Family Planning Perspectives*, 30, 218–222, 235.
- Nappi, C. M., McBride, C. K., & Donenberg, G. R. (2007). HIV/AIDS communication among adolescents in psychiatric care and their parents. *Journal of Family Psychology*, 21, 637–644.
- Nappi, C., Thakral, C., Kapungu, C., Donenberg, G., Hasselquist, E., Brown, L., et al. (2009). Parental monitoring as a moderator of the effect of family sexual communication on sexual risk behavior among adolescents in psychiatric care. *AIDS and Behavior*, 13, 1012–1020.
- NIMH Multisite HIV Prevention Trial. (1997). Screening, recruiting and predicting retention of participants in a multisite HIV prevention trial. *AIDS*, 11, S13–S19.
- Oregon Social Learning Center. (1990). *Parental monitoring and supervision constructs*. Technical reports. Eugene: Oregon Social Learning Center.
- Orr, P. R., Blackhurst, D. W., & Hawkins, B. S. (1992). Patient and clinic factors predictive of missed visits and inactive status in a multicenter clinical trial. The Macular Photocoagulation Study Group. *Controlled Clinical Trials*, 13, 40–49.
- Pequegnat, E., & Szapocznik, J. (Eds.). (2000). *Working with families in the era of HIV*. Thousand Oaks: Sage Publication.
- Perrino, T., Coatsworth, D., Briones, E., Pantin, H., & Szapocznik, J. (2001). Initial engagement in parent-centered preventive interventions: A family systems perspective. *The Journal of Primary Prevention*, 22, 21–44.
- Prado, G., Pantin, H., Schwartz, S., Lupei, N., & Szapocznik, J. (2006). Predictors of engagement and retention in a family-centered substance abuse and HIV preventive intervention for Hispanic adolescents. *Journal of Pediatric Psychology*, 31(9), 874–890.
- Prado, G., Szapocznik, J., Mitrani, V. B., Mauer, M. H., Smith, L., & Feaster, D. (2002). Factors influencing engagement into interventions for adaptation to HIV in African American women. *AIDS and Behavior*, 6, 141–151.
- Prinz, R. J., Smith, E. P., Dumas, J. E., Laughlin, J. E., White, D. W., & Barrón, R. (2001). Recruitment and retention of participants in prevention trials involving family-based interventions. *American Journal of Preventive Medicine*, 20, 31–37.
- Rutledge, S. E., Roffman, R. A., Picciano, J. F., Kalichman, S. C., & Berghuis, J. P. (2002). HIV prevention and attrition: Challenges and opportunities. *AIDS Behavior*, 6, 69–82.
- Saunders, S. D., Greaney, M. L., Lees, F. D., & Clark, P. G. (2003). Achieving recruitment goals through community partnerships: The SENIOR project. *Family and Community Health*, 26, 194–202.
- Shaffer, D. (1991). *Diagnostic Interview for Children (DISC 2.3)-child version*. New York: Columbia University.
- Silva, M. (2002). The effectiveness of school-based sex education programs in the promotion of abstinent behavior: A meta-analysis. *Health Education Research*, 17, 471–481.
- Smith, M. D. (2001). HIV risk in adolescents with severe mental illness: Literature review. *Journal of Adolescent Health*, 29, 320–329.
- Spoth, R., Clair, S., Greenberg, M., Redmond, C., & Shin, C. (2007). Toward dissemination of evidence-based family interventions: Maintenance of community-based partnership recruitment results and associated factors. *Journal of Family Psychology*, 21, 137–146.
- Spoth, R. L., Goldberg, C., & Redmond, C. (1999). Engaging families in longitudinal preventive intervention research: Discrete-time survival analysis of socioeconomic and social-emotional risk factors. *Journal of Consulting and Clinical Psychology*, 67(10), 157–163.
- Spoth, R., & Redmond, C. (2000). Research on family engagement in preventive interventions: Toward improved use of scientific findings in primary prevention practice. *The Journal of Primary Prevention*, 21, 267–284.
- Spoth, R., Redmond, C., & Shin, C. (2000). Modeling factors influencing enrollment in family-focused preventive intervention research. *Prevention Science*, 1, 213–225.
- Trauth, J. M., Musa, D., Siminoff, L., Jewell, I. K., & Ricci, E. (2000). Public attitudes regarding willingness to participate in medical research studies. *Journal of Health & Social Policy*, 12, 23–43.
- Vaughn, T., Sarrazin, M. V., Saleh, S. S., Huber, D. L., & Hall, J. A. (2002). Participation and retention in drug abuse treatment services research. *Journal of Substance Abuse Treatment*, 23, 387–397.

- Wu, E., El-Bassel, N., Witte, S. S., Gilbert, L., Chang, M., & Morse, P. (2005). Enrollment of minority women and their main sexual partners in an HIV/STI prevention trial. *AIDS Education and Prevention, 17*, 41–52.
- Zand, D. H., Thomson, N. R., Dugan, M., Braun, J., Holterman-Hommes, P., & Hunter, P. (2004). The recruitment process: Factors that predict African American adolescents' initial engagement into an alcohol, tobacco, and other drug prevention study. *Journal of Ethnicity in Substance Abuse, 3*, 43–54.